

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 12 September 2016

Members

Ms Maree Edwards — Chair

Ms Cindy McLeish — Deputy Chair

Ms Chris Couzens

Mr Paul Edbrooke

Mr Bernie Finn

Ms Emma Kealy

Staff

Executive officer: Dr Greg Gardiner

Witnesses

Ms Christine Lyons, acting CEO, and

Ms Robyn Stephen, acting president, Speech Pathology Australia.

The CHAIR — Thank you for attending our public hearing 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 will be able to make factual or grammatical corrections if necessary. I will hand over to you now to make your presentation. I thank you again for coming along today.

Ms STEPHEN — Thank you very much for inviting us to speak today. Speech Pathology Australia is the national peak body for over 7000 speech pathologists in Australia, and we have over 1600 Victorian members. Whilst I am appearing today as the acting president of the association, I also own and operate a private paediatric speech pathology practice in Box Hill, and I have had the privilege of working with children with autism spectrum disorders and their families for the last 20 years. I am also on a specialist autism assessment team with a paediatrician and a psychologist. I have today with me Christine Lyons, who is currently the acting CEO of Speech Pathology Australia, and Christine is a dual trained teacher and speech pathologist.

Speech pathologists are the university trained allied health practitioners who specialise in diagnosing and treating communication and swallowing disorders. We are an essential part of the multidisciplinary diagnostic intervention and support team for individuals with autism spectrum disorder and their families. For the majority of people with autism spectrum disorders, speech pathology is essential across their life span for them to achieve social relationships and educational and employment outcomes. As we know, autism spectrum disorder is a lifelong condition. The severity of the difficulties for problems with ASD will vary, with some people having severe impairments, such as quite limited speech, whereas other people will have speech and language skills in the normal range but their problems will be in understanding the inference of what is being said, depending on the context, and understanding and using social communication.

Speech pathology uses evidence-based approaches to address and improve the core speech, language and communication difficulties experienced by the person with ASD and to develop their functioning in social situations. The level and frequency of speech pathology will vary depending on the severity of symptoms, the goals of the individual and the family and whether or not there is a co-occurring condition, such as a developmental delay or an intellectual disability.

Unfortunately at present the levels of access to speech pathology services in Victoria for people with ASD is inadequate. That is why we are here today. Problems with access are across Australia and were examined recently by a federal Senate inquiry that concluded that the demand far outstripped supply. Even with the rollout of the NDIS this is absolutely the case in Victoria. We can discuss further with you the specifics of the problems people with ASD have accessing speech pathology services. Cost is only one factor, and availability and location of services, adequacy of services, workforce issues and eligibility criteria all act as barriers. Whilst we hope that our appearance before you today will help your understanding of how speech pathology fits into the picture of ASD services in Victoria, we really want to take this opportunity to highlight some tangible things that the Victorian government could do that would improve services for people with ASD.

We are keen to speak to you in detail about these ideas, but for the Hansard record I would like to address our key recommendations. We recommend that the Victorian government in the first instance begin to systematically gather, report and analyse prevalence data on the number of Victorians diagnosed with autism spectrum disorder, and this of course will help all future policy and program planning.

There is no getting away from it; increased resourcing needs to be directed to autism services, specifically to publicly funded, no-fee speech pathology services. The imperative for early diagnosis is well known, and this requires specialist autism assessment teams, which include a speech pathologist, and we would recommend that paediatric services be prioritised. In addition specialist autism programs also need to be prioritised across education, housing, sport and employment services.

We think that there are a range of changes that could be made to existing services that would fundamentally change access without significant additional cost. Changes such as using telepractice for speech pathology, using hub-and-spoke models of service and shared care arrangements between specialist and general speech pathologists would be of great benefit not just for those people in rural Victoria.

Finally, in Victoria many government primary schools have access to speech pathologists. This is not the case in some other states. Despite this, in-school speech pathologists are overwhelmed with workloads, and they are often asked to focus their time on assessment. Whilst this is important, access to treatment and intervention is necessary in order for a student with autism spectrum disorder to actively participate in the curriculum through the social environment of the classroom. The speech pathologist needs to work in the classroom alongside the teacher and in the curriculum planning to provide treatments and expertise which will help teachers provide high-quality individualised teaching to these students so that the students with autism spectrum disorder can learn to their full potential.

It is our view that significant investment needs to be made in this area of government services. It is easy to get lost in the many issues facing our autism service delivery sector in Victoria, but I think it is important that we not lose sight of the fact that people with autism spectrum disorder are part of our community. If we wish these individuals and families to participate as fully as possible in the social and economic life of our society, then they need to be able to access the right supports at the right times in their lives. We hope we can help highlight what those supports could and should be. Thank you.

The CHAIR — Thank you very much, and thank you for your comprehensive written submission as well, which outlines your recommendations at the back there. We have heard a lot already just from people who have presented to us and from written submissions about the importance of speech pathology, particularly in early diagnosis and early intervention. We have also heard a lot about early intervention therapy, so I guess what I would like to know from you is whether you have a view on which of those early intervention services are evidence-based and proven to be successful and how you fit into that bigger picture.

Ms STEPHEN — I think that, often, speech pathology is the first service that parents come to, because their child is delayed in that they have late speech and language development. So, way back, the maternal and child health nurse may send them to a speech pathologist at a community health service. Community health does not deal with children who have complex issues, and so that child is then to be referred on to another service, which is usually early childhood intervention services, or they may go through a paediatrician, who then would refer them through to a private speech pathologist or a private psychologist to begin some sort of assessment. Your question was about what treatments or interventions work.

The CHAIR — Pretty much, but also how you, as speech pathologists, fit into that.

Ms STEPHEN — So part of the early childhood and intervention services, the speech pathologists are part of those teams. Then very often now they are being run with the key worker model, so the families are saying to us that they really know that the child needs speech pathology, and the parents want the training in how to provide the intervention at home in the naturalistic setting which has, from our evidence, shown to be a very effective evidence-based method of intervention. But they cannot get access to a speech pathologist, even within that model.

Once the child is diagnosed, then they are eligible for the federal package, the Helping Children with Autism package. But there is a real block in terms of the diagnosis. Often these families can be moving around in public hospitals, community health and early intervention services without a diagnosis, and it is only when they actually get a diagnosis that they are eligible for the federal funding, and then they can actually create their own eclectic comprehensive team around the individual child, and then a speech pathologist would be part of that, and an occupational therapist, a psychologist and special education teachers would be part of it — a team. Would you — —

Ms LYONS — I think that what you are asking is specifically: what is it that a speech pathologist works on in early intervention?

The CHAIR — Yes and no. We have heard about a lot of intervention therapies that are clearly evidence based, and one of those was presented at our last public hearing. It is based around maternal and child health, early intervention. Some of them are evidence based, and some of them are not. Clearly speech pathology is evidence based, because you are one of the first services that people go to when someone is diagnosed with ASD. I am trying to picture in my mind the structure. If someone is diagnosed — a child is diagnosed — you have kind of explained it a little bit. Where do they go? How do they get referred to a speech pathologist? What do you do? And then, what do you do after you have done what you do? So where do they go next? Or do you stay with that child right through?

Ms STEPHEN — I think you are asking some fantastic questions.

Ms LYONS — And it is very complex. I guess that is what you have heard also. Listening to the presentations this morning, you can see that there is not one size that fits all. So generally, as Robyn said, what the parent tends to notice first is either that the child is not talking or that there are difficulties with behaviour. So whatever the pathway is, if they find themselves with a speech pathologist, what the speech pathologist is going to do is look at their development in their understanding of language and their use of language and their social communication.

The CHAIR — So do you work closely with behavioural therapists?

Ms LYONS — Yes.

Ms STEPHEN — All behaviour is a communication. So what we need to do is to say, ‘What’s the behaviour that the child is exhibiting? What’s the child trying to tell us through this behaviour?’. So we need to work closely together, and that does not necessarily happen at the moment, I think. I am on a private team in the Royal Children’s Hospital at 48 Flemington Road, and this is one of the things that I see — that parents can have all sorts of different advice about the management of behaviour, but behaviour in fact is a communication. You actually need a multidisciplinary approach.

The CHAIR — That is what I am kind of getting at, yes.

Ms LYONS — Often speech pathology would be that first port of call, often because that is a soft option, or seen as a soft option, for parents. Parents do not want to necessarily be told that there is this significant issue with their child, and we would see that it is a nice entry point often into therapies and looking at the needs of the child. Often there will be that criticism that you are looking for deficits and looking for weaknesses, but I guess from a speech pathology point of view, you look at the child holistically and also at the family, and what you are trying to see is what is happening for this child, where their strengths are, where their weaknesses are, and then provide support to the family. And often, as time progresses, that will be in consultation with a paediatrician or a psychologist or an occupational therapist, depending on what the child’s needs are.

The CHAIR — Does that happen always?

Ms LYONS — No.

The CHAIR — There are gaps, aren’t there, between — —

Ms LYONS — Yes.

Ms STEPHEN — I mean, it is really interesting. It is still fascinating for me, given the progress that actually has been made in terms of autism services over the last 20 years. I was at a childcare centre in Rockbank recently doing an assessment, as part of assessments in the clinic there is an assessment of the child interacting with their peers in the child care centre, and there was a child that was just coming to diagnosis at four and a half ready to go to school, and there was another child within the setting that clearly had an autism spectrum disorder but had not even started the pathways, and the childcare centre was really struggling to try and manage that child within that setting. That is just an example. I go about an hour out of Melbourne in these centres, and that is what is happening. So there are huge gaps, even an hour out of Melbourne.

The CHAIR — That could also be per chance that the parents did not want a diagnosis or had not accepted that there was a problem that needed to be investigated, or there could be any number of reasons why there was a delay in that child seeking support. So is what you are telling me, really, that the wraparound services exist but they do not actually wrap around?

Ms STEPHEN — No.

Ms LYONS — There are gaps, so there are inconsistencies. So whether it is entry to a service, access to a service, timely access to a service — it really does depend. And often it does depend on the parents’ skills. As someone mentioned this morning, often the parents become more knowledgeable than the health professional that they are going to see. I mean, we would hope that that is not the case, but sometimes that does occur. The

parent may go to the GP and be told, 'No, don't worry. Your child is a boy, he's the third child in the family, so we would expect that his language is delayed'. So there is a lot of misinformation out there.

Sometimes families, you are right, are not ready for a diagnosis, and I guess the main thing that we want to stress today is that the diagnosis should not be the only pathway to support. It should be very much based on what the needs of the child are, whether they have a diagnosis or not, and if there are needs for that child, then they should have access to the support that they need, and that is not occurring. And it should be multidisciplinary, and it should be team based, and it should be family centred.

We know what works and we know what that service should look like, but that is definitely not available to everyone, and we know that in Victoria in particular. The Murdoch Children's Research Institute spoke about this to the Senate inquiry. They showed a map of Victoria where they had mapped the needs of children in Victoria based on cognition and language, and then they had overlaid services — speech pathology services — on that, and they were all in the eastern suburbs predominantly and very few in the regional and rural areas.

The CHAIR — I think we are probably very aware of that.

Ms LYONS — Yes. That is so unjust. The people who have the greatest need have the least access to services in Victoria. And what we do know is that early intervention works, so the earlier you get in to support these families and children, the greater the outcomes are going to be. You can maximise their strengths and you can work on their weaknesses and you can get them transitioning into mainstream primary schools, predominantly, and get them learning.

That is the other issue that we have. It is that often these children are undercapitalising on their potential for academic success. Often people underestimate them and they think that they will not be able to learn to read and write, particularly in special developmental schools. We hear time and time again that the focus is more on life skills rather than academic skills and that even some of the students who have quite complex communication problems can actually learn to read. But they are not being allowed the opportunity to do that, because there is this low expectation of what they are actually going to be able to achieve. So that is certainly something that we need to work on. There needs to be a lot more education about what people with ASD can achieve if they are given the right opportunities.

Ms STEPHEN — I think that there is not nearly enough support for the people in education at whatever level — early intervention education — the people who are trying to support the individuals with autism spectrum disorder and the families. There needs to be a lot of information, a lot of education, because with the right information that is when you can make these things possible. With the right information about how to educate students with autism spectrum disorder, you can get amazing results. Most of the time in the classrooms we see that teachers really are scared and are lost and often rely on the support of integration support to make sure that the child is kept safe in the classroom rather than actually being educated in the classroom.

The CHAIR — Thank you very much.

Ms McLEISH — I have got a couple of questions around the process of referral. How often do maternal and child health nurses refer to speech pathology?

Ms LYONS — I would not have a figure, but I would say that — —

Ms McLEISH — Gut feeling?

Ms LYONS — Fairly frequently. That certainly has been my experience in my practice — that I would often receive a referral from a maternal and child health nurse. I was working in the private sector, and usually what we try to do is develop really good relationships with the maternal and child health nurses in our areas, because we know that by building up those relationships, that is going to support them to then make those appropriate referrals. I used to go along to the mothers groups and present on what is typical language development and so on and tips on how they can support their child's development.

Ms McLEISH — What about ages? Do they send them off at, what, two or three?

Ms STEPHEN — It depends on the knowledge of the maternal and child health nurse. I think overall they have a good understanding of red flags, and so now they are probably referring children early, which would be

two years of age. But we are now seeing referrals as early as 12 months of age for those who are experienced and have the knowledge. As Christine was saying earlier, support can be provided. I think we are focusing on the individual or the little child with autism spectrum disorder, but this has a massive emotional and physical impact on families.

I would just have to say that one of the really positive things about diagnosis is, if you have got a child that you are using all of your natural instincts in terms of raising and it is all not working and everyone around you is telling you that you are not a good parent and you just need to set firmer boundaries, that places a massive strain on relationships, and so a diagnostic process in itself helps relationships and families to understand what is going on and you actually see a lot of progress in the family and in the child even through the diagnostic process.

Ms McLEISH — What about the referral process from GPs? How often does that happen by comparison?

Ms STEPHEN — I think that is very low in comparison.

Ms McLEISH — So you would get most of your referrals from — —

Ms STEPHEN — Maternal and child health, the very early ones.

Ms LYONS — Self-referrals, maternal and child health nurses.

Ms McLEISH — Not necessarily the very early ones.

Ms LYONS — Typically referral from GPs for speech pathology is low. It has improved over time, but there is still some work to be done in that area. I think there are a whole range of reasons why that might occur. One of the presenters this morning spoke about going to the GP for a cold and ending up at the paediatrician because the GP had noticed that there were obviously some other difficulties. I was really heartened to hear that, because I do not think that is often the case. Typically you are going along to a GP because there is some medical issue, and unless they are very skilled at asking the right sorts of questions and delving deeper, the child's behaviour, the communication and those sorts of things may not even be discussed at that time.

There is some work being done in that area. HealthPathways Victoria are developing some clinical pathways. They are working on one for behaviour at the moment. They are the sorts of things that we need which provide really concrete information about what to look for, what questions to ask, so that when a parent brings a child and specifically if they are bringing the child and saying, 'I'm concerned about them not talking or about their behaviour', the GP has the right knowledge and skills to be able to ask the right questions and then determine what that pathway might be.

Typically in Victoria it can take up to two to three years for a formal diagnosis to be made from when the parent is first reporting concerns. Those concerns might be to a maternal and child health nurse, another family member or a childcare worker, but there is a long delay between them first saying, 'I'm a little bit concerned about something to do with their development', to when that diagnosis is actually made.

Ms McLEISH — Through the process of schools, where you said if there is a speech pathologist linked to a school they are primarily focused on assessment rather than taking them to the next stage and helping that person, what then? So the school speech pathologist assesses somebody, and then what do they do?

Ms STEPHEN — The assessment that we are talking about there, sadly, is not necessarily for autism spectrum disorder.

Ms McLEISH — It is general?

Ms STEPHEN — Yes. It is just general assessments of children that have been referred to them by the school. I just wanted to add that I think the next level of referral comes from kindergarten teachers. I think kindergarten teachers are very good at identifying children who are struggling with the social learning environment of the kindergarten. So it sort of goes from maternal and child health to kindergarten, and then sometimes in between you will get some childcare educators who have had experience in this area.

But back to the schools, if the school speech pathologist thinks there is an autism spectrum disorder involved, then they need to refer out to another team for assessment. But they do have — —

Ms McLEISH — Another team or a private practitioner?

Ms STEPHEN — There are several teams in Victoria that will do a diagnostic assessment, or you could refer out to a private practitioner who would create their own teams. You are referred out to a speech pathologist, and then they would work with a psychologist and there would be a paediatrician involved.

Ms McLEISH — I would assume that if the school speech pathologist recognised some ASD, they would be very quick to refer.

Ms LYONS — You would hope so.

Ms McLEISH — You have not had many?

Ms LYONS — Well, I think we also have to understand that there sometimes is a gap in knowledge in the speech pathology profession as well. A lot of the speech pathologists who are working in the education department are young, new graduates who potentially do not have the knowledge and expertise and may not have the support and supervision that help them to develop the skills to be able to identify these children. If you are looking at school-aged children who do not have a diagnosis, then it is not always really clear-cut. You really do have to delve down. If they have not been diagnosed until they reach school, it often is not an easy thing to diagnose.

Ms STEPHEN — And it will be more around, again, behavioural concerns that start to emerge.

Ms LYONS — And often girls as well. So a lot of girls will slip through the system, and it will not be until they actually reach perhaps grade 3 or 4 when issues with friendship groups start to emerge or concerns about either them being accused of bullying — or vice versa, that they are being bullied by their peers — and that often has a lot to do with their difficulties with social relationships.

The other thing I think to point out with the speech pathology workforce in schools is that at present they are not being used in the best way that they can, so it is not best practice speech pathology that is being offered in schools. Best practice speech pathology in a school setting is response to intervention where you have the three levels of support: you have universal classroom activities, you have small group support and then, if needed, you have one-on-one support. That is not being universally used in schools, firstly, because there are not enough speech pathologists to provide that support; also because there is not a strong understanding of response to intervention in the school setting — in the individual schools themselves — so they are not asking speech pathologists to be involved in their schools in that capacity. We also do have to do some work with our speech pathology workforce to also train them up as to what is best practice and how they can advocate for them using best practice within schools as well.

Mr FINN — I am just wondering about the reluctance of parents to accept that there is a problem. How do you deal with that when somebody — for example, an infant welfare nurse — refers the matter to you and the parent says, ‘Oh, no, no. There’s nothing wrong with my child’. How do you go about tackling that?

Ms STEPHEN — I think from my 30 years of experience in the area there is no one way to deal with any particular family. That is important for the skill and expertise of the speech pathologist, so looking at the particular family circumstances, the cultural circumstances can often be very sensitive. What is best practice in terms of best practice, if you cannot actually provide a diagnosis, is intervention; it is actually getting some support. I do not think there is a hard and fast rule. I think every family needs to be dealt with by looking at all of those circumstances.

If you want a blanket statement, it is that you are going through a detailed and internationally best practice process of having a psychologist looking at all of the emotional issues in the family and the family dynamics and attachment, the speech pathologist looking at the language and the paediatrician looking at the medical situation. I think when a family actually goes through that best practice, at the end of that they can say, ‘Yes, I can see what’s happening here, and I can see that we need the support’. Often when it is rushed, when maternal and child health might suggest it, and then they go to a speech pathologist or if they go from maternal and child

health straight to a paediatrician and it is diagnosed, families are often shell-shocked. That is not international best practice, and that is why.

Ms LYONS — I think also we have to get away from the stigma. In my experience the reason why parents did not want a diagnosis was often that they thought or they had experienced either with another child or seeing children in the community that they were worried that their child was going to be discriminated against. So I have had parents who have said to me, ‘Please don’t tell the school that my child has a diagnosis of autism, because they will be treated differently and I don’t want that to occur’. So we need to get away from there being the stigma around the diagnosis of autism. If children are diagnosed with asthma, no-one discriminates against them. So we need to make sure that that is the same with autism. It is just a difference. There are many strengths that people with autism have, and we need to be focusing on them.

It is also about education. If parents understand what autism is, if their wider family understands what autism is, if teachers, if childcare educators and so on, if we have a greater awareness in the community of what autism is and we get away from the stigma around it, then parents will not be so reluctant to go down the path if they have a diagnosis, because they will understand that it does not mean that this is a life sentence for their child. It does not mean that their child is not to go on to be in the workforce or get married or have children. They are often the things that people are most concerned about when you start to talk about autism. Will they be able to talk? Will they get a job? Will they be able to go to mainstream school? Will they get married? Will they have their own children? And often the extended family, because of a lack of knowledge, are saying to them, ‘No, there’s nothing wrong with them; they’re fine’, because they do not want them to go through this upset of there being a problem.

Ms STEPHEN — I think also, and I have to come back to reinforcing what Christine said about the education of society, it is also about the very high level education of how you support these children and families, because I think the stigma also comes from fear of, like, ‘Oh, my goodness. If we’ve got a child with autism in our family or a child with autism coming to our child care, how do we deal with this? We don’t know how to manage’. As we always know, in society fear leads to these stigmatised reactions.

Mr FINN — We have heard and certainly I have heard, over a number of years now, from parents who had a diagnosis delivered, and they are just sort of left to their own devices. From your perspective, what happens now after a diagnosis is given, and what do you believe should happen?

Ms STEPHEN — Thank you for that question, Mr Finn. I think it is a key question. I think that the family needs a huge wraparound support at that time of the diagnosis in terms of where to now. What they want is education and they want intervention, and they want to know how to do the intervention themselves if that is the right method and the right choice for them. They actually need people around them that can give them evidence-based, experienced advice. I think once the family go on that journey, then they very much can take over a lot of that self-determination themselves and really have very successful outcomes.

Of course I think what concerns me a great deal is the waste of time, the waste of opportunity and the waste of knowledge at each of the transition points for children with autism spectrum disorder — from the diagnosis to the early intervention to the school transition, through primary school and the secondary school transition and the workplace. At each of those points there is so much loss of opportunity and knowledge about that particular individual’s potential.

Mr FINN — What should we be doing? From the day that the diagnosis is delivered, what should we be doing?

Ms LYONS — I think that we need to have an approach to how we manage that. At the moment what we find is that, for instance, with the commonwealth government funding through the Helping Children with Autism program there are four funded sessions for assessment, but there is no funded session for a feedback session or collaboration between the parties involved — so the health professionals involved. So that I guess sets up this gap straightaway because it is not promoted within the funding scheme. We do need to have something very systematic. We know what works, so we know that the families need the opportunity to sit down with the health professional and talk about what the diagnosis is and ask all the questions that they need to ask, and that can take a lot of time.

Rob, you had experience with that this morning, where you had to rush off when the parent most needed you to continue the conversation, and that was after an hour's conversation. These conversations can take time, and the parent needs thinking time as well. They need to go away and they need to be able to have the opportunity to come back and sit down with a health professional to talk about what it is and what questions come up for them. Then they need to be provided with all of the advice about what their choices are regarding intervention.

Ms STEPHEN — Ideally in a scenario where you had one person connected to that family that was the link between all of the services — I am just talking Eutopia here — but this is what happens.

The CHAIR — A one-stop shop.

Ms STEPHEN — I think that is a possibility — I see what you are saying — but it is more about that there is an expectation that there is a best practice model. We know the best practice, and that should be a best practice model that diagnosis should begin within three months of concerns and then early intervention; we know exactly what that looks like. Then there is a big gap to transition. The child could have a fantastic early intervention program, and then you as a speech pathologist can be blocked at the specialist service door when they start in primary school. Their PEC system which you have developed with them can be left at home because they are going to have a new PEC system at school which takes six months to set up. It is like telling a kindergarten child, 'You're not allowed to speak now that you are going to school. You're not allowed to speak anymore. You have to wait until we give you permission to use the words we use at school in six months time'. I think it is about best practice. We need a pathway of best practice, we need that expectation and we need the services to support that pathway.

Ms LYONS — And that best practice is known. It is not like we are going, 'Well, we don't actually know what is best practice'. Best practice is known; it is articulated. There are clear guidelines about how diagnosis should occur, and there is clear evidence about what works in early intervention. It is just joining up all the dots.

Mr FINN — Speaking of best practice, world's best practice demands that each child receive 20 hours of early intervention a week. At the moment my understanding is that with publicly funded early intervention you would be lucky to get two or three; in fact it would be quite remarkable if you did. How does that hamper your job in helping the individual child with so few hours of early intervention?

Ms STEPHEN — I think in terms of the world's best practice of 20, 23 to 25 hours of intervention we have a range of evidence-based interventions. Evidence-based interventions in terms of parent coaching and parent applying the intervention in the naturalistic setting at home and other family members doing the same can be part of that 20 to 25 hours of intervention. It does not have to be where you take a child to a centre and to a clinic. Speech pathologists work across a broad range of approaches but are particularly confident in that area of parent coaching and parent intervention, so the child has an intervention.

But, yes, it is still very much inadequate in terms of the actual hours of service. I mean a speech pathologist might be trying to do that sort of intervention once a fortnight. I see children once a fortnight, and you have a 45-minute session, or you might run parent programs in the evenings where you are coaching parents, doing home visits and helping them to put that into the home. So I think that is a question about the adequacy of the service, and I think it is inadequate.

Ms LYONS — I can give you a really good example.

The CHAIR — I am mindful of the time. I am sorry. It was a great question, but Paul would actually like to ask a question.

Mr EDBROOKE — Thanks, Robyn and Christine, for coming to the hearing today.

Ms STEPHEN — Pleasure.

Mr EDBROOKE — I understand as speechies you have got a unique perspective, I guess, across the board. Earlier on you mentioned that sometimes it can take up to three years to complete a diagnosis. That seems like an awfully long time of missed opportunities and being able to treat weaknesses and prop up strengths. You have outlined some of the hurdles that attribute to that, I guess. What is the solution to get through that? Very quickly, what are some of the things you can see as speech pathologists to get through that three years, because the earlier we can conclude a diagnosis, the earlier we can start treating?

Ms LYONS — We certainly need to have, whether it is national or state-based, someone who says this is what a diagnostic process looks like. At the moment in Victoria we do not have a mandated diagnostic process for ASD. People are confused about how to go about the process and who should be involved, so that is one of the barriers to getting an early diagnosis and a quick diagnosis. We need a lot more education about what some of the early signs are of children with ASD, so education, training — —

Ms STEPHEN — And I think we actually do need many ASD specialist autism assessment teams available on a no fee basis, because we have had people come to the practice and have one assessment session. We are trying to do it as economically as we can, but we do need to see the child in their childcare environment, and the parent cannot afford to have an out of rooms visit to complete the assessment.

The CHAIR — Thank you very much. I have two quick things. One is we were talking a lot about diagnosis, and at the start of your presentation you mentioned that to break down the stigma we actually have to move away from diagnosis and treat children based on what their needs are, whether that be speech or behaviour or whatever, before that diagnosis is made or needs to be made or has to be made. It is kind of catch 22 really, is it not?

Ms LYONS — It is.

The CHAIR — I just quickly wanted to acknowledge that we have on the one hand the need for early diagnosis but on the other hand a real need for society to break down the barriers around what autism is and what people with autism can and cannot do and to perhaps that individualised approach to early intervention before diagnosis even commences.

Mr LYONS — I think the NDIS gives us the opportunity to move away from needing to have a diagnosis before you are provided with early intervention. So I guess that is the model that we would be supporting, and it is not one size fits all. As Robyn said, sometimes that diagnostic process is really important for the family, and then there are other families who say, 'I don't want to even know what the diagnosis is. I just want to know how to help my child'. So if we can provide them with the opportunity that if they want to have a diagnosis, they have got somewhere they can go and they can go there quickly and easily and at low or no cost, but if we can also provide other families with the support to know how to work with their child and optimise their strengths and work on their weaknesses, then that to me is best practice.

The CHAIR — Thank you so much for your presentation today. We really appreciate it.

Mr LYONS — Thank you.

Ms STEPHEN — Thank you.

Witnesses withdrew.