

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 29 August 2016

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Associate Professor Jill Sewell, deputy director, Centre for Community Child Health, and

Ms Charmaine Bernie, senior occupational therapist, Royal Children's Hospital.

The CHAIR — I welcome you both to today's public hearing. Katrina Williams, director of developmental medicine, is an apology today. Associate Professor Jill Sewell of the Centre for Community Child Health and Ms Charmaine Bernie, senior occupational therapist from Royal Children's Hospital, Melbourne, thank you again for coming along today. All evidence at this hearing taken by the committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege. It is a contempt of Parliament to provide false evidence. Recording of the proceedings will commence today and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections. I am very mindful that we are very, very behind our schedule today, so I would ask you to perhaps present for just 15 minutes, if that is okay.

Assoc. Prof. SEWELL — Yes, we are very mindful of that and intended to do so anyhow, so that is all right.

The CHAIR — Our apologies for keeping you waiting.

Ms BERNIE — We understand.

Assoc. Prof. SEWELL — We prefer to leave more time for discussion. I just do want to add Katrina's specific apologies. She has been called away with a family emergency and was not able to get back in time. Thanks for this opportunity to speak. We are really representing the Children's Campus, so we represent a very strong, clinical understanding about autism and other neurodevelopmental disabilities. The Melbourne Children's Research Institute, just like Cheryl's, is a very strong and broad-ranging research institution — of course the University of Melbourne is very interested in the training of all sorts of health professionals and others as well.

I would like to start by just briefly describing what I would call the state of play at the moment. The state of play is basically lots of gaps. You probably already had some of those pointed out, but there is a lot of unmet need. As Cheryl has been speaking about, there is a gap in the capacity for diagnostic assessment across the state of Victoria, and access to services for all who need them. I really want to talk about that it is one thing to get good early diagnosis, but it is wonderful if you have got good early intervention to follow good early diagnosis. That is the big problem in Victoria — it is not just the waiting for accurate diagnosis, whether that is earlier or a bit later, it is access to sufficient early intervention for the children who are diagnosed.

Then we also want to emphasise the really significant importance of coordination of care, particularly between health services, disability services and education services, because we do fall down there. We also see the gap for professional training, which I heard Cheryl mention. Although there is a lot of research going on, there is still a lot more that is required to really understand what we are dealing with here and how best it can be helped. You get this vicious cycle of the incomplete or delayed diagnosis, and delayed or inappropriate intervention, which leads into less ability to meet the ongoing needs of children with autism. Then you have got the fewer accessible services in other ways for those who are waiting.

I am not sure whether you are aware that in Victoria — I will just do another sort of prefacing-type comment: as paediatricians and other allied health working together in a setting like the Children's we see lots of kids with autism, but we see lots of kids with other sorts of neurodevelopmental disabilities, and an absolute difference between those is not an easy thing. They are like overlapping Venn diagrams a lot of the time. So we take a broader perspective at the beginning and say, 'What is it that we are dealing with?', and if we think there is a strong autistic component obviously we will go down that diagnostic pathway, but we are against in principle an autism pathway because what about all the other children who will overlap with autism? I will just state that from the beginning.

But from another perspective the way things are set up in Victoria, is if you have got one developmental delay in early childhood — so, for example, if you had language delay, which many children present with if they are on the autism spectrum — many others do as well — then they are able to get allied health early childhood services from a community health centre. If you have got more than one developmental problem, then you have to go into early intervention. So I see children in whom the maternal child health nurse has noticed something and referred them to community health centres for speech pathology maybe. The speech pathologist realises that there is something else going on, so the child immediately is stopped being seen by that community health

service and goes onto another waiting list for early intervention with some sort of diagnostic process in between. So this whole sort of separation of services and separation of diagnoses is the big problem, I think.

You asked Cheryl some questions about prevalence. This is quite an interesting graph from a study that was done in Sweden, and the blue line is the sort of level of, if you like, autistic traits, which at the time that this was done about over about 20 years and representing about 1 per cent of the community — we can argue about whether it is 1 or 2 per cent, but let us just say 1 per cent — they did a longstanding twin study, and they showed the actual diagnostic rate going up over this time, even though the absolute level of traits in the community is much the same. So this is about the greater awareness and the greater recognition of children on the autism spectrum, even though sort of the underlying range is probably much the same. There may well be some biological influences, as Cheryl has just said. I do not think we really know, and people around the world do not know. Everybody is looking at it and nobody really knows absolutely for sure.

There is a lot in this slide. This is how we think about it from an overall, you know, health and developmental service point of view. So we have got primary care services for all kids in the bottom part of this pyramid. Obviously that is maternal and child health nurse, general practice, community health centre-type activities, and they do a lot of general support for families. This is a very good surveillance program — the one in Victoria is by far the best in Australia — to be thinking about children with particular problems. So they identify potential developmental difficulties, and they will provide some support and access to first line-type interventions, which might be language support, it might be parent training — all sorts of things that are out there.

Then we get onto the secondary level services, which is where the more diagnostic services occur using paediatricians, child psychiatrists, allied health teams and children getting onto early intervention teams, which are sometimes required, and then the early intervention teams refer on to assessment. Then once you have assessment, then a wider range of early intervention is available, including access to the HCWA funding, which of course has been rolled into NDIS, so all that is going to change, and we do not know quite how it is going to change as yet.

And then we have got some tertiary services. That should be a tiny little bit of the pyramid at the top. These are for the children who have really major concerns. We talk about CAMHS, child and adolescent mental health services, providing diagnostic, but they are very geographic. They will only do their geographic region, and they are mostly for children with significant mental health issues as well as their possible autism diagnosis and often parents with significant mental health issues as well. So they see a very, very small percentage of children. They will never see a big percentage because of the way their services are set up. But some of those children really require very, very expert attention and care with the really complex conditions that they have got, again overlapping comorbidities that we see all of the time with these sorts of children.

Now, Cheryl was speaking a bit about the way paediatricians diagnose autism spectrum. There was a study done recently of general paediatricians in Australia, so this is not specialist developmental paediatrics in specialised services. What does everybody out there in the streets of metropolitan wherever or regional wherever — what are they seeing, how are they doing their diagnosis of children? So this is a questionnaire-type study. This is what the paediatricians out there are saying — over 80 per cent of them do their own observations, which are very important. Three-quarters of them take parent report, but of course that is very significant. Forty per cent take teacher or childcare report, so this is what happens in a different setting, but it is much more so from child care than teachers.

Once the kids are at school there is much less access to teachers for various reasons. A third of them use the speech pathologist diagnostically and 30 per cent of them use the psychologist to get a cognitive assessment. So that is telling you it is not ideal ASD diagnosis, but it is telling you what the real world is like out there in terms of access to the sort of services that are required to do an appropriate full diagnosis.

Here you get the waiting list times. Say, in my paediatric clinic, if I was a general paediatrician in the community, half of us will say we have got a wait time somewhere between 4 and 11 months, but most of us will see kids before 12 months is up. A public or a bulk-billing psychologist is somebody who is very, very thin on the ground, and over half of them have got either no service at all — the reality — or we have lumped together over 12 months wait as well. And only 37 per cent can see kids under 11 months, so there is not many bulk-billing public psychologists. Private psychologists — they whip in and see them straightaway. There is only a 6 per cent wait to see them.

It is the same thing with speech therapy: 31 per cent say that they either do not exist or there is a more than 12-month wait, whereas 55 per cent can see them within that 1 months. But private speech therapists, they will get in there and see these kids. A lot of what the funding has done is to shift the HCWA funding — and there are graphs to show this. There are undoubtedly shifted funds from the public into the private sector, because these allied health professionals have moved out of the public sector into the private sector because there is a funding mechanism to do so, and the original issue of making those services more available to families, more accessible, has been made difficult because, just like lots of doctors, private psychologists and private speech pathologists charge a gap on top of their Medicare rebate.

The CAMHS services also have an over 12-month wait or a long wait in the meantime, and other multidisciplinary services also have a very long wait. So that graph just tells you that for paediatricians working out there in the community this is what they have got to deal with on their day-to-day; where do they send a kid for assessment? We can find assessment services for children under school age, but there are virtually no public services or absolutely minimal public services for assessment after the child has reached school, unless there are very significant mental health service problems as well and they can access a CAMHS service. It is a very, very big problem for us to try and help those children reach diagnosis and reach the sort of intervention that is required at school, even if they have missed out on early intervention.

So what we see is that we have got health services doing a lot of stuff, schools doing a lot of stuff — some of it very good. Disability services do stuff. What NDIS will bring into that we are not absolutely sure yet, but there are roadblocks and barriers all the way into the integration, and what we want to see is those services acting well together with the child and the family right in the centre. We want to break down those funding, geographical, professional, language paradigm barriers that occur between these things. We are all sort of talking about the same child, but we use different language to speak about them.

We would also argue for a centre of excellence which links up the wide range of clinical services plus education plus research, and provides availability to reach out into the broader community as well. A centre of excellence should always have an extremely strong statewide and outreach-type program where translation of the research is done, where training is done and where support for evidence-based early intervention is done as well. This sort of thing might help. For a diagnostic assessment you have got to have high-quality services in every region of Victoria. You have got good coordination between those primary, secondary and tertiary services that I mentioned before.

We have got to have better access overall. I am sure that other people have said to you already this morning the access in places like the western region of Melbourne is just pitiful — absolutely pitiful. Of course we work in the western region all of the time at the Children's hospital. And we have got to improve coordination and access to expertise across these areas, but we have really got to build on what is there now, build on local partnerships. We have got a fabulous maternal and child health service in Victoria. Other sorts of linkages to other services could be done much better and be much better coordinated.

Then we need to link the regional centres to central expertise, the sort of expertise that Cheryl can give about certain aspects of care, and the expertise that somewhere like the Children's can give with that sort of broader focus on neurodevelopmental disability overall, with autism as a very significant part of it — and having that capacity then to collect data and evidence so that we can measure what we are doing and do better into the future. So then we would reach what we hope would be that virtuous cycle of better diagnosis, which represents an access issue, an equity issue and a workforce capacity issue.

Clarity of needs: and we are hoping that with the NDIS that it will be a needs-based assessment for these young people. You do not have to have a formal diagnosis to get going with needs. Then appropriate intervention and support across the life span, and hopefully, as Cheryl said, decreased needs as early intervention is functioning well. And then you have got more resources available for others across the life span. I will stop there and be very happy to take some questions.

The CHAIR — Thanks very much, Jill, and thank you for your submission to the inquiry. Your work here in this area is much appreciated. You hinted at your concerns around the NDIS. Can you elaborate on that and how you think the rollout will impact on people with ASD?

Assoc. Prof. SEWELL — Look, I think the principles of NDIS are fantastic. We are all looking forward to it when it is really properly up and running and we are using it. But it is unclear because it is still at a rollout

phase. So, for example, having had the Barwon site as a trial site, we have now got the north-west Melbourne rollout, and we do see some children from that area, but it is still pretty unclear. It is not ready for rollout; it is still rolling out.

With autism spectrum disorder I am very pleased that it is going to be needs-based rather than diagnosis based in early childhood — I think this is really critical — but we do not know yet what those needs look like. So, for example, with autism spectrum disorder, it is a spectrum. We know that the kids at that end of the spectrum are going to have a lot of needs; this end of the spectrum will be those sort of shy, nerdy adults that we all know. You might even have some of them in Parliament; I do not know — —

Mr FINN — We have got a few, yes.

Assoc. Prof. SEWELL — I have certainly got some colleagues like that at the Children's hospital. Apart from good services across the community overall, good maternal and child health surveillance, good child care, good kinder, good schools, there are lots of people who are on the spectrum of all sorts of conditions who do very well and do not necessarily need some specialised support. It is the grey area of children that are the ones that in our service, the Centre for Community Child Health at the Children's hospital — we see a lot of those kids in the grey area. It is easier in a way if they are at the far end with associated major comorbidities. But it is the children who you are not quite sure — it might be, it might not be; you know if you do some good early intervention it would probably improve their outcomes. It is the sort of thing that in the past has driven a diagnosis in the sense of, 'If I've got a diagnosis, I'll get some funding to do something', and that is really the wrong way around and puts a lot of perverse incentives into the system.

So I think NDIS has got a good opportunity to make a difference with that. Once we know what their needs-based assessment tool is capable of measuring — and whatever sort of funding you have got, there has got to be a cut-off, so I am always interested in the kids on the edge of the cut-off — —

The CHAIR — So in the trial in Barwon have you seen how is it actually working down there? Is it working well, or do you think there are people falling through the gaps?

Assoc. Prof. SEWELL — There will always be people falling through gaps. I do not think you ever stop doing that. But I think there is capacity for less falling through the gaps than there was. There are a few reports coming out of Barwon now. The reason I am hesitating a bit is I have not seen it sort of ready for implementation for the kids that I see from north-west Melbourne as yet. I am really looking forward to doing that, but I think that the principle of what they are doing is likely to have a better pick-up, as long as we do not expect it to pick up every single child on the spectrum, because I think there are some kids on the spectrum that can be managed, as I said before, with normal community services, and again I think we do that well in Australia overall and we do it very well in Victoria. We have good mainstream services for all children, and that will help a lot of kids with mild problems. And then our aim is to get the kids with a bit more need into an early system.

They might get through a diagnostic without falling through the gaps, but early intervention services are so thin on the ground in so many places. NDIS is not going to suddenly make that better. You are not going to suddenly have 20 paediatric speech pathologists to put into the western metropolitan region of Melbourne like that. You are not going to pull people out of the private sector back into the public sector, I do not think, for a long time yet, until we work out what is going to happen. Of course this is family driven. Families are going to be able to buy services, but we would like to have services out there that families are happy to go to rather than trying to work out how to buy services for their kid. That is not good for the families, really. We should have good local teams who provide good diagnostic assessment, good therapeutic early intervention that families feel confident to go to. The choice mantra of adult NDIS is not so important for children, because it is out there and ready for them. That is what we should be aiming for.

Ms McLEISH — Thank you for coming in today. What do you see as the main factors that can be there to break down geographical barriers? Most of us are from country areas, and it is always an issue. I do not just mean the large towns like Bendigo, Shepparton and Geelong; I represent all small communities, where 5000 people will be the largest town.

Assoc. Prof. SEWELL — I think it is workforce capacity overall, and that is for all sorts of reasons. In a small town you are not going to have a highly specialised service, but you should have well-trained maternal

and child health nurses and well-trained GPs who can do a lot of this baseline work. You are not going to have a paediatrician in the small towns that you represent, whereas you can have them in Bendigo or Ballarat. So it is strong links to those GPs, and in the end that means much more in the way of things like telehealth services — using modern technology for much better communication. We have got so many artificial barriers. You drive for 2 hours, see me for 20 minutes and drive home for another 20 minutes. We use telehealth, but there is a lot more that can be done about that in the future.

But it is actually providing the workforce that is there — your childcare centres, your kindergartens, your schoolteachers — with some overall understanding about children with neurodevelopmental disabilities, including autism, what they can do in their ordinary, everyday setting to improve the chances for that child and help the families in their great need for support, but also then have access to a planned process of next stage and next-stage help. That, I think, can be really helped by — we commented in our report on the rehabilitation model, where you got a sort of statewide model where there is a responsibility for the major centres to be providing workforce support and education and training as well as outreach-type clinical services into the broader reaches of Victoria. I do not think it will ever be easy to have a kid with autism in one of those small country towns that you represent.

Ms McLEISH — No, they often leave.

Assoc. Prof. SEWELL — Yes.

Mr FINN — Thank you so much to both of you for coming in today. You have given us a very good idea of what you are up against every day. I have a very simple question — or maybe it is not; I do not know; we are about to find out — those issues that you do come across or come up against every day, how much will it cost to fix them?

Assoc. Prof. SEWELL — Well, I could use the word ‘lots’, but what I think is that we have actually got a lot of good services in place, and I think what we should be putting funding into is better systems and collaboration. We do not want to invent a whole lot of new services; we want to make what is there much better, and I think the cost of that is not as great as you might imagine.

Mr FINN — I will be very, very pleased if they are not.

Assoc. Prof. SEWELL — I am sure you would. I have been around for a long time, and you need to be realistic. In all the work we do in the Centre for Community Child Health we are trying to think, ‘What’s already out there and how can we build on what’s there?’, rather than, ‘How can we put a new service in that hasn’t been there before?’. We do not need to do that with kids. But we have all got different databases. The education database does not talk properly to the health database. You need all of that sort of thing to happen, and then you can start to break down barriers. They are often much better done in small country towns where everybody knows each other — much, much better done than in metropolitan Melbourne. There are pockets of metropolitan Melbourne that operate like communities, but the small regional towns actually do a lot better with that sort of coordination.

It shows how it can be done where you talk to each other, run into each other down the street, but I think we need the systems behind it — the data systems for the collection and evaluation of data. If we could put all of those together, we would have so much more information about how we could improve the system. That, I think, is critical to what needs to be done. So if you can build on the last 20 or 30 years of getting data linkage in Victoria, like they have in Western Australia, I would be very pleased.

Ms COUZENS — Thanks for coming along today. My question is more around research. From your experience, what do you think the focus of research should be?

Assoc. Prof. SEWELL — I think the focus on research should be effective intervention. We already know about some things that have been shown to be effective, but we have got to be realistic about intervention as well. For example, ABA, applied behavioural analysis, has been shown to be effective for kids with severe autism. You need about 40 hours a week to do it. You are talking about maybe 1 per cent of the autism community who can afford that. What about the others? What can we do that is a bit more realistic for ordinary everyday people in the street, and what is the most effective way to change the outcome for those sort of people? So I think it is about realistic intervention evaluation. That is what we need much more research about.

The CHAIR — Thank you so much for coming today. Your public submission has been very valuable, so thank you very much. I think we are seeing this morning that there is a lot of great research going on out there. How we actually implement that is our challenge.

Assoc. Prof. SEWELL — Yes. I do not envy your task.

The CHAIR — Thank you again for coming today.

Assoc. Prof. SEWELL — Thanks very much for the opportunity.

Witnesses withdrew.