TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 29 August 2016

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Professor Cheryl Dissanayake, founder and director, Olga Tennison Autism Research Centre, La Trobe University.

The CHAIR — Welcome to these public hearings, Professor Cheryl Dissanayake, founder and director of the Olga Tennison Autism Research Centre, La Trobe University. Thank you for attending here 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, Professor, to make a brief presentation to the committee. Thank you.

Visual presentation.

Prof. DISSANAYAKE — Thank you very much, and thank you for inviting me to speak with you today. I am a developmental and behavioural scientist and so I come from a background of very early child development. As you mentioned, I am also the director of the Olga Tennison Autism Research Centre.

Just to provide some context, we were established in mid-2008, and there is a nice picture of Bill Shorten with more hair than he currently sports. Bill opened the centre for us because he was parliamentary secretary for disability at that time. Our mission, really, within the centre is to advance knowledge on the nature, causes and treatment of autism spectrum conditions. Across the centre our research spans across the lifespan — beginning with signs in early infancy, early diagnosis and early intervention — and to how best to facilitate transition into adulthood and helping people with autism, trying to understand barriers and enablers, into the workplace. But what I would really like to do today is focus on the first two years of life, because I think we as a society can do our best work here to alter the developmental outcomes for these children and their families.

We have a lot of expertise at OTARC in very early development and on the very early signs of autism in infants. We have used this knowledge to train community-based professionals to identify children developing autism within the first two years of life. Much of this work has been undertaken in Victoria, but we are also working nationally and internationally to promote very early identification. Dr Josephine Barbaro, who is a research fellow at our centre, is leading much of this work in very early infancy.

I would like to provide some key facts about autism prior to moving forward. These conditions affect 1 to 2 per cent of the population. We know now that the onset of autism is variable across the first two years of life. So some children show signs soon after birth, while others develop typically and then the development simply plateaus. Others seem to develop typically but then actually lose skills around 18 months of age, but some children regress even later than this. The early signs are very subtle, and hence are often missed. However, these can be used as markers to identify autism prospectively, and diagnosis of autism is possible from as young as 18 to 24 months of age, with high rates of stability in early diagnoses. Of course this is important, because early identification and diagnosis enables early intervention, which we know promotes much better developmental outcomes in young children. What we do know is that early intervention really is able to increase the learning capacity of children with autism and there are consistent findings now of gains in cognitive functioning following access to early intervention.

Another fact is that parent and family stress is high and quality of life is low in families affected with autism. This is not just compared to typically developing families but to other families of children with developmental disabilities. So families of those with autism have the highest levels of stress and the lowest quality of life. We also know that early identification and diagnosis leads to a reduction in family stress and an increase in their wellbeing.

So one way of promoting positive outcomes for these families is, of course, by promoting early identification and diagnosis. However, currently in Australia children are diagnosed at 49 months. This paper was based on data from the Helping Children with Autism package, so we know this is an actual underestimate because it is only under seven-year-olds that access the HCWA package. Of the under seven-year-olds the mean age in Australia is 49 months, and so it would be older if you took that cap off. The mean age in Victoria is 50 months and, in fact, currently fewer than 3 per cent of children are diagnosed by two years of age.

We believe we really can do better. You might be aware of some of our work in Melbourne where over 30 000 babies have been monitored within the Victorian maternal and child health system using an approach we developed called social attention and communication surveillance. We have trained over 300 maternal and child health nurses in this state on the very early signs of autism and on how to monitor babies during their routine check-ups at 12, 18 and 24 months.

Across two very large studies what we found was that 81 per cent of the children referred to us by these nurses receive a diagnosis of autism by 24 months of age. The remaining children who did not have autism had either a language or a developmental delay and so were referred earlier than would have otherwise been the case. So we did not get any true false positives. Typically developing children are not referred. In fact in our first study we had 1 per cent of children referred to us by the nurses — that is, 1 per cent of children they monitored were referred to us — and we had an estimated prevalence of 0.84 per cent of autism. However, in our more recent study you will see that the referral rate has increased to 2 per cent and in fact 1.75 per cent have a diagnosis of autism, so this accords well with the increase that has been reported over the last few years and with what we say now, which is that between 1 to 2 per cent of the population will meet criteria for an autism spectrum condition.

I just want to tell you about the outcomes of these children. We have been following up these children from the first study we did. We saw them at 48 months and we saw them again at seven to nine years, most recently. We found that 86 per cent of children at age four retain their autism diagnosis which was given at age two, so there was a high stability. But 27 per cent of children had left the spectrum by school age — that is, by between seven to nine years of age.

But most remarkable, and I have put it on this graph, are the cognitive outcomes of these children. We did not provide these children with intervention; they went into the community and accessed what interventions they could. What you will see here is the verbal developmental quotient and the non-verbal developmental quotient separately, but if you can just focus on the pink, which is the overall developmental quotient, or, at school age, the full scale IQ, you can see the increase in IQ over time of these children. In fact what is most remarkable is that at 24 months, 64 per cent were meeting criteria for an intellectual disability, that means a DQ less than 70 IQ points. By school age only 8 per cent were meeting criteria for an intellectual disability.

We also recruited a group of children who were diagnosed between three to five years. So we had our sample that was diagnosed by 24 months and we recruited a sample that were diagnosed between three to five years, so before school age. We found that 77 per cent of our children who had been diagnosed when they were little were accessing mainstream primary school versus only 57 per cent in the older diagnosis group. Also, 60 per cent of our children were still receiving some ongoing support versus 90 per cent of children diagnosed between three to five years. The reason for this is very clear. Our children are diagnosed on average about 18 months earlier than the children who we recruited, the comparison group, and because they were diagnosed earlier they began intervention earlier so they actually received on average about 11 months more early intervention. This really does impact on their development outcomes.

So we believe that monitoring children using developmental surveillance very early provides a model where we can build capacity in primary health care professionals to reliably identify children developing autism. We need to train early childhood professionals on what these very early signs are. We are currently doing a full statewide implementation of this in Tasmania. We have just begun this work with Autism CRC and we have just trained all of their — they call them — CHAPs nurses in Tasmania. We are also undertaking this work internationally. We have been doing this work internationally since 2011 and, in fact, in Melbourne's sister city, Tianjing, in China, we have got the SACS into their seven-year health plan. There are 100 000 babies born in Tianjing each year as opposed to 60 000 babies born in Victoria.

There are several barriers I think that we need to talk about to early identification and diagnosis. The first is awareness of the very early signs, not just amongst parents but also amongst professionals. So, for example, a paediatrician saying this child is too young to diagnose with autism is not uncommon. GPs and paediatricians continue to think that this is not possible in very early life, so I think we need to change that. Of course you get pockets of excellence but across the board it is not recognised that very early diagnoses are possible.

A further significant issue, and I heard this referred to in the presentation previously, is, of course, the waiting lists for diagnosis. So even though some children might be identified early, in a timely manner, because we have done all of this training with these maternal and child health nurses, they end up ageing while they are on a waiting list for a diagnosis. Many of these waiting lists are between 6 to 18 months — we have done an audit of these waiting lists — which is a really long time in the life of the developing brain of a small child. In fact because of these long waiting lists the CAMHS teams prioritise children in their year before school. Now, I understand why this is the case, but ultimately it is really detrimental to child outcomes. So the CAMHS teams are not seeing children under three; mostly they are seeing older children and that is because of the lack of expertise on those teams in those very early years and because they have such long waiting lists they are trying to get those children a diagnosis before they enrol in school. So then families try to access private diagnoses to get a diagnosis quicker and, of course, because you need a multidisciplinary diagnosis, this is costly. It often costs around $2000.

On the basis of all of this we decided a number of years ago when we finished our first study to approach a number of philanthropic organisations. I went cap in hand, I gave many presentations, and with some funds we set up the first clinic of its kind in Australia, an early assessment clinic for autism, where we focused on just the under three-year-olds, because we realised that there was expertise in that older age group. A lot of the nurses were ringing us up and saying, ‘What do we do now?’ when our study was over, which really led us then to develop this clinic.

The way we ran it was that we saw two families a week. They came from all across Victoria to access the clinic. We just thought that we would be serving the north and the west but that was not the case. We undertook the developmental assessments using the gold standard tools for assessment and diagnosis and on the basis of these and, of course. clinical opinion. we referred children to the paediatrician for confirmation of the diagnosis so that they could then access the HCWA package.

This graph tells you about the referrals of the children — where they were referred to us from. We actually got more referrals from the maternal and child health nurse, but then they referred to the paediatrician and then the paediatrician referred to us so there is a little bit of a pathway that is represented there. We saw children between 12 and 36 months — under 36 months — so our mean age was 27 months. In fact this would have been younger, but we had a very kind intake worker who tried to fit in children just before they turned three, so you can sort of see the peak there at 35 months. That represents her preferential intake. But in fact as we moved on with the service we did go to the younger ages. Seventy-five per cent of children referred to us met criteria for autism. The remainder had either a language or developmental delay, so once again, just as with our studies, we were not seeing typically developing children being referred to us. Generally, when we saw children, we were always referring them for further services.

This is how we funded the clinic and in the years of running this clinic I had hoped to get state government funding for it — there is nothing like it across the country — but I was spectacularly unsuccessful in doing this. It took me more than a year to even secure a meeting with DHS, only to be told that all funds were expended into CAMHS and I had already done the trail around CAMHS, knowing that these children are not being seen by CAMHS. So very sadly last year I closed the clinic, in spite of our success in diagnosing these children very early, which really does currently mean that no-one is doing this work now. I think in not doing this work we are really failing 1 to 2 per cent of our children in this state.

In the meantime, and probably also because of some of our frustrations, we partnered with the fourth-largest IT company in the world. Luckily for us, the Asia-Pacific senior executive has a daughter with autism, and when we approached him, he decided that we would build it on the basis of their philanthropy model at salesforce.com. So we built our app and the way we have worked is we have taken our research with the primary health professionals, like nurses, and we have tried to put this into the hands of parents. We won the national iAwards a couple of weeks ago. We won the Victorian research and development award — we won the state one — and we are pitching for the national one tomorrow. The gala dinner is on Thursday and we hope that we might take home the prize.

The CHAIR — Good luck.

Prof. DISSANAYAKE — This app is, as I said, is based on the SACS study. It is video-led so that parents respond to a series of behavioural items by watching videos of a typically developing child, showing each item, and an atypically developing child, showing that item. Parents are then asked if the child rarely or mostly shows these behaviours. On completion, via an algorithm that we have developed, they are informed immediately whether their child has a high likelihood or a low likelihood of developing autism. They immediately then get an email notification with the child’s performance on the behavioural items printed out. The app is suited for children from 11 to 30 months of age so that when the parent enters the child’s age and registers the child the correct items come up. The parents are encouraged to print out the email and take it to their medical professional for a formal developmental assessment, and we are now looking to also develop a professional version of this app. We also direct parents to a website which is dedicated so that they are supported through their journey into autism.

On the basis of all this, both research and our clinical practice, I have highlighted what I feel we need in Victoria. We need a greater understanding of autism and its early signs within the primary health care system and also amongst early childhood educators because we all have our children in child care. So we are also doing research on training childcare workers to use the SACS items to facilitate early identification so we can get timely referrals.

We need greater understanding of the evidence base supporting early diagnosis among GPs, paediatricians and paediatric psychiatrists who will often still tell you that you cannot assess a child until they are between three and five years of age, which is really, quite frankly, not correct. We need a rollout of developmental surveillance across maternal and child health services statewide, and really in Victoria we have probably got the best service. We have looked at services across the other states and they really do not match what we have in Victoria. We have an excellent universal service here which we should be using.

We need to establish a number of early diagnostic centres across Victoria to reduce the waiting times and lower the average age of diagnosis. We used to have a two to three month waiting list. When we first started the clinic I just had money to run it one day a week and within two months of opening we had a six-month waiting list. I then went back to philanthropy, got more money to run it two days a week and we were immediately able to reduce the waiting list. It really never went up over three months.

I think we have got a wonderful model to develop such early diagnostic centres and I think this will really serve to increase the capacity within the public health system to foster a timely diagnosis of autism and thus earlier access to intervention. Our research is showing that earlier access is really impacting on the cognitive outcomes in these children and we would be very happy to share our expertise at the Olga Tennison Autism Research Centre to achieve this outcome with you, so do please call upon us as you need. Thank you for your attention and also the opportunity to share some of this with you and talk to you today.

The CHAIR — Thank you very much, Professor. We were very keen to hear from you based on what we knew about the research that you had done which is very comprehensive and my understanding is that it is international best standard practice now with the early detection and early intervention services that you were providing. I want to congratulate you first of all on that work because I think it really is potentially going to make a big difference to outcomes for children with ASD.

Prof. DISSANAYAKE — Thank you.

The CHAIR — Based on what you have told us today, what is your view on the increasing prevalence of ASD in the community?

Prof. DISSANAYAKE — I think there is never going to be one reason for that increase; I think there are many reasons for that increase. One of the reasons of course is greater awareness in the community. I came into the field in 1984 when what we called autism was very narrow — early infantile autism or autistic disorder. Now, what we recognise as part of the spectrum has really increased. The spectrum has widened throughout my career and so that naturally will lead to greater numbers.

But I think there are a lot of biological mechanisms also at play here. Some of the risk factors we know are older parents, particularly older fathers. That has been a consistent finding. For example, what has increased over the last 20 or so years is that people are leaving their parenting until much later. Also, women are more educated and so delaying parenting, and often mums' and dads' ages are highly correlated, so the older the woman the more likely the older the man.

In addition to that, what has also increased is the breakdown of monogamous relationships. We have much more serial monogamy, so fathers are sponsoring many more second families. Again, there is that biological risk put into the environment; they are older when they have their children in their new relationship. We are also doing marvellously well in saving premmie babies. Many more babies are being born prem now; prematurity is a risk factor for autism. So a lot of these biological mechanisms I think are also serving to increase risk in the community, and this is not just here. It is being seen internationally.

There might be some other factors that we do not know about, but I think that increase is very real, even just seeing it through our work. We started our first study in 2006 and ran it in 2006–08. In fact when we started that study we worked on the assumption that it was 1 in 160 children, and we found approximately 1 per cent. Now in our second study it is nearly 2 per cent, so I think the increase is very real.

The CHAIR — Do you think the new criteria for ASD and the DSM-5 have had any particular benefits for health professionals or people with ASD? Secondly, do you think that the loss of the Asperger's category has had any impact?

Prof. DISSANAYAKE — We have just submitted a paper, probably be three days ago, on this. You saw that paper using the HCWA package, that was based on 15 000 children, and that was between 2010 and 2012. We have now got more data from the Department of Social Services to look at data up to 2015. So what we have done is we have looked at the pre-DSM-5 data of children accessing HCWA and the post-DSM-5 data on children accessing HCWA. Interestingly what we have found is a clear increasing trend up to 2013, and since 2013 there has been a slight levelling off in the trend. So the number of children accessing services has not kept on the same trajectory that we saw from 2010 to 2013. There has been a slight levelling off.

We cannot tell on the basis of this data what has contributed to that levelling off. We suspect that it is because of the introduction of DSM-5 and maybe fewer people accessing services, because some of those children are now meeting criteria for the new social communication disorder. Interestingly we have charted the number of Asperger's diagnoses, and the minute it comes to 2013 that has just levelled off. No, I do not have it on my memory stick. I could have shown you some lovely figures.

The CHAIR — That is okay. Perhaps you can provide a copy to the committee.

Prof. DISSANAYAKE — Yes, I would be happy to.

The CHAIR — That would be great.

Prof. DISSANAYAKE — We think that it is not a reduction by any means; it is just a levelling off. There has not been a reduction in the rate.

The CHAIR — Do you think that trend will continue?

Prof. DISSANAYAKE — In the plateauing? Time will tell. I suspect it may well. But I wonder what is happening to those children who are getting a diagnosis of social communication disorder.

The CHAIR — Exactly. Yes.

Ms McLEISH — Thank you, Professor, for coming in. I have got a question about the paediatricians that you have mentioned that it is commonly thrown around that you cannot diagnose under a certain age, and you are saying, 'Well, actually that is not quite right'. Is there a lot of work being done collaboratively to change that view, or is it very much an entrenched philosophical difference?

Prof. DISSANAYAKE — I have seen a change between our first and our second studies. We get fewer paediatricians on the phone — we got lots of paediatricians on the phone in our first study — and with the second study there is less pushback. I am not saying there was no pushback; there was still pushback, but there was less pushback. So I think it is changing, but I think there still needs to be more training. The reality is that these medical professionals are really busy, and when you run training they are often no-shows just because of their busy schedules. So I think we need to look at training becoming embedded within courses — within their studies at university and so on, but also within continuing education. For example, with nurses now at La Trobe we also train about these early signs and so on within their formal training.

I think this needs to happen across the board, not just with nurses, not just with paediatricians and GPs. Any professional that is going to be working with children needs to know what autism looks like in early childhood, because we are talking about 1 to 2 per cent of children. Just one lecture on autism I think is not going to cut it. We have introduced an undergraduate subject in autism now at La Trobe University. It is very, very popular. I think we need to embed training around autism across the board for anyone who is going to be working with children, including early childhood educators.

Ms McLEISH — Just with the paediatricians, how will you make that happen or how can we make it happen that you embed this training with their specialist skills?

Prof. DISSANAYAKE — I think it is working within the different colleges and so on. As I said, there are pockets of excellence where good practice is happening, but I am not sure at what level good practice is being disseminated. There needs to be more of a national approach to this.

Ms COUZENS — You have answered quite a few of my questions in that one. I was curious when you talked about the 27 per cent that left the spectrum, I think it was in the first study. Do you know why?

Prof. DISSANAYAKE — That is a good question. In most samples you get around 14 per cent of cohorts over a long period of time. You do find some of these children leaving the spectrum. It does not mean that they do not have any issues. They are no longer meeting criteria for autism, and it is important to continue following them up. They still will have subsidiary things like anxiety and sleep difficulties merging into depression often in adolescence. There have been so few good longitudinal studies that it is hard to tell, but generally there is about 14 per cent in most cohorts that will no longer meet criteria for autism, and that is because of good interventions, good access. I think our cohort has a greater percentage because we got in very early, and so those children were then able to access services. But I think we will grow old with these cohorts. I do want to follow up the second cohort from the second study as well, because our outcomes were so positive. They were almost too good to believe, so I really do want to follow up the second cohort to see if we are matching this first cohort.

There has been some really nice work in the States that looked at the predictors of what they called optimal outcome children, this 27 per cent. What they found was the best predictors for that optimal outcome were early diagnosis and access to early intervention early. You know it, but then seeing it and being able to validate it with research is really important I think.

Mr FINN — Cheryl, thank you very much for coming in, and let me put on the record that the work you are doing out there is just extraordinary.

Prof. DISSANAYAKE — Thank you.

Mr FINN — You are clearly leading the field. It is one of the very few places that I have left over the last 18 months and felt like skipping. It is just absolutely wonderful. Clearly finance is a problem that you face out there. What could be done if more money was available for the work that you are doing? What is the next step that you would take if more money was to come your way?

Prof. DISSANAYAKE — Well, to come my way — I am going to answer this in two ways. I do think we need to develop these early assessment and diagnostic clinics in different regions in Melbourne so that parents who suspect the signs, they have the free app, they are worried and they can access and get a diagnosis in three months at the longest. No-one should be waiting over three months for a diagnosis. We are killing these parents. We are telling them early intervention is important, and then we are keeping them on waiting lists, so we are plunging them into mental health chaos, really. If it came my way, we have the Victorian Autism Specific Early Learning and Care setting. These are the six centres that were developed through federal funds. So we have the Victorian one at La Trobe University. If money came my way, I would set up a centre. I have even got a name for it, Bernie.

Mr FINN — Why am I not surprised?

Prof. DISSANAYAKE — It is called ‘Diagnosis, assessment and treatment for autism - DATA’. It is underpinned by research, but it is best practice. Currently we do wonderful work in early intervention. We are funded by the Department of Social Services. We have had block funding — we have got block funding till 2018. By then we would have rolled into the NDIA and the NDIS. We do not know fully what that will look like yet, but what I would do is I would build more clinic rooms. At any one time we have 80 to 120 children on our waiting list to access our early intervention. So I would build more clinic rooms and offer some one-to-one therapy as well as our group-based therapy that we run. We are also trialling running our early intervention program both in the mainstream as well as in a segregated setting to see if there are different outcomes in children. Right now we are not finding any differences.

But into that I would also build the early assessment clinic. I would build an early assessment clinic like the one I spoke about, including a paediatrician doing a couple of days in some rooms there so that we could have somewhere where babies are referred through maternal and child health. They come in and they can get a timely assessment and diagnosis. They can access services using their NDIS funds, one-to-one therapy for that child, parent training and parent-mediated therapy, and having the therapy centre there. So you are not only building capacity in parents, you are running an education program. You run programs for GPs, you run programs for paediatricians and you run programs for maternal and child health through a centre of excellence. You use that as a hub and you support excellence in spokes elsewhere.

Mr FINN — One last question. We are all in furious agreement that early intervention is important. I would like you to tell the committee why it is important.

Prof. DISSANAYAKE — Intervention is important because you can change the way the brain develops. The reason why the typically developing child learns and develops so quickly, so seamlessly and so easily is because that baby comes into the world with their sensory systems already tuned to other human beings — towards their faces, towards their eyes. We know babies at birth process the human voice more than they process the sound of mechanical objects. We know they will preferentially look at eyes; we know that they will preferentially look at faces. If a baby is born without their sensory systems tuned in towards other people, you are going to immediately impact their learning, because how babies learn is from other people. So for example, by looking at other faces, we all develop the face fusiform area for face recognition. It is a specialised part of the brain. If you are not looking at faces, that speciality is not going to develop. If you are more tuned into objects, if you are not motivated to look and engage with other people, that is going to impact your learning. So the sooner you can get a child identified and diagnosed and start working with that child, and get that child back into the social loop, the child can begin to learn from other people.

That is really what good early intervention does. It basically rewires that brain that is not processing the social world. We do not want to change autism. It is fine to be autistic. What we want to change is the impact autism can have on the ability to learn. So the sooner you get in you can prevent intellectual disability from happening in many children. It costs $55 000 more a year to raise a child with autism and intellectual disability than a child with autism alone. So you can really impact not just the child and the family outcome but your purse as well.

Mr FINN — Thank you, and good luck for Thursday night.

The CHAIR — Thank you very much, Cheryl. We really appreciate it. All the best for Thursday. You certainly are a deserving recipient and we wish you well. Thanks again for attending today.

Prof. DISSANAYAKE — Thank you very much.

Witness withdrew.