

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 6 March 2017

Members

Ms Maree Edwards — Chair

Mr Paul Edbrooke

Ms Cindy McLeish — Deputy Chair

Mr Bernie Finn

Ms Chris Couzens

Witnesses

Emeritus Professor Bruce Tonge, and

Dr Avril Brereton, Monash University Centre for Developmental Psychiatry and Psychology.

The CHAIR — Can I welcome to this afternoon’s public hearing Emeritus Professor Bruce Tonge and Dr Avril Brereton from the Monash University Centre for Developmental Psychiatry and Psychology. Thank you both 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 be able to make factual or grammatical corrections if necessary. Thank you both, and we will hand over to you for your presentation.

Visual presentation.

Prof. TONGE — Thanks very much. While that is being loaded I will give a few introductory comments. What we are going to address today are three questions that were put to us by Dr Gardiner. We will relate that to relevant research that the Centre for Developmental Psychiatry and Psychology has been doing over the last 30 years at Monash University. Therefore I can guarantee that what we are going to talk about is evidence based, not speculation or wishful thinking. Certainly a lot of it is not high-tech, fortunately perhaps.

The CHAIR — That is okay. We have had a big dose of that today.

Prof. TONGE — But it is evidence based. We are going to cover three areas. We are going to look at autism spectrum disorder and mental health, we are going to look at autism spectrum disorder in females, briefly, and we are going to look at public mental health and population interventions, which can be aimed at whole populations and for which there is an evidence base. I do need to pause because — —

The CHAIR — That is okay. While we are waiting, can I just thank you for your submission to the inquiry. It is much appreciated. Clearly you are well and truly ahead of the pack when it comes to research in this space.

Prof. TONGE — While we are waiting I can talk to this next slide. Twenty-five years ago a colleague of mine, Stewart Einfeld, and I started a longitudinal study of several thousand children with intellectual disability in Victoria and New South Wales. It is the world’s largest study of children with intellectual disability. It has been going ever since, so these children are now adults. We have been following up their mental health over that long period of time. There was a group of several hundred children in that group who had autism, so we have very compelling evidence about what the life course of these children is. I would have to add that the majority of the children had intellectual disability, so we cannot comment as readily on children who have autism who do not have intellectual disability, which is about 30 per cent, perhaps, of the population. We must remember that a good proportion of children with autism have intellectual disability — many of them with no language and many of them with very poor language.

When we started that study back in 1990 we demonstrated, using a questionnaire called the developmental behaviour checklist — a very robust parent-completed and teacher-completed questionnaire — that over 70 per cent of children with autism have significant mental health difficulties, they are clinically significant, and that these problems are over and above what might be due to their autism.

The CHAIR — Can I just ask while you are on that point: is there a particular age when the mental health issues become more prevalent?

Prof. TONGE — Yes, from as soon as we can measure them.

The CHAIR — So there is no defining between a person under 10 or a teenager?

Prof. TONGE — No, we started with three-year-olds. They were from four to 18 when we started. What this slide will hopefully show you is that of all the children with various forms of intellectual disability, and just the representative sample as well, the children with autism have the most emotional and behavioural problems of any other child with an intellectual disability. Those with Prader-Willi syndrome are also highly represented, as well as those with something called Williams syndrome, but the children with autism are right up there at the top, unfortunately, of that particular league table.

The CHAIR — Can I ask another question while you are on that?

Prof. TONGE — Yes, of course.

The CHAIR — Those comorbidities — are they diagnosed post the autism diagnosis or pre the autism diagnosis?

Prof. TONGE — They are usually diagnosed, if they are diagnosed at all, post the diagnosis, because particularly today, with reliance on some standardised assessment tools such as the ADI and ADOS, which we have played a part in training people to use, there is no in-built system in that for diagnosing what we call comorbidity — that is, associated mental health problems. To make a diagnosis of autism, the DSM-5 now requires that you put in descriptors. You need the child's intellectual ability, you need the child's medical health and you need to describe the comorbidity, and not everybody is capable of doing that, and so a number of these children would slip under the radar.

We will move on to this next slide. There is the diagram. The red bar, at the time we commenced in 1990, are those with autism; The dark blue bar is the representative sample of children with intellectual disability. As you can see, those with autism are way above the prevalence of mental health problems in kids with intellectual disability, and I might add, they are still two to three times that of the general population. So if you have an intellectual disability, you have got a greater chance of having mental health problems or emotional and behavioural problems. If you have got autism, you have got even a greater chance.

What happens over time as these kids move into young adult life is that you will see the red bar actually falls — and that is a significant fall — so the emotional and behavioural problems do improve over time. However, they are still two to three times that of the general population. So mental health difficulties remain a problem throughout the life cycle, and we can go right into the elderly as well. But they do fall. They do not become more prominent; they become perhaps less. We are still talking about 60 per cent of the population rather than 75 per cent. So that is the longitudinal study. It is still going. It is published worldwide and it gives a broad snapshot. Let us look at the next one — —

Ms McLEISH — Could I just ask on that time line and time 4 —

Prof. TONGE — Fifteen years —.

Ms McLEISH — Are you doing it every five years?

Prof. TONGE — Yes.

Ms McLEISH — So where are you up to with time 5?

Prof. TONGE — We are time 6 now. We are into — —

Ms McLEISH — Okay. So you just have not got time 5 up?

Prof. TONGE — No. But actually time 5 is virtually no different than time 6. As we go through adult life there is very little change, except in the elderly, where it seems to improve. But that is a survival issue. You have got to be really resilient and tough to have an intellectual disability and survive into old age.

On to the conditions that we are talking about. We will talk briefly about these, but it is not going to be comorbidity 101. We are talking about anxiety disorders, depression, attention deficit hyperactivity conditions, obsessive compulsive disorder, post-traumatic stress disorder, one called schizotypal disorder, which many people have not seen or know about but I want to highlight that, and psychosis, which occurs in late adolescence and early adulthood, schizophrenia, and bipolar disorder, which again I will not talk about today.

Let us look briefly at anxiety disorder. It is a significant problem in children with autism. At least 50 per cent of children with ASD have significant impairments in social skill family functioning that are due to anxiety. This is over and above their autism, and their long-term outcome is adversely affected. We have got evidence for that. Why is this important? Because we can treat anxiety using a number of psychological, pharmacological and environmental manipulations, and therefore you can help the life of a child with autism if we can reduce their anxiety.

Let us talk about depression briefly. Children with autism are significantly more likely to have depression than the general population of kids with intellectual disability. That is the red line at the top. You might notice moving from time 1 to time 2 that there is an increase, and that is as children with autism enter adolescence. We know there is an increased prevalence of depression then as some of them gain insight and also find the social world much more challenging.

The CHAIR — Is there a gender difference there?

Prof. TONGE — We did not find it, but there might be in those that are higher functioning. I will talk about gender difference in a minute, which is interesting. Across the board there has been a finding that often there is not a gender difference, although I know that it is a hot topic at the moment. We did not find that with depression.

The CHAIR — I just thought about the teenage years and the difference that girls and boys go through — —

Prof. TONGE — It is. That is generally in the population but with autism we did not find it and others have not either. In other words boys are also more likely to get depression if they have autism, and boys are more common in terms of the prevalence of autism, so that makes it important. Over time then it remains a significant problem. Depression really does impair kids' lives.

Let us look at attention deficit hyperactivity disorder. This is a bit of a complicated slide, but the blue line is autism. If you go right to the right-hand side of it, that blue dot is the overall level of attention deficit hyperactivity in kids with autism. You can see that children who do not have autism but who have attention deficit hyperactivity and not autism have less emotional and behavioural difficulties than those with autism compared with the normal population down below. If you have a child who has autism and ADHD, and although the figures vary, at least probably 30 to 40 per cent of children with autism do have developmentally excessive inattention and hyperactivity, the yellow line shows how many emotional and behavioural problems they have. What our research shows is that if you have got autism and ADHD together, you have got monumentally high problems with emotions and behaviour. It affects around 90 per cent of that particular population. Again, why should this matter? Because we have a number of environmental, educational, psychological and medication treatments for attention deficit hyperactivity disorder. Unfortunately kids with autism do not respond to those as well as the general population, but at least they might to some extent, so there is another point for intervention.

The next slide is on OCD. Just briefly, we can diagnose obsessive compulsive anxiety disorder in children with autism, particularly teenagers, and this is different from the rituals and repetitive behaviours of autism. The rituals and repetitive behaviours of autism the child quite likes doing; with obsessive compulsive disorder the obsessions and the compulsive behaviours the child does not like, and they are doing it to try and escape from anxiety — a very important differential point. Again, OCD is treatable by medications and psychological interventions. It is then worth diagnosing.

The next one is on PTSD. Children with autism often experience significant traumas in their life and emotional distress. Unfortunately not many of us think about looking for emotional and behavioural difficulties which are due to post-traumatic stress disorder, and some of those mirror autistic symptoms, like repetitive play. If a child has been involved in a motor car accident and has been very upset about that, their play might become repetitive crashing of cars, and we might say, 'Ah, there is autistic ritualistic behaviour', when it is not; it is actually a disorder.

I am going to talk briefly about this condition called schizotypal disorder, which is not well recognised, although it is well described in DSM and ICD-10, where particularly the child has pervasive social and interpersonal difficulties, somewhat like autism, where they have a reduced but not absent capacity for close relationships but importantly they have a number of cognitive distortions.

For example, they may be very paranoid, they may believe that everybody around them is talking about them. They have some very odd beliefs, so that they may be influenced by a monster or a ghost. They have odd, unusual perceptions — that is, they can have auditory hallucinations, tactile hallucinations — a range of different perceptions that are not real. Many of them have very eccentric behaviour, like insisting on wearing their three-year-old tutu to school every day of the year and getting very much locked in their world of fantasy.

They have very rich fantasies, and that can be very different from a child with autism. They lack social friends, but they do have some, and they have a high level of social anxiety which is usually associated with their paranoid fears.

The CHAIR — Can I just ask then: there is a clear association between these symptoms and autism, and clearly there must be some times when a person is — misdiagnosis would be very common, I imagine.

Prof. TONGE — Indeed, there is. Misdiagnosis is common but also sometimes children with autism also have this condition.

The CHAIR — So how do you define them?

Prof. TONGE — Well, indeed. You define it by having good clinical skills and being able to take a good and comprehensive history.

The CHAIR — There would be few people that would have the clinical skills to be able to differentiate this disorder from — —

Prof. TONGE — Yes. Child psychiatrists do, well-qualified and trained behavioural paediatricians do and some clinical psychologists do.

Let us just look at what we have done. I think it is worth raising this because it is part of this female confusion problem in girls. We designed a couple of years ago the Melbourne Assessment of Schizotypy in Kids (MASK), a semi-structured interview, which has a checklist, and it is an interview of the child and the parents. We gather information and we spend time with the child. We have done some studies on this assessment tool where we compared around about 40 children with typical development, those with ASD without schizotypy and a group of kids with schizotypal disorder.

The next slide: this is a bit of science, but if you can just look there at those little boxes, the boxes on the left relate to typically developing children. You can see the middle line through that box is very much lower than the next group, which have got autism spectrum disorder; and it is very much lower than those with schizotypal disorder on the right. That is, if you like, the scientific evidence that we have got that we can differentiate these conditions with a standardised and structured interview — not exactly like the ADI and ADOS, but a bit similar to that.

On the next slide, so we start with this. When we look at the items in the assessment tool, we find that those items cluster into two groups. There is a group of symptoms around social and social skills abnormalities, and there is a group around these schizotypal symptoms — the paranoia, the suspiciousness, the being locked into your own fantasy world and the perceptual disturbances.

When we looked at our total sample this way we found that the schizotypal symptom factor clearly differentiates those who have autism from schizotypal disorder, and we found that it is more common in females, whereas the social pragmatic disorder, if you like, belongs more to those that have autistic symptoms. In other words, the MASK does explore symptomatology in children with autism, those that have schizotypal disorder and those that have a mixed picture.

I will speak in a minute about females again, but I just want you to remember that there are a number of females who we think are misdiagnosed, who do not have autism; and there are some who do have autism but who are also at risk of having this condition called schizotypal disorder. Mind you, boys can have it as well. They are very different, and they are often a puzzle to diagnosticians because they stand out as being odd and bizarre in their behaviour in the school situation, for example.

Now, let us look briefly at autism spectrum disorder in females. This is just brief and it includes some of our own work, but I will start with, I think, an interesting summary from workers overseas. In the absence of additional intellectual or behavioural problems, girls are less likely than boys to meet diagnostic criteria for ASD at equivalently high levels of autistic-like traits. This might reflect gender bias in diagnosis or genuinely better adaptation and compensation in girls. I think that is the way we are heading.

If the girl has autism but also has intellectual disability or superadded emotional and behavioural problems, then they are likely to get a diagnosis, but if they are quiet and sitting down the back of the classroom and they in fact

have no disorder, even though they might meet symptoms, then they will not be getting a diagnosis — because who is raising that as an issue?

So are we here moving on the spectrum out of the area of disorder into an area of personality, style and temperament which still is odd and different but is not necessarily bringing those girls always into difficulty? It might of course. We are firmly of the view, and there is evidence for this, that you can diagnose autism as easily in girls as boys by applying the criteria. Girls with autism do not have different criteria for the diagnosis of ASD. They may present differently in relation to their surrounding mental health difficulties and behaviour, but autism is autism. We do not see any evidence for something called ‘female autism’ which requires different diagnostic criteria.

The CHAIR — Would this explain why a lot of young girls are diagnosed later in life?

Prof. TONGE — Indeed, because they are quiet — let us go on to this. Christenson found a male-female ratio of four to one. That is a very recent study. In other words, that proportion has not changed when it is looked at very firmly.

Ms McLEISH — Has not changed since when?

Prof. TONGE — Since the 1960’s.

Ms McLEISH — But I thought you were comparing it to previous — —

Dr BRERETON — Back in the 1960s.

Prof. TONGE — Yes. It has not changed since then.

Ms McLEISH — That was my question. Since the 60s.

Prof. TONGE — That is right. It is still there. Our study involves a number of workers, including Nicole Rinehart, who was here earlier this morning, I understand. One study where we were looking at young people who have intellectual disability found a four to one male to female ratio, but the adolescent females as they moved towards adult life were more likely to deteriorate behaviourally, particularly in their social relating and self-absorbed behaviours, and in fact this is a disaster. In other words, they just collapse into their inner world and cannot go anywhere. These are girls with intellectual disability. They are an at-risk group.

We also found that females were more likely to have more severe levels of intellectual disability than males. So if intellectual disability is involved, because it is less common in females, females seem to have it worse. I know that is a different picture from what we presented about those who are high functioning and do not have intellectual disability.

Let us look at the high-functioning group. Again, some studies were done by Tamara May in our centre, again with Nicole Rinehart. In females with high-functioning autism there is no difference in social difficulties from males, but the women, the girls, are less inattentive and hyperactive. That again may be why they are not picked up as easily, or it might contribute to underidentification perhaps, or it might just be a reflection of it being less common and driven by a number of genetic factors.

Ms McLEISH — And how does that reflect just normal society?

Prof. TONGE — It does in part because ADHD is much more common in boys than girls in normal society. The male brain is different; it is not nearly as competent and as well put together as the female brain and therefore males do have more difficulty in organising themselves, concentrating and being calm and quiet. That is in normal society.

The CHAIR — We already knew that.

Prof. TONGE — Of course, and let us celebrate that.

Mr FINN — Playing to your audience!

Prof. TONGE — What we are going to move onto now is what we would like to talk about briefly — that is, some public mental health population interventions for which there is evidence that they actually make a big difference. This is in a field where still there is very little evidence that helps much with autism, in spite of all the rhetoric and the anecdotal claims being made, particularly about individual interventions. We think that the public dollar — government dollars, my and your taxpayer dollars — should be spent more profitably on public health and population interventions, which have some evidence.

The CHAIR — Can I just ask there, Professor — sorry — do you mean then that early interventions and behavioural therapies such as ABA make no difference?

Prof. TONGE — No, not at all. Early interventions are usually population interventions. They are available to all children, are spread through things like preschools and are educationally based and so forth. ABA does have some evidence, at least in the short term, although the long-term outcome is less doubtful, and there have been some good published papers about that. It contributes. Mind you, some ABA techniques can be taught very well as a public health population intervention that is delivered by parents without having to spend large amounts of money.

Anyway, what we would like to present now is the evidence that we have got for some population-based interventions, which are not highly technological but which work.

Dr BRERETON — In particular we want to talk to you about parent education and parent skills training models. We want to talk about the importance of transition planning, and we want to talk about professional education. We were asked by Dr Gardiner to tell you about the autism consultation and training now, the ACT-NOW strategy, that we developed. So I am going to talk a bit more about those things.

Professor Tonge has already said that we are involved in research and finding out information about what works and what there is evidence for, because there is a great risk when there are dollars to spend that they will not be spent wisely and you do not actually know if you are getting proper bang for your buck, if I can put it that way. It is better to be spending money on things that there is some evidence for. So we spent a considerable amount of time funded by National Health and Medical Research Council funding to develop evidence-based parent education and skills training programs.

This is one of them — *Preschoolers with Autism*. It is used worldwide. Back in 2009–10 across Victoria we rolled out training for professionals, and we trained about 100 early childhood intervention practitioners in this 20-week program for parents. We trained as see-one-do-one, come along and watch us and then you have a go yourself. That program is still continuing in some places in Victoria, but there is no current funding to pay early childhood practitioners to roll this program out.

The CHAIR — So where is that current funding coming from?

Dr BRERETON — If a practitioner is working within somewhere like Noah's Ark, some of those practitioners that we trained might be delivering that program to parents, but if they look at the constraints on their budget, they may choose not to run that parent program even though we know that it is helpful.

This is just one example showing you how we know this works. Particularly look at the blue and green lines. We had about 100 families come into this program when we were doing the research. We looked at the children's autism symptoms before the program and at one and two-year follow-up. You can see the blue line goes down. So what happened was that the autism symptoms were greatly reduced when parents attended a program like this, and that is good news. When you compare that to the green line, which is the control group — their parents did not attend — they were just going to a locally available kindergarten or early childhood services. In fact their autism symptoms increased over two years. We think this is a really strong argument for getting in and working with parents soon after the children are diagnosed to help them when they really are very vulnerable and they need skills under their belt to make them feel more confident and know more about ASD. So that was the program we developed for little kids.

We did another one where we were particularly looking at parents who had children who were between about 11 and 15 years of age, so they were entering into adolescence. It is a time when typically parents are feeling unsupported. They would make comments like, 'We felt that we had more going on when our children were

little. Now that they are teenagers, what do we do? We are looking for help and support'. So again we developed a program that ran for 20 weeks working with parents.

This time I am going to show you a graph which is actually showing you the impact that we can have on parental mental health. The families that were coming into us pre-treatment really had quite high levels of mental health difficulties. They were anxious, they were worried and they were certainly worried about the future. We could see that post-treatment — after about five months — we really had an impact on how well those parents were managing, coping and feeling in themselves.

There was also a spin-off that they were actually losing less days from work because they were managing better and their kids were managing better, so there was a very good and important result.

Ms McLEISH — Is this based on 100 families?

Dr BRERETON — We had about 100 families in this adolescent program as well. Actually that program has been taken up nationally in New Zealand. It is available to all parents who have a teenager with ASD in New Zealand.

The CHAIR — Is it run through the — —

Dr BRERETON — In New Zealand it is run through each of the local health groups.

Prof. TONGE — Yes. Just so that we are not just, if you like, talking about the program we designed, another example of a parent education and skills program is something called the Stepping Stones Triple P Project. You have probably heard of Triple P. Stepping Stones is a development of that, which is a program for parents who have children with any developmental disability, but that includes autism.

Together with Matt Sanders in Queensland and Stewart Einfeld in Sydney, we have got a big program grant — NHMRC — and we are rolling this out in those three states as a public health intervention, free of charge. We are training a lot of practitioners in its delivery, and it has been modified or tailored to include some special interventions for families that have children with autism plus some other conditions, like Prader-Willi syndrome and Williams syndrome.

The benefit of this particular program is that it has a number of systems of intervention. There is a media and communication strategy in which we talk to local newspapers and get on the television about the importance of helping your child if they have got a developmental disability. We have a seminar program, just one or two seminars, where we give brief parenting advice to parents that have kids with developmental problems, including autism. There is a more focused parenting support program running groups or individually for parents over three sessions delivered by a clinician. Then there is a more broad intensive program of education and skills across 10 sessions for families, and finally a more intensive family intervention for very complex families — for example, foster parents who may have three children with autism that they are caring for and do not even know where to begin. So it has got all these levels, which is quite attractive.

In Victoria to date we have trained 281 professionals in the delivery of this program in a range of agencies — like Noah's Ark, Anglicare and so forth — and in private practice. We have a subgroup of kids that they have seen — 387 families randomly selected. In 43 per cent of those families the children have autism, so that is why we are presenting this today. It is highly relevant. We have looked at children between the age of two and 12. Some of them have intellectual disability or developmental delay and some do not. We are addressing here its value for kids that do not have intellectual disability. We can give some data on 12-month follow-up.

There has been some significant decrease over time in their total score of problem behaviours, and in some subscales, disruptive behaviour, self-absorbed behaviour, communication disturbance, anxiety and social relating. In other words, in all of those areas the children have improved significantly compared to a control group.

Parent outcomes: again, a decrease over time in parental perceived depression, anxiety and stress. Once again, there is really strong evidence that a parent education and skills program can make a big difference that lasts. It is not our own work; it is around the world. We keep on asking the question, 'Why isn't this almost mandatory for families?', particularly when we are spending huge amounts of taxpayers dollars on individually focused, often non-evidence-based interventions. Here we have got something that can be rolled out throughout a

community. For example, at the moment now the government in Queensland has taken it up nationally, and the parent of every child with a disability has the availability of starting off on a good step and learning how better to understand and respond to their child.

The CHAIR — Is there an adaptation of the program for parents who might have an intellectual disability or themselves have autism?

Prof. TONGE — Yes, there is. That is, if you like, in the level 5, where it has got to be tailored and monitored to that. There has been some work on that where the parent might have an intellectual disability and may have some care of the child but be working with a foster family. They are sometimes combinations, or the child might be in care but the parents still have contact and access. They need guidance on how to respond to their child with autism. That is only a small part of the work, but it is an important one.

Dr BRERETON — In the other programs that I was talking about — the ones for parents who have got little children with autism and those who have got teenagers with autism — in the research program itself we definitely had parents who had autism themselves, some of whom also had a mild intellectual disability. The beauty of that program was that because we had group sessions and individual sessions, you could make sure in the individual sessions that families understood what was going on, they had an opportunity to talk to you privately, to ask as many questions as they wanted to. Sometimes we had parents who could not read very well, so we actually taped sessions so that they could listen to them in the car on the way and they did not have to worry about being embarrassed about reading the manual. You need to tailor make these programs for who you are working with, and it is possible.

Prof. TONGE — In other words, although there is a structure to the program, there is the capacity to tailor it and to respond to the particular need, but that is a feature of many of them around the world. We do not want to claim that these are the only two. We are making a claim, though, about the evidence for educating parents and giving them some skills to manage the sorts of emotions and behavioural difficulty I was talking about at the beginning.

Dr BRERETON — Another thing that we wanted to mention was the importance of transition planning. We know that children with autism do not like change, so when we are thinking about changes of educational placement, this is really difficult for them. Particularly when we are thinking about the transition into primary school, there are so many changes that children are trying to cope with, and you really do need to plan for this — plan and support it.

We did some research where we were talking to parents who had children who were teenagers and up until about 30 years of age. We asked questions about what sort of support they had had at school when they were moving into primary school or secondary school and beyond. We found that those who had had even a small amount of transition support were doing better and in fact had less mental health problems because they had that sort of support at those really crucial times.

Prof. TONGE — This is even at the age of 30.

Dr BRERETON — One of the things that we did was again look for an evidence base. We developed a program, which we called Planning a Successful Transition to Primary School. This was part of the work that we did in the ACT-NOW project. This was very successful, and we ran workshops back in 2011 across Victoria and trained about 120 transition teams. So this was about planning for little kids who had been in early childhood intervention services moving into primary school and the sort of support that they needed.

Some of the initial feedback was that the ECIS workers were saying, ‘We haven’t had all of the usual problems that we have’, and where families were no longer saying, ‘It’s just gone pear shaped’. Because there was some planning for this transition into primary school, parents were feeling more comfortable and school staff were feeling more comfortable. So in these workshops you bring together early childhood staff, parents and, at the receiving school, the teachers, so that there is a planned approach to children moving into primary school.

We also developed training packages so that other people could be us, if you like, so it was a train the trainer program, and we trained all of the — at that time — autism coaches that were working in Victoria. There were about nine of them at that time, and they were rolling out these transition programs.

Subsequent to the ACT-NOW funding the Department of Education and Early Childhood Development, as it was called at the time, funded us to develop the same sort of training and train the trainer modules for transitioning into secondary school, and also the important step of moving little kids out of early childhood home-based programs into a kindergarten setting, because in fact that is probably one of the earliest transitions children make and it needs to be handled well. So that is some of the transition work that we have been involved with.

Prof. TONGE — And that is the booklet that is owned by the education department, that transitional book.

Dr BRERETON — The education department owns all of those now — each one of those transition manuals. They are all put together in one big package about transition.

Prof. TONGE — But they are not available to parents.

Dr BRERETON — We were asked to spend some time talking about the ACT-NOW program, how that came about and what happened. So I need to take you back to 2002 when there was the *Autism in Victoria: An Investigation of Prevalence and Service Delivery for Children Aged 0–6 Years*, which was a very comprehensive inquiry. One of the recommendations from that was this — that there was a continuum of developmentally appropriate and coordinated services at a regional and local level that are timely and effective, they are family centred, delivered by informed and skilled staff, building community awareness and an understanding of autism, and that they are evidence based and subjected to regular and objective evaluation.

We were up for that. So we put in and we proposed this autism secondary consultation and training strategy which we were able to provide. We had community development activities, information resources, training and secondary consultation, and the whole point of this was that we really wanted to enhance the capacity of the universal early childhood services and early childhood intervention services, and other specialist practitioners, to better support children with autism and their families in their local communities.

Initially we were funded in 2004 through to June 2007, but because we did pretty well with this we actually got funding another three times, so the program in fact went from 2004 right through to 2011. We trained in excess of 15 000 clinicians and early intervention staff. We trained every maternal and child health nurse in the state in 2011. We trained paediatricians, and we trained GPs. We wrote, we trialled and we rolled out training in the transition to primary school program, which I told you about. We trained clinicians in the delivery of the ASDs in the preschool years program and the parent education program. The preschool years one was a really interesting one because we had three 2-hour workshops that kindergarten teachers, or early childhood practitioners and parents attended, and they learned across 6 hours some basics about autism. And by having the teachers and the parents together it really built up a very nice collaboration between the two. It was not seen as an us and them — one person owning the information; it was learned together. It was very successful.

We also developed a website. We had a training calendar. We had fact sheets. We had journal club and newsletters, so it was really keeping the professionals and parents and others who were interested in autism across the state of Victoria up to date with new information, with evidence-based information, to help their decision-making about what they did with their time. One of the best things I ever heard from a talk was from an American researcher called Anne Donnellan. It was back in the 1980s, and she said, ‘Every child with autism needs a T-shirt that says, “Don’t waste my time”’. I can remember her saying it then, and I still think it is really important — don’t waste my time — and perhaps we should be adding, ‘and don’t waste my money’.

So an integral part of this ACT-NOW strategy was that we developed regional autism consultation teams, we called them ReACTs. So what happened was there was us in the ACT-NOW program. We developed these teams. The teams decided for themselves what information and resources they wanted, what training they wanted and what secondary consultation they required, and this worked very nicely. It is no longer funded, that program. We were fortunate that it was funded for eight years or so, and it really did make a difference. The fact sheets are still available on the Monash website, the education department still has a number of those fact sheets and they are used widely internationally.

The CHAIR — So your funding for that was from 2002?

Dr BRERETON — Right until the end of 2011. In 2004 our funding began; the inquiry was in 2002. Some of the sorts of things that we did too were because we think it is so important that diagnosis and assessment is

well managed. We thought it was very important to have some teaching around how to assess and diagnose children, so we had paediatricians, psychologists and some other allied health workers who were trained in the use of the ADI-R and the ADOS.

We trained people, particularly ECIS practitioners, in the PEP-3 — it is a very nice play-based developmental assessment — because there is absolutely no point if you take a child for a developmental and IQ assessment, and because of their behaviour or their lack of language they are not able to be assessed. There is no point in writing a report that says ‘unassessable’. That helps no-one. So with this play-based assessment, which was developed quite some time ago in the States, you can assess very low-functioning children, and it gives you developmental age and it gives you a profile of the skills that the child almost has. So it actually gives you a strategy for where to begin your teaching. It is a great tool.

The CHAIR — That could be adapted for use with our little robot friend.

Dr BRERETON — I don’t know. Maternal and child health nurses, we developed a whole package of information about ASD for them. We called it watch, wait and wonder or watch, wait and worry, because that is what happens. That is the reality for many parents who have little children with autism. We taught them about ASD, early signs, surveillance, about how to talk to parents about concerns, about how to refer on and we provided them with tip sheets. So even now when you go for your check-up with your six-month-old, your 12-month-old, your 18-month-old, nurses have a little tip sheet about what they should be asking about at that developmental age and stage. On the back of that sheet I wrote what are the warning signs, early signs, of autism, to be asking about at that point.

Prof. TONGE — So this is the red flags that maternal child health nurses now routinely use to indicate a referral on.

Dr BRERETON — We do know that that is working, because now when we are meeting families they will say, ‘It was my maternal and child health nurse who sent us on to you’, or ‘who raised this concern with us’. So that referral process is coming along pretty nicely.

Ms COUZENS — So it is now about eye contact too, isn’t it, from a very early age?

Prof. TONGE — That is one of the red flags, not the only one.

Dr BRERETON — That is one of the things; there are a number of them.

Prof. TONGE — Play, interaction, social interaction.

Dr BRERETON — I mentioned that we developed this series of three workshops about ASDs in the preschool years. These are still pretty widely rolled out, and it is basic stuff but important things for ECIS staff and parents to know about what is autism, how do we communicate with these children, about interacting and playing together, and understanding and managing behaviour. It is sort of demystifying what these early days are about. We have a manual, DVDs, PowerPoint slides, film footage, and handouts and fact sheets, and we train the trainers and have provided some accreditation for them.

So we want to end sort of where we started, and that is that we think the recommendation that the government of Victoria suggested back in 2002 is still really very pertinent now in 2017. We do have to have regional developmentally appropriate and well-coordinated services which are timely and effective for families, which are family centred; and that they are delivered by people who know what they are talking about; that are building a community awareness and understanding of autism; very importantly, that they are evidenced-based; and that somebody is overlooking this to actually review and objectively evaluate what is going on.

The CHAIR — Thank you very much. That was a very comprehensive presentation.

Dr BRERETON — That was a bit of a fly-through, but there we go.

The CHAIR — That is fine. Bernie, I know you have to leave us. Did you have any questions?

Mr FINN — I could ask questions of our two witnesses here for quite some days. I noticed before that you made a comment about misdiagnosis, and that concerned me enormously. What is causing the misdiagnosis, who is responsible for that and what can we do about it?

Prof. TONGE — Diagnosis depends not on a blood test or an X-ray but on clinical judgement. The diagnostic tools that try and organise that clinical assessment, such as the ADI and ADOS are referenced against a gold standard of a comprehensive clinical assessment completed by an experienced person. Therefore those assessment tools have in-built into them a positive and a negative error. In other words, the ADI and ADOS will miss some children and will diagnose some children that do not have autism according to a comprehensive assessment. So that is one source of error. The second one is a lack of training in some clinicians, who perhaps rely more completely on a parent-completed checklist to make the diagnosis. Again, those checklists have errors built into them.

The third form of, if I can put it this way, diagnostic enthusiasm might relate to recognising that a child has needs and difficulties, and wanting them to receive help for that and knowing that help is available in terms of money from programs like Helping Children with Autism funding and in due course the NDIS and other sources. Therefore — I do not want to impute any unethical behaviour — I think that, given push comes to shove, you might err in the favour of, ‘Well, let’s make a diagnosis anyway, because at least they’ll get some funding’. So that is another reason.

There is also genuinely an increase in prevalence, because the diagnostic criteria have relaxed over the past few years; therefore we are picking up more children. We are also picking up more children because of things like what we are doing, where people are picking up early signs and are making a diagnosis now in children who in the past would have not been diagnosed because they are intelligent — we call that high functioning — or where they were very significantly intellectually disabled and they would have just been regarded as disabled. So it is a very complex area.

Mr FINN — Just a very quick one, and this might take a while to answer, but I will throw it in anyway: we have seen over recent years a significant increase in the number of diagnoses of children with autism. Do you think that that is happening as a result of better techniques for diagnosis, or do you think that there is something happening out there that is creating more children with autism? In other words, have we in years gone by seen mental institutions, for example, filled with people with autism who now we diagnose with autism?

Prof. TONGE — Yes, that is so. For example, with the closure of the Ararat asylum hospital some years ago — back in the 1980s I think it was — there were a large number of men in that place who had no diagnosis, even though they had files a metre high. A number of them had psychosis, no doubt. I was involved in a review of a number of those people with some colleagues, and we found that quite a number, around about 20 per cent, actually would have received a diagnosis of autism had it been looked at in the past. So part of the increase in prevalence is because of softening of diagnostic criteria. Part of the increase in prevalence may be because of a wish for kids that have developmental difficulties — sure, they have problems, but do not have autism — so that they can receive funding. Finally, is there something out there happening in the community that is leading to a true increase in incidence. All sorts of things are being suggested, like measles, mumps, rubella vaccination, which is not so; that is a bankrupt and pernicious idea. That is a possibility, but there is no really good evidence that that is happening. I am not saying it is not impossible.

The ageing population, particularly of men — of fathers, first-time fathers — may be increasing the prevalence because of the tired sperm syndrome, if I can use that term. That might be adding to it. It is complex. The increased number of children born to IVF, there is a little bit of evidence that perhaps that increases the risk. The increased number of babies being born to complex, obstetric interventions around, say, caesarean sections and so forth. There is a six-fold increased risk of autism in children who have had a complicated, damaged and difficult birth. Mind you, that only accounts for a small number. So there are lots of factors.

Mr FINN — But we are still a very long way from finding the real reason for autism.

Prof. TONGE — Yes. We know the reason for some cases. It will not be one cause, but we are a long way still — but lots of things are happening. We have animal models now — our own team, for example. Genetics are burgeoning. We know much more about the human genome and about gene-environment interaction. One has to remain hopeful, and I am sure one day it will happen. It is a bit like tuberculosis, really.

The CHAIR — That was a very comprehensive presentation and you have pretty much answered all the questions that I had. Of course our inquiry is about services that are available to people with autism across Victoria and that indeed is our focus. You talked a lot about diagnosis and assessment. From your point of view what do you see as the gold standard of assessment tools in the very beginning? Is there one, or does each person require something different?

Prof. TONGE — Autism Victoria, as it was called, was involved some years ago in coming up with some recommendations about assessment. There is currently now another inquiry going on driven out of Western Australia about that. There is a gold standard, and that is adherence to one of the two or both of the internationally agreed diagnostic criteria — either DSM-5 or ICD-10. They are different currently, but in a sense they describe to a great extent the same children. So you have to then come up with a scheme whereby children can be identified with these developmental symptoms. That requires a comprehensive clinical assessment, interview with the parents and assessment and observation of the child, preferably also in their natural setting like a preschool or with a family group.

The CHAIR — Does that include allied health?

Dr BRERETON — There is a national protocol that was put in place about five years ago, and it does include a multidisciplinary assessment team, including speech and language assessment, an OT's assessment not just looking at sensory needs, which seems to be on the radar and forgetting the other bits, but actually how the child manages daily life, also keeping in mind what is happening with the child's ability to hear and see.

The CHAIR — That was a national assessment process?

Dr BRERETON — Protocol, yes.

The CHAIR — Five years ago?

Dr BRERETON — Yes. In fact we started working on that in 1990 at the old Autism Victoria.

The CHAIR — You have been doing this a long time.

Prof. TONGE — That is right. This does not mean that those particular clinicians that we have mentioned make the diagnosis. They contribute to it.

Dr BRERETON — I think that has got lost somewhere — this notion that there is a workup part because all of those things inform the diagnosis. You need to know about the child's speech and language abilities, about their adaptive behaviour, about their IQ — how bright they are — or their developmental level, and when you are thinking about symptoms of autism and the DSM criteria or the ICD criteria, you need to be making a call on each one of those symptoms in light of what you know about the child's functioning level in terms of speech and language, adaptive behaviour and their intelligence.

Prof. TONGE — Someone experienced in diagnostic assessment and pulling all that together actually makes the diagnosis. That currently is probably best a developmental paediatrician with training, a child psychiatrist or some clinical psychologist that have had training and experience, and perhaps some educational psychologists as well, but particularly, multidisciplinary assessment informs that final pulling together of all the threads.

Dr BRERETON — I think what is really important about that multidisciplinary assessment too is that the diagnosis is just the beginning, but you want the diagnosis to be made in light of all of this information about child and family because that is where intervention begins. You have got the information that you need to send that family off and say, 'This is what is required at this point', not just to say, 'Yes, he or she has autism', but, 'This is what we know about them and this is what we recommend'.

Prof. TONGE — For example, they may have autism and very impaired language development, if any language at all, and not yet be capable of thinking symbolically. They may go out into an early intervention program and be immersed in a communication system which uses line drawing pictures, something called Compick. That will not work because they are not yet able to understand that a line drawing of an apple represents something physically like an apple and represents something that you might put in your mouth. That is a simple example of that.

Dr BRERETON — I think another really important part of a very comprehensive assessment is to be mindful of what is happening with the child's emotional and behavioural state as well. We know from our clinical experience that we might see children as young as two and a half or three, but they already are very anxious, or they might already be very sad, and you need to know that and it needs to go into the mix of services that are provided for that child and family from a very early age. It needs to be on that radar early.

Ms McLEISH — Evidence-based research always appeals to me, and we are so thankful for the amount of time that we have got. You touched on this a little bit earlier and again when you were talking about the importance of a clinical judgement. I will put this in the context that I was speaking to a radiographer at a very large public hospital not so long ago, and I was telling him about this inquiry. He said, 'We have at our hospital many, many people who come through for an MRI for diagnosis'. Dr Brereton, you look surprised to hear that.

Prof. TONGE — Not really.

Ms McLEISH — He is astounded because always nothing comes up, but this is a very common practice at a very large public hospital.

Prof. TONGE — If you are looking at a country like Sweden, they have a diagnostic suite of activities —

The CHAIR — I think we are going to Sweden.

Prof. TONGE — which includes a comprehensive clinical assessment, multidisciplinary assessment — all the things we have spoken about — but also includes a pretty standardised medical workup —

The CHAIR — What does that mean?

Prof. TONGE — including a genetic screen, physical examination and neurological examination, because children with autism also have, more likely than not, motor problems with gait and coordination, which is another disability some of them face. They usually too have an EEG, an electroencephalogram or brainwave measurement, and, at least in some parts of Sweden, a CT scan or perhaps an MRI scan.

Dr BRERETON — That has been going on since the 1980s. Christopher Gillberg was the person who said these are essential parts of an assessment.

Prof. TONGE — If you look at that, if you do an EEG of a child with autism, it depends on the study, but probably at least 60 per cent of them will have an abnormal EEG showing that their brain is not functioning, that their various computers are not working together. There is lots of information about dysfunctional brains in children with autism where we have local overconnectivity in that there are too many brain cells in local areas but regional underconnectivity — in other words, one computer not connecting as well to another — and that accounts — —

The CHAIR — I am no expert on any of this, but would not that be more to do with intellectual disability?

Prof. TONGE — No. You can get that in children that are bright. It accounts, for example, in some very bright children for their not being able to shift set or move task or not be able to see the whole picture. They cannot even see the wood for the trees because they get focused on the lichen on the bark, and that happens in very bright young people with autism as well. You get abnormal EEGs. A portion of those will actually manifest into epilepsy, because there is an increased risk of epilepsy in kids with autism spectrum disorder, including those that are bright.

Dr BRERETON — About 30 per cent.

Prof. TONGE — Yes. Risk periods being early infancy and again in early adolescence. In those children who have symptoms of possible epilepsy, yes, those kids definitely need EEGs. But being able to show that the EEG is vaguely abnormal and not diagnostic of anything, what is it contributing to the diagnosis? It is, I think, a waste of resource. An EEG should be only used when there is a clinical indication for it.

The CHAIR — Similarly, an MRI then.

Prof. TONGE — Most definitely an MRI; they are very expensive. Again what you might show are some general changes — for instance, the back part of the brain; the hippocampus, is usually larger. But there is nothing we can do about that; there is no operation.

Dr BRERETON — And it is not a diagnostic.

Prof. TONGE — Interestingly, in about 20 per cent you will often find a brain abnormality, like one of the cisterns in the brain is a bit larger or you might find a lump; it is not a tumour; it is a bit of scar tissue. That might contribute to the cause, but again it does not lead to symptoms. Mind you, if a child had a lump in their brain and they had neurological symptoms from that, of course you would do an MRI scan. The other thing about MRI scans is they are terrifying for children with autism. We are doing MRI scans on these kids with schizotypal disorder and with autism to compare their brains — that has got ethical approval and so forth — but we have to spend a lot of time preparing these children to go into the scanner and put up with the loud noise and the claustrophobic feelings. Even then some kids cannot do it, and of course we do not make them, because you are in the MRI scanner for up to 40 minutes. A CT scan may be okay because that is brief, but of course it is a dose of X-ray. Again my own view — —

The CHAIR — It is still not a diagnostic.

Prof. TONGE — No, it does not diagnose autism. I think gene screen, yes, because there are a number of genetic abnormalities which we know cause autism. They are rare, but it is reassuring sometimes for parents to know that there is a cause, and they may be linked with a known genetic abnormality, for example Prader-Willi syndrome, which has some extra problems on top of it like a voracious appetite and gluttony, and obsessive compulsive disorder. If we know that that is what the child has got as well as their autism, we have got some interventions. I think these days the genetic analysis is relatively inexpensive and is going to become even more so. That is probably a necessary one.

Ms McLEISH — Just one final one: with regard to the training that you said you have undertaken with various professionals over time, was that one-off training, or did they go back for follow-up?

Dr BRERETON — We had people who attended just about everything we did, but there was follow-up mentoring and supervision that we provided for people who had come along and had done that training with us. They also left — —

Ms McLEISH — Was it like a year later or six months later?

Dr BRERETON — It was often whenever they wanted it, so particularly if they were running out a parent program or they were running out a series of workshops to be delivered to the kindergarten teachers and parents, they would check in with us when they had completed that training. We also got them to fill out some feedback questionnaires and the people who attended that training to do that as well, because we wanted to find out whether the people that we had trained, we had trained well enough and that what they were presenting was well received. So there was follow-up; it was important.

Ms COUZENS — You have answered most of the questions I had, but there are a couple of things. You talked a lot about the mental health issues. Would you see a need for specialised services within the mental health services — I would not say we have got them now; certainly in my region we do not — and how you would see that potentially rolling out if that was the case?

Prof. TONGE — The simple answer is yes, there is a need because I think we were making the point that a lot of these conditions are often undetected or poorly diagnosed. Certainly a number of psychologists working in schools or working in early childhood services have increasing training in their background to be able to pick up at least the common ones. Sometimes with survey questionnaires you can pick up anxiety, depression and so forth, and of course they may have training in some of the psychological interventions. So they are a workforce that could be built, but they exist.

Certainly paediatricians are vital. We have a clinic up in Woodend, but there is no paediatrician basically beyond Bendigo, and there are not enough in Bendigo. So there is a national shortage of paediatricians in rural practice. Mind you, one of the biggest demands on paediatricians in country practice is for behavioural

paediatrics — that is, dealing with kids that have got emotional behavioural difficulties, and most of those will have autism. So they are another workforce.

Dr BRERETON — Autism assessments used to be within the remit of and delivered by CAMHS services.

Prof. TONGE — We set that up a long time ago out at Irabina with the observatory clinic, or what is now the Alfred CAMHS, and with the Austin CAMHS where each CAMHS in the state had regional responsibility to provide all of the autism assessments. They have now moved on from seeing that as their reasonability. Even though I have a CAMHS background, I am very regretful that that has happened. But that reflects the demands on them for other things.

Ms COUZENS — Would CAMHS be the most obvious — —

Prof. TONGE — Yes.

The CHAIR — Or is there an alternative?

Prof. TONGE — CAMHS would be the most obvious because they have this broader view about mental health difficulties, and after all autism is in DSM. It is a neurodevelopmental condition. It is the business of mental health services.

Dr BRERETON — Particularly those that are named ‘child and adolescent mental health services’.

Prof. TONGE — But child and mental health services often do not go down into little children.

The CHAIR — So that is where the maternal and child health nurses — —

Prof. TONGE — For some reason they have shifted into seeing kids who are at school now, because early childhood services are meant to be dealing with that.

The CHAIR — And then for the adult perhaps Headspace or organisations such as that.

Prof. TONGE — That is right; all of that. Not to be hard on CAMHS, they have such huge demands on them that they cannot even deal with what they are meant to there. But that is a logical place. I think to have to develop a whole new service just for these children would not be appropriate, and I do not think it is equitable either, because it is not just autism; there are all these other conditions which fortunately now NDIS will recognise apart from autism that also have similar and related difficulties and often share those problems.

Dr BRERETON — I guess there is the overlap too of when you have got a child who has got autism but also developmental disabilities. So then does this become the remit of disability services or is this mainstream mental health services?

Prof. TONGE — And of course we have been involved in training disability services workers in some of these ACT-NOW things too, and that is another, if you like, silo problem — the disability services having a different bureaucracy and remit than child and adolescent mental health services. I know why that has to happen. Sometimes we call it diagnostic overshadowing. If the child is known to have an intellectual disability and mental health problems, CAMHS might say, ‘It’s not our business; it’s disability services’, or disability services say, ‘It’s not our business; it’s mental health’.

Ms COUZENS — And then nobody gets the services.

Prof. TONGE — Nobody.

The CHAIR — And the child gets caught in the middle.

Prof. TONGE — Education plays a role too. I mean, school counselling guidance services are again flat out doing assessments and so forth, but they still do play a role in supporting teachers, and there is no doubt that aide support and funding for special programs for children in schools, be they special schools or mainstream schools, are vital. Apart from home, school is the place where these children live, work and operate, and if the teachers understand how to help them better and have got some support to help them work in the classroom, rather than being sent home because of their disturbed behaviour, then that is a win for everyone too.

Ms COUZENS — My final question is just around the justice system and what your view is in terms of how many kids are actually going through the justice system that have ASD.

Prof. TONGE — A simple answer to that is that we actually do not know for sure. Our group has had a couple of attempts to try to get some funding from the NHMRC to look at that. Maybe one day — we have not got it yet. But certainly when I was chair of Amaze we had a number of interactions with the police force, for example, about how to deal with kids with autism who have been naughty or got into trouble or have been picked up by the police and how to handle them, but a lot more work is needed there.

But there is no doubt that there will be a number of young people in the juvenile justice system who have what we would have called particularly Asperger disorder; now it is just an autism spectrum disorder. In fact Avril did this work on looking at the difference between kids with Asperger disorder, with high-function autism — that is, a history of language delay, but bright — and normal kids and found that those with Asperger disorder had more difficulties with socially inappropriate acting out behaviour and were likely to be in touch with the police, but I cannot give you a figure.

A member of the gallery — I am from Aspergers Victoria, and we get queries at least every couple of weeks about justice issues.

The CHAIR — I think that is something the committee has noted — that there is a lack of reliable data from both the department of justice and corrections around the number of inmates currently who might have autism. Certainly we know the Thomas Embling centre is the only facility that currently assists — —

Prof. TONGE — And of course it really complicates crime, doesn't it, if the person is not able to understand that the other person has a mind or is empathic or develops a fixed view about somebody misbehaving. For example, kids at school with autism might see a child breaking the rules in football as committing some sort of cardinal sin and then will make it their business to punish that child, thinking that what they are doing is perfectly right and proper; from their point of view it is. You can imagine that extended out into the community and someone taking the law into their hands, for example, in an incident of road rage or in some incident where they think another member of the public has broken a rule and not done the right thing.

The CHAIR — Can I thank you, Professor and Dr Brereton, for coming in today. We much appreciate it. That has been a very comprehensive little session that we have had.

That concludes our public hearing for today and indeed our public hearings for this inquiry. We will proceed now to pulling together our report, along with some further research that requires to be done. Can I thank everyone who has presented at our public hearings once again and those who have put in written submissions. Can I also thank Dr Greg Gardiner and staff, Hansard and my fellow members of the committee for their work over what has been a very long period of this inquiry. Thanks, everyone.

Committee adjourned.