LEGISLATIVE ASSEMBLY OF THE NORTHERN TERRITORY

12th Assembly

Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder

Public Hearing Transcript

9 am, Thursday , 29 May 2014

Litchfield Room, Level 3 Parliament House

Members: The Hon Kezia Purick, MLA, Chair, Member for Goyder

Mr Gary Higgins, MLA, Member for Daly

Ms Nicole Manison, MLA, Member for Wanguri

Mr Gerry McCarthy, MLA, Member for Barkly

Mr Gerry Wood, MLA, Member for Nelson

Witnesses: Menzies School of Health Research

Professor Alan Cass, Director

Professor Sven Silburn, Director, Centre for Child Development & Education

Ms Heather D'Antoine, Associate Director, Aboriginal Programmes

Aboriginal Peak Organisations

Ms Priscilla Collins, Chief Executive Officer

Mr John Paterson, Chief Executive Officer

National Organisation for Foetal Alcohol Syndrome & Related Disorders

Ms Vicki Russell, Chief Executive Officer

National Drug and Alcohol Research Centre

Dr Courtney Breen PhD, Research Fellow

Professor Lucy Burns, Associate Professor

Foundation for Alcohol Research and Education

Mr Michael Thorn, Chief Executive Officer

Ms Sarah Ward, Senior Policy Officer

Telethon Institute for Child Health Research

Clinical Professor Carol Bower, Winthrop Research Professor

Department of Health

Dr Jo Wright, Executive Director, Strategy and Reform Division

Dr Steven Skov, Chief Health Officer

Department of Children and Families

Ms Jodeen Carney, Chief Executive

Ms Lee-Anne Jarret Sims, Senior Policy Officer, Prevention and Family Support

Department of Education

Mr Ken Davies, Chief Executive Officer

Ms Vicki Baylis, Executive Director School Support Services

Australian FASD Association

Professor Elizabeth Elliott, Professor of Paediatrics, NHMRC Fellow

Madam CHAIR: Good morning and welcome. Minister Bess Price is an apology - she is on the committee - and Gary Higgins, the member for Daly, is coming. He is driving up from the Daly this morning and left at daylight so he will not be too far away.

On behalf of the committee I welcome everyone to this first public hearing. I welcome to the table to give evidence Professor Alan Cass, Director of Menzies School of Health Research, and Ms Heather D'Antoine, Associate Director, Aboriginal Programs Menzies School of Health Research.

Thank you for coming before the committee. We appreciate you taking the time to speak to the committee and look forward to hearing from you today. This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee applies.

This is a public hearing and is being webcast through the Assembly's website. A transcript will be made for use of the committee and may be put on the committee's website. If at any time during the hearing you are concerned what you say should not be made public, just ask the committee for a closed session and we will take evidence in private.

I will ask each witness to state their name for the record and the capacity in which you are appearing today.

Professor CASS: My name is Professor Alan Cass, Director of the Menzies School of Health Research.

Ms D'ANTOINE: I am Heather D'Antoine, Associate Director, Aboriginal Programs at Menzies School of Health Research.

Madam CHAIR: Professor Cass, would you like to start with some opening comments?

Professor CASS: Thank you. Firstly, we want to say it is a privilege to speak to the committee and address you on such an important issue as actions to prevent foetal alcohol spectrum disorder. From Menzies' point of view, to say up-front, we are in the Northern Territory, we want the issues we address to be the most important for the population of the Territory and to be the relevant priority issues you are considering as policy makers. For us it is crucial we engage, listen to and understand the critical issues you are trying to address. We want to state we are very willing to engage and see what expertise capacity we have to work with policy makers in addressing issues, including foetal alcohol spectrum disorder.

We have made a submission in which we attempted to pull together what is known generally about the issue of foetal alcohol spectrum disorder, what specifically is and is not known about the burden and approach in the Northern Territory, and to make some suggestions about key areas of practical, relevant research that might help us better understand the burden of the problem and think through it, develop and implement and evaluate best evidence-based strategies to address it.

We believe - we can talk about this and this is why we are having this inquiry - that this is a significant problem for the population of the Northern Territory. Good things to note are that some research has occurred in the Northern Territory looking at the burden of this problem.

It is a very difficult area to research, which we have talked about in the submission. It has been a challenge pulling together consensus about definitions of the different components of the spectrum. When you do research that just uses records of hospitals or doctors, you get different answers as to when you go out and actually screen and look at all members of a community or population. There are lots of challenges in how you interpret the information available.

What do we know? We know it is in the Northern Territory. We know it exists both in our Indigenous and non-Indigenous populations, so where there are women who drink during pregnancy there are problems around the effect of alcohol on the developing baby and child development generally.

We know that many of the estimates we have in Australia and internationally will tend to underestimate the burden of the problem. Remember that where there are concerns about different aspects of the definition, there is the most agreement on the strictest, smallest part of the spectrum. You can get estimates that will say one or two per 1000 births for foetal alcohol syndrome, but of course there is a whole series of other ways in which development is affected where people may not have all the classic facial changes, for example, that need to be there for foetal alcohol syndrome, but might still have very profound effects on development related to the mothers intake of alcohol and that environment during pregnancy.

That is one critical issue. There are some really good things occurring in the Territory. We were the first jurisdiction to collect information about maternal alcohol intake during pregnancy routinely in our midwife data collections …

Madam CHAIR: He is there.

Professor CASS: We will wait.

Professor SILBURN: Hello, Sven speaking.

Professor CASS: Sven, it is Alan, great to have you here. Why not say who you are for the members of the committee.

Professor SILBURN: I am Sven Silburn. I head up the Centre for Child Development and Education at Menzies.

Professor CASS: It is wonderful for me - and something I meant to say earlier - with Sven here now. With Sven and Heather - you have, in Sven, undeniably one of the national and international leaders in child development who has an incredible depth of understanding about issues affecting the Northern Territory population, Aboriginal people in remote communities and across the whole population. I am a kidney specialist in my own training, so I have been talking at length with Heather and Sven about these issues. Every article I read seems to be authored by Heather D'Antoine, so the other two members here on the panel are people who have been deeply invested for many years in practical research trying to address this issue. Soon I will be quiet and let them take over and talk as well.

I have made a few points in introduction. We did try to think carefully about what we felt could be done in terms of practical research and how to address this. Again, when you think about if it is to collect information and the wonderful efforts of our paediatric services and primary care services to address complex problems in the NT - we do not start from a blank slate, but I suppose that we also need to think about what is practical. For example, a notion that you would set up highly specialised clinics focusing only on this in multiple places around the Territory would be something that would not be feasible.

What we focused on in our recommendations is: what are the important things we can do with current data collections to make them more complete and accurate and use them to understand patterns of alcohol consumption and its impact on the development of children? What are critical things we need to do in training our primary care doctors, nurses, allied health, midwives and paediatricians, so that we ask every pregnant woman about alcohol; so that we explore around those issues and we train people to recognise and address child development issues early? What can we do, building on what is currently available, to improve developmental screening and advocate for things we know the evidence would suggest will have an impact?

That is my brief introduction, whether Sven and Heather have something specific to add? Although we are also very happy to answer questions and discuss with the committee.

Madam CHAIR: Just for my information, Sven are you based in Perth or based in Darwin, and just happened to be in Perth?

Professor SILBURN: Can you relay that, I could not hear it?

Professor CASS: The question was, are you based in Darwin or based in Perth? Sven has been head at the centre here based in Darwin for a long period. He is currently a bit split between Darwin and Perth, but he is a full-time employee of Menzies and spending some time in both places currently.

Madam CHAIR: Fair enough. Sven or Heather do you wish to add any comments in the opening part?

Ms D'ANTOINE: Just a couple. I think the research that has been done in the Territory and in Australia and other places shows that it recurs in families. If a mother has given birth to one child and drinks in pregnancy with the next child there is a high likelihood that she will have another one with FASD. That was one and I think that the other one to highlight is that there is a lot of research happening nationally and we are linked into that, so we can see a linking of what is happening currently or what is planned to happen. I think we will have a lot of lessons to learn from what is happening in the Fitzroy Valley which are relevant to the Northern Territory.

Madam CHAIR: Fitzroy Crossing or Fitzroy?

Ms D'ANTOINE: Fitzroy Crossing, but the whole valley in the Kimberley.

Professor CASS: That first point that Heather made, I think, is really important because sometimes people say, why bother to diagnose this, what does it matter, should we not just be reducing alcohol consumption? I think her first point is a critical one, that research shows that the syndrome recurs in families. If we are going to really address this, it is clearly true that not every woman who drinks has a child with Foetal Alcohol Spectrum Disorder, but if we are going to do something about preventing cases and working with families, for example, there are clears benefits of diagnosis, so that you can target working with those families to prevent alcohol consumption in future pregnancies. That is one question.

The other one when she talked about - in two weeks Heather is going to an interview in Canberra at the NHMRC for a national centre for research excellence in Foetal Alcohol Spectrum Disorder, where we in the Northern Territory, Menzies and the paediatric services are collaborating with people in Western Australia and other states. The notion is that there

is a pulling together of absolute expertise around this issue so that we can co-ordinate national efforts to better understand the problem and how to address it.

Madam CHAIR: Can I just ask a quick question? You said a mother can drink during pregnancy and the child could not have FASD. A child could be born ...

Ms D'ANTOINE Not every woman - from the research done worldwide - who drinks alcohol will end up with a child that is FASD.

Madam CHAIR: Okay.

Professor CASS: It is the same as not everyone who smokes will get lung cancer, not everyone who is overweight will have a heart attack. Clearly …

Ms D'ANTOINE: You will not know which one.

Professor CASS: That is true, but clearly it is in the context of alcohol intake, particularly heavy alcohol intake that the syndrome occurs. I think Sven - when he chimes in and responds to questions - is involved in doing some very interesting research looking at the strong relationships between - looking at areas across the Territory where there is heavier alcohol consumption, particularly where alcohol consumption is more frequent amongst pregnant woman and how that relates to childbirth outcomes and development.

We are beginning to look at where there are places where we know more women drink during pregnancy, and what the school outcomes are for the kids. How do they relate to that? Are they using various accepted - early development index? Are they ready for school? What are their outcomes when they are in school? We can really begin to understand the implication and impact of alcohol consumption during pregnancy on those critical child outcomes.

Professor SILBURN: Could I chime in there? Alan, I am not sure if you got that e-mail with the attachments of that analysis that John did, but we did a quick analysis looking at the regional level associations of the data that we have about maternal alcohol consumption – the rates of antenatal maternal alcohol consumption and the average rates of children being developmentally vulnerable on the Australian Early Development Index. When you look at that as a crude association, not taking into account other factors that might differentiate between regions, there is a very clear association between rates of alcohol intake and the proportion of children who are developmentally vulnerable when they commence school.

What is important about that data is they pinpoint there are some regions where the issue is a much greater concern. That is useful for where you need to be targeting you prevention and treatment efforts. Is that chart available?

Professor CASS: It will not be available to show. I have seen it - what you sent this morning. It is a wonderful example that we are now working closely with many of the government agencies - with health data, education data, data from the office of Children and Families and others, where we can really pull together critical information that comes out of what a midwife collects in a hospital, what a primary care doctor or health worker might collect out in the community and information we collect from all our school kids when they are attending school. By doing that, we can piece together a much more comprehensive picture.

The one key issue Sven said is that helps you target where the critical areas are, but it also helps us to begin to unpack what might be some of the critical causative things. What are the steps in a process where we might be able to intervene? Not just what is the right place, but what are the things we might need to address.

Mr McCARTHY: As a child - I have memories I have related to this debate, and I can remember the raising of a glass of champagne at the wedding and I remember my mother raising her glass. Then I can remember raising a glass at the announcement of the baby coming, and my mother running around taking the glass out of the hand of the mother, and that is where the conversation started with me.

Alcohol and alcohol consumption has been a cultural thing across all generations and all ethnic groups. Where it the line between having a drink, as we have already talked about, and foetal alcohol syndrome?

Ms D'ANTOINE: That is a really important question and is asked a lot. The answer is we do not know if there is a line. We have always gone with the message that no alcohol in pregnancy is the safest choice to take, because you just cannot do – it is difficult to say whether this much would …

Madam CHAIR: What is a glass?

Ms D'ANTOINE: …'What is a glass' is an important comment as well. On that we always just advise women the safest thing is just not to drink alcohol.

Professor CASS: So that is absolutely the current national advice, but I think your question points to something really important where there is a need for us to engage. We have to think how to best do that with the community about messages which will be taken up, and that people will not react to it immediately and say, 'That does not relate to me,' for example, but in ways that focus on issues for pregnant women or women thinking of becoming pregnant. We also know that a very large proportion of pregnancies are not planned, so it is about young women. We can come up with effective community campaigns that raise people's awareness and are based on some evidence about what are ways to encourage people to change behaviour.

Mr McCARTHY: Just another – when I started working with tribal Aboriginal communities, I learned a lot and I am still learning, but one of the cultural nuances was that the mother did not announce the pregnancy and culturally there were all sorts of traditions around that and the reasons why. I will not go into my learnings on that, but I found that to be very interesting coming from a European background where mum used to grab the glass out then make the big fuss at the party. So is Menzies looking at that as well?

Ms D'ANTOINE: Aboriginal women's cultural practices in …

Mr McCARTHY: Yes.

Ms D'ANTOINE: Not specifically at this stage. I do not know if we would be able to – if we would do that. It would just depend, I think.

Professor CASS: As a general question when we work with communities we are very interested in people's understanding of health and illness, and how that impacts on how they make choices to go to doctors or take medicines or change their behaviour. So I think I said earlier I myself am not a foetal alcohol researcher, but someone who researches kidney disease, diabetes and heart disease - there, for example, we have done a lot of just sitting and talking with patients about their understanding of kidney health and illness and what they do. We do that type of research.

I think Sven's group are probably currently some of the leaders at Menzies looking at foetal alcohol and child development issues. He has talked already about some of those data linkage efforts they are doing, but Sven, you are also doing a lot of work with families and young children around development issues generally, so maybe you should talk about how you are interacting with families in that way.

Professor SILBURN: Yes, our work goes across a number of areas and we are particularly interested in the early years of a child's development, in the years before they go

to school, because almost 80% of their brain mass will have developed by the time they enter school. The environmental conditions during that time of most rapid brain development have lifelong implications and all the current research is showing that this period of life is much more important in determining how children will do in their life, for example, how they are going to manage school and how they are going to develop in terms of their behaviour and wellbeing. The work that is happening through the education system where schools are now reaching out to families before children arrive at school through programs like Families as First Teachers is a very important mechanism for engaging with parents of very young children to give them the knowledge and skills that they need to successfully rear their children.

There are other programs around managing behaviour and those parenting programs have been very important in helping deal with problematic behaviour. This is the 'Let's Start' program. In the Fitzroy Valley there is currently a program looking at helping parents who are dealing with children with foetal alcohol syndrome who present with really difficult to manage behaviours. They are trialling a parenting program and I think this really needs to be looked at because giving parents the skills to manage those difficult behaviours and strategies that can make a big difference – if those strategies are put in place early it can make an enormous difference to how that child will cope at school and their chances of not getting into much more serious behaviour problems when they reach adolescence and are at high risk of becoming involved with the justice system.

We think that there is a place for parenting programs as part of early intervention for families dealing with a child with foetal alcohol syndrome.

Professor CASS: Maybe take from that back to Heather's initial point that foetal alcohol issues recur in families. It will be critical to follow up on your point to say we want to be working with parents before they have children, or have had another child, for the subsequent pregnancies to try to change behaviours …

Professor SILBURN: That is logical.

Professor CASS: … which will be crucial for prevention. A strong focus of our work is trying to engage with teenage and young adults in high risk environments and understanding –we know from our own teenage kids that kids can make silly decisions and take high risk behaviours and think they are indestructible irrespective of where they live and who their parents are …

Madam CHAIR: Did we not all do that?

Professor CASS: We probably all did that; we need to understand more about that, and they also respond differently to different messages. We can tell a 16-year old not to do 'X', it will do something to you when you are 50. They think 50-year olds are dinosaurs. That is what my teenagers tell me I am, so that is a crucial focus of work.

Mr McCARTHY: As a comment, there was some really good public health education material produced in the 1980s and I have been monitoring it. One of the best I saw was the 2D poster of the mother - one blue and one red – which was about the intake of alcohol and tobacco. I have been monitoring it over decades now and it seems to focus on the third trimester and assessing the cultural link about the first trimester. In terms of research and now putting it into practice, we need to shift that back. Professor Cass, it is great to hear the story out there is to get down to early intervention.

Ms D'ANTOINE: I think one of the things missing in the past has been the lack of support for men to provide support to their partners. A lot of the focus has been on the woman, and it is about the father, the family and extending out to the broader community to support women to not drink in pregnancy.

Professor CASS: Some of the research talks well to that, that women – I think we have talked about one of the national surveys in our submission where women who drank during pregnancy - when they are talking about what will influence them as to whether or not they might continue in subsequent pregnancies, they will talk very much about their family, their partner, and if they drink. If they stop drinking they themselves are likely to stop drinking, and that again makes sense. If we focus only on the pregnant woman the interventions we put out there will not work.

They are part of a family, part of a community and people makes decisions in families about their behaviour.

Madam CHAIR: On a technical point, who collects the information about the child that presents – assuming you do not have any of the programs and assuming the child is born and has foetal alcohol syndrome, who is collecting the data? One of the questions we will have to grapple with is how big is the problem in the Territory and where, but who are the collection points?

Professor CASS: The basic things we do not collect population-wide data about – we strongly believe what we think about the prevalence - what we know is an understatement of the problem. There are a whole series of relevant data collections, so we have obviously talked a bit about the midwife collection and things about the pregnant mother. The children obviously interact with childcare services, paediatric services and education services so when we have a child born in the NT or other parts of Australia there are points along their

path where things are routinely collected. That is where some of that work that Sven is talking about can help us, by pulling all of that together and relating it to what we know about the conditions of the pregnancy and whether the mother drank.

We can understand some things, but you talk to another problem which we address in the submission, that we need to train our primary care services, allied health and people in paediatric services. There are tools available and nationally there is agreement that they need better skill and adeptness in using screening tools about child development that tell us about foetal alcohol and other causes of child development, so that we can be much more comprehensive in knowing where the problems are and then trying to work out how to address them. We lack that.

Madam CHAIR: Then I guess the agencies, if I can call them that, have to talk to each other because you are doing your work. Let us assume the mother has a child and the child just grows up and then just goes to school, and it is only at that time that they start to realise there are some issues. That agency then has to talk to the health and allied people, and I do not think that is probably happening at the moment.

Professor CASS: That would not be unique to the Northern Territory. That is very difficult, that inter agency discussion. It is the same in research and delivering clinical services. I think in policy people have particular things they need to achieve and we are challenging them to think across a whole series of focuses and agencies. Sven, I think that is directly relevant to that work you doing currently.

Professor SILBURN: Are you referring to the Alice Springs zero to four, pre-birth to four collective initiative?

Professor CASS: That might be a good - if there is an example like that where people are trying to pull things together in that sort of cross agency way, that would be worth discussing.

Professor SILBURN: I think one of the most promising developments that I have seen is happening in Alice Springs. It was an offshoot of the Alice Springs redevelopment plan but basically it is called the Pre-birth to Four Initiative, and forms a collective impact group of all the non-government agencies and government agencies that provide services to children and families. They come together to basically look at how they can work more collaboratively.

It has taken them about 18 months of talking; it is being led by Anglicare and the Desert Knowledge Centre. They have now got a framework of how they are collaborating to

address things which they each cannot do on their own, but to get better outcomes for children all of them need to be doing better. They have identified some of the key areas that they are going to work on, and they have developed a set of indicators that will tell them whether they are making progress in all Alice Springs children doing better in terms of any development by the time they are aged five. They are going to produce a report called the State of Central Australia's Children, and that is due out later this year. That will provide the baseline for the collective's collaborative approach that they have worked out between them.

I think that kind of initiative is a very good example of overcoming the silos between agencies. One of the artificial causes of those silos has been the way in which services have been funded between NT government funded services and Commonwealth funded services. There has been an absolute patchwork of separate agencies being funded to do certain things with an enormous amount of duplication and wasted resources. I think that this approach

Professor CASS: As you said, Madam Chair, it is crucial we do this. Again, in our submission there is not Australian evidence, but we looked at international evidence about the cost of foetal alcohol spectrum disorder and estimates of a $14 000 or $15 000 per child per year impact on services, health utilisation and extra supports that might be needed around behaviour, school and education. As a researcher, you need to work with policy makers. The way of piecing that together and making the argument to Treasury - if we come together collaboratively to address that we can be much more efficient in our use of government and public finances because we will address a costly, difficult problem. That is one way we are keen to engage and try to provide evidence and information that might help.

Ms MANISON: Staying on the issue of data available for earlier exposure to a child being born with and who will live with the disorder: clearly, through all the submissions, it looks grossly underestimated - Indigenous and non-Indigenous?

Professor CASS: Yes.

Ms MANISON: It was interesting listening to the professor talk about the case study in Alice Springs and his talk of silos. One of the things this committee is trying to get down to is to find the real extent of FASD in the Territory. What are the real numbers today so we can make recommendations on how to reduce FASD in the future? Given Menzies is one of the expert bodies looking into the issue of FASD in the Territory, if you had an ultimate wish list of what you want to see today to improve data quality and collection so we can get an accurate reflection of what is happening in the Territory and how big FASD picture, what would it be?

Professor CASS: In our submission we have made some recommendations. We believe there is a critical need to - there are key aspects of data collection happening. We need to look at their completeness, accuracy and quality. Some of that is about training of staff to ask the right questions in the right way to get the answer, and that is a critical issue in the Territory and other jurisdictions. One is about ensuring we have complete data from midwife data collections and other things so we can pull them together.

Heather said, and might follow it up, that within the next few months we should get some reports out of the studies in Fitzroy Crossing and the Fitzroy Valley. With a very significant investment of funds they have done an active case ascertainment study in a remote area that would be very similar to many of the remote community environments we would be addressing in the Northern Territory. We work closely with many of those researchers, so the interview Heather is going to in Canberra in a fortnight is - there is a lot of input from the Menzies end and groups working on the Western Australia work.

We would be very keen to talk with you as we digest what comes out of that active case ascertainment study to understand what it tells us. You would think – and it would be good to hear what Heather and Sven say - there has been so much investment to do that and a focus in Fitzroy Crossing that will provide excellent information, but could not be replicated in every remote community across remote Western Australia or the Territory. It would not be efficient. Do you then say we need to choose a few key areas where we combine a level of case ascertainment with study of what services are available, and how healthy providers approach diagnosis, screening and treatment? You could think about a quite integrated and very practical way of researching. Are there a small number of key areas to do this? Can we do some more in-depth investigation, but combine it with looking at how health services approach this and other services diagnosis screening and management, and come up with something that would be very practical and directly inform what you might need to do by way of interventions?

Ms D'ANTOINE: One of the things is the flow of information. When a women presents in her pregnancy she gets seen by the midwife and the obstetrician and those that deal with pregnancy, and then when the baby is born there is another team almost, that comes in and a lot of that information does not flow through what has happened in pregnancy. If a child has been exposed to alcohol prenatally it would be good to see that that information just slots across, so when they see the paediatrician or the speech therapist that information is right there in front of them, rather than trying to ascertain what happened back here.

One of the things that showed up in the surveillance that was done nationally is that the average age of diagnosis is around three years of age. What you have is the exposure has happened here, and when the child presents at three because they are maybe not speaking properly or something like that, it is really hard to then backtrack. If you can have a nice flow of information that would be a really important starting point.

Professor CASS: Which is, I think, where Sven says that three of your first four or five years, which are so crucial to your development across the life course, we have missed. That is a profound area where shifting that to earlier and trying to screen for, address and understand and intervene, as early as is feasible with families, would make some sense.

Sven, do you …

Professor SILBURN: Yes. That is absolutely true.

Professor CASS: If there is anything you wish to add – I feel bad with you on the phone. It is a very nice phone that you are speaking out of though, Sven, and you are well represented here.

Madam CHAIR: Gerry has a question.

Mr WOOD: This question might be to Sven. You talk about this program between zero and four, and I realise I am only a layman, but I have tried to read a little bit about the brain and you know that there are some books out about the elasticity of the brain - can a child who might be at risk from alcohol syndrome be helped from day one? Because my understanding is the brain, once the baby is born, picks up all the noises and sounds and everyone around it at that stage. Is that a time which would be extremely important to try and reverse some of the possible impacts that alcohol has had before the baby is born? Can we say that someone who is affected by alcohol syndrome can be turned around? Are there programs that have been proven that will basically – I do not like to use the word normal, but they would average people?

Madam CHAIR: Make them better.

Mr WOOD: Yes, make them better. Is that possible?

Professor SILBURN: That is a very difficult question to answer, but there is some evidence from very recent research on epigenetics, which is how the human genome actually gets modified with chemical signals that attach to the genome, and that comes from the environment. The effects of alcohol during pregnancy have an epigenetic effect on brain cells and how they replicate, but there is also evidence that positive experiences can do – if there is good parenting, consistent parenting, good nutrition and all the things that make for optimum development, that can mitigate the effects quite considerably. There is also growing evidence that some of these early effects may in fact be somewhat reversible, but

again it depends on how severe the exposure has been. At the lesser end of the spectrum these other factors can completely mitigate the effect, but at the more extreme end you are really looking at a much higher risk of lifelong disability.

Professor CASS: In the submission we did, there was a systematic review done in 2009 looking at interventions for Foetal Alcohol Spectrum Disorder. That showed little solid evidence about interventions that could have a specifically targeting, and it would have solid evidence as to what was effective. We would be very willing to look again to see whether there is newer evidence. There have been a number of further innovative programs to try to address this.

In the area Sven works every day there is some evidence about some of those home support programs through intensive nursing support, particularly with programs in Alice Springs and parts of the Territory. There is growing evidence from the Let's Start program that Sven and his team lead from Menzies of working with families early when children have developmental problems, behaviour and developmental education, all sorts of problems.

What I think we need to do – there has previously been little international evidence about specific things addressing FASD. We need to look at what has been implemented and evaluated in the NT environment about working with families and children early, which is shown to work, and then working together to ask, 'What might we implement in a controlled way and show this is what it takes to sustain this?' This might be something that is a priority for the government to implement in a controlled way, evaluate and show it is effective, sustainable, represents a good expenditure of money and what the impact is. Again, as researchers, new ways of partnering with you in saying, 'This is what we think is the best thing to do'. There may not be perfect evidence, but we all want to do something anyway even if there is not perfect evidence.

That then challenges us, perhaps ,to be quite frank and say, 'The best evidence is this might work. Let us pilot this'. The evidence says in the Barkly, or wherever there are the heaviest rates of alcohol consumption in pregnancy, there are concerns about child development. Let us choose critical areas to pilot things, see what it takes to sustain them, show that we can get the right skilled staff, we can evaluate their impact and government can then say, 'This is a good value for money and will have this effect'.

Mr WOOD: Can FASD get mixed up with other issues in child development? We hear behaviour in school can be caused by autism, or some other factors might cause it. Can you separate that clearly or is it better to say, 'Children with certain development problems - we should address that as a whole row rather than trying to break it up into categories?'

Madam CHAIR: Are you talking about the possibility of misdiagnosis?

Mr WOOD: Yes, that is right.

Ms D'ANTOINE: It does get mixed up with other conditions. Attention deficit hyperactivity disorder is the classic one. Some children diagnosed with FASD also have autistic traits, so those three conditions are very – this is where you need the paediatricians with expertise in this research area - but trying to unravel that is very difficult because we do not have biomarkers for those.

Some of the paediatricians in Australia have written papers specifically for paediatricians about trying to distinguish between ADHD and FASD. I have not really looked at that, but they are aware of these conditions that are difficult to separate. There is also the impact of the environment. Like Sven was saying, if you have children growing up in a home environment that is perhaps a bit chaotic, that could be having an impact on their behaviour. It is very hard to …

Professor CASS: It is certainly possible to misdiagnose. The pure foetal alcohol syndrome has much tighter diagnostic criteria involving quite specific facial features, for example. Again, people need to be well trained to pick that up. However, there is a spectrum where some things are less clear and where it can be mixed in with other causes of child development problems.

We need a general response to the early pick up of child development problems and a way of skilling and training our primary care practitioners and paediatricians to deal with that. We need to look at a general approach to development screening, how it is relevant in the Northern Territory environment and what we do.

I think going way back to when Heather said - in the context of a mother who drank alcohol in pregnancy, and maybe her heavy alcohol intake and poor health, where there are features of more clear foetal alcohol syndrome and where we know this syndrome recurs in families is where a benefit of diagnosis and real engagement with that family about this issue could have a profound impact on subsequent pregnancies, for example, and help target the nature of how you need to work with that family. Does that answer that?

It is a complex area; we need to be doing something about child development issues generally. There are some real benefits in equipping people to diagnose the condition and targeting some work with the families.

Madam CHAIR: Assuming the alcohol consumed is substantial, is the impact on the unborn child or the child when it is born just in the brain and a few facial things or are they sometimes born physically deformed?

Ms D'ANTOINE: It does affect other parts of the body, so they can be born with other birth defects and a classic one is a cleft palate, and holes in the heart.

Madam CHAIR: So it is not just a brain thing?

Ms D'ANTOINE: No, it is not just a brain thing; it can affect other organs as well.

Mr McCARTHY: To unlock what Gerry is talking about - it is interesting research out of Canada in that correctional services system, so if we then back track then to the juvenile justice system in this case, and Nicole's point about the silo affect in all agencies - it is refreshing to hear that good education, awareness and nurturing programs can support any child development issues and would pick up all those moderate cases that can be a crossover. That is a great recommendation for government and a very pragmatic one.

I am going to hit you with something a bit harder. As a medical researcher from my mother who was a nursing sister, to a teacher in north western New South Wales in the early 1970s, I started asking the questions: why is this not being diagnosed? Why has it not been resourced and why are these kids - I am talking about Walgett, which was a very interesting area - not being supported? Then all the conspiracy theories develop, so we will leave that to one side. As a medical researcher, where we have seen so many resources go into cancer and all the other diseases and issues, how come there has not been a resourcing into this area of child development?

Professor CASS: I think that is changing, would be one answer. I think there is also, as Sven talked about, emerging evidence that we need to keep communicating about, about how crucial the first four years of development are, and really getting across to the community that what happens in those first years lays a pathway for life. It is not immutable; we are not saying things are totally predetermined, but how important those early years are for success at school, as you say, laying a path. It might mean people into the justice system as against developing skills that can take them to higher education or jobs etcetera.

That is one thing. Secondly, clearly we know that when people are impacted in their families or community by cancer and things like that, that becomes a critical issue that people want addressed. At Menzies generally we think there is a need to target health research and health expenditure to one of the main population burdens and critical issues for

our population in the NT and Australia. Clearly, this is one of the critical ones so there needs to be more work there.

Sven, did you want to add to that?

Professor SILBURN: Yes, I think that the need for investment in children's early developments has certainly been picked up by state and territory governments and the Australian government over the last five years. In the Australian Early Development Index you have got a comparison for the Northern Territory between 2009 and 2012 and some of the biggest improvements that have been seen nationally actually happened for Indigenous children in the Northern Territory. Looking at that, the percentage change we saw equated to something like 200 fewer children arriving at school who would almost certainly need some form of special education. That is a very big change over a three-year period.

The other cause for optimism is where maternal and child health services are really targeting teenagers just at the time they are becoming sexually active in remote communities. There is a very good example in Maningrida where they have been very proactive in reaching out to young women and seeing they have access to Implanon. Since they have done that - this is long-term contraception - there has been quite a significant reduction in the number of pregnancies among school-aged girls. That bodes well because we know as the age of childbearing is delayed there is much less likelihood of there being issues with alcohol and pregnancy, and also there are generally better pregnancy outcomes for older women. That is an important step in the right direction and we would like to see much more of that happening across the whole Territory.

Madam CHAIR: Does the research and work of Menzies focus on people in Aboriginal communities plus people in urban communities? Is there more prevalence of the problem with Aboriginal women or is it other Territorians in mainstream communities?

Professor CASS: Generally our work covers the whole of the Territory. When you look at the Australian evidence it shows an increasing burden in Aboriginal and Torres Strait Islander Australians, but it is a whole-of-population problem nevertheless. Where there are …

Madam CHAIR: Is there a (inaudible) for it?

Professor CASS: In our submission there is some evidence from the NT. For example, there was a review of a decade of case records in the Top End of the Northern Territory where rates were higher in the Indigenous births - the births where there was an Indigenous mother rather than non-Indigenous - but they were present in both. It is consistent with

international evidence that there are more disadvantaged groups and we would have the ability to look at differences in alcohol intake using the records we have in the Northern Territory to relate that to child development.

Ms D'ANTOINE: When we talk about the prevalent study happening in the Fitzroy Valley, there is a tendency to go into Indigenous communities or where there are known high rates of alcohol consumption, like parts of South Africa. They tend to go into where they expect to find it. When they have done school-based studies in places like Rome, the rates go up because they are systematically going through a school population which is more representative of the general population.

Madam CHAIR: I was thinking as I was driving in of some of the European and eastern European countries with their heavy alcohol consumption of the vodka-type drinks. Are there studies or work from those countries?

Professor CASS: There has been a massive increase in alcohol intake in Russia, and there has been - I am personally not aware of direct evidence about changes in foetal alcohol, but there have been clear impacts on longevity and a whole array of health indicators in Russia with broad changes that have included much heavier alcohol intake over recent decades.

Ms D'ANTOINE: In countries like France, where they have what they call regular drinking, not the binge drinking we have, when they have looked for it, once again, they have found it. It is there, it is just they look for it a lot harder in Indigenous populations and where there are high levels of alcohol consumption. If we were to look into a classic town in Australia somewhere I am sure we would find cases we would not expect.

Professor CASS: We think it is critical to look across the Territory to where the heaviest burden of the problem is, find the regions it is in, and often these problems are women, partners and families in disadvantaged circumstances, who might have less access to effective health and social services. We know the types of populations in the Northern Territory and regions where that often is and that is normally a very good place to target preventative and treatment efforts.

Mr WOOD: Can I just ask another question?

Madam CHAIR: Yes, go on.

Mr WOOD: I was at that forum we had the other day at Menzies and the mother there, Mrs Russell, had a child who obviously had some problems, but those problems were not actually seen until puberty and then there were family problems. What I was going to ask was do people know that they are FAS people? As they get older do they actually know that their mother drank and that is the reason for their behaviour, or if they do know that and they know they have got some problems, perhaps with violent outbreaks or very moody or whatever, are they able to try and overcome some of those problems themselves? Is there help for those people so they can try and sort their lives out a bit or is it just a case of, 'Too bad you have got it, and you are going to live like that for the rest of your life'?

Ms D'ANTOINE: In regard to whether people become aware of it when they get older, there is only anecdotal evidence of where people have been approached after they have done a presentation on FASD, where someone in the audience has come up to them and said, 'My mother drank in pregnancy and I behave like that. I think I have got that condition,' or 'I think my child has that condition'. I cannot think of any research on that. Does it help adults when they get older? I think the focus has really been on children and women in pregnancy, and countries that are more advanced in their program of research are starting to look at adolescents and adults. We have not really gone to that stage yet.

Professor CASS: I would have thought we do not have the systems in place so people would access – we need to be more comprehensive in our way of trying to pick it up, ascertain it, work out where there is a heavy burden of the problem and provide support services that families and the individuals need. I would have thought, like in many other complex problems, many people in Australia frequently fall through the cracks. This is not saying we do worse in the Territory or something.

Madam CHAIR: Any more questions?

Ms MANISON: Just going back to diagnosis and early intervention when a child has been born with the disorder; I looked at the House of Representatives report from a few years ago where the committee recommended that there was a roll-out of FASD diagnostic instrument. I am not exactly sure how far along that has gone since the Commonwealth report was released, but from Menzies' point of view, would it be constructive if we had a formal process introduced across the Territory, working with health organisations to look at having an instrument in place at a very young age if you have seen that there has been exposure to alcohol consumption. Or is it something where we should be looking at a whole of Territory adoption of a diagnostic tool?

Ms D'ANTOINE: Yes, and that has been done, that is completed works. At the centre for research excellence where we are going for an interview in a couple of weeks, one of the chief investigators is a paediatrician and she will be working with that. She has been

approached by paediatricians here to do training, so there is a request for that to happen. This is where what happens in the Territory can link up with what is happening nationally.

Professor CASS: There was that work to try and develop and reach consensus around those tools. I think what people have identified is that there is a need for ongoing training in the use of those tools, people's awareness and working out where and how to implement them and I think that is something that would be important. I remember seeing the Royal Darwin Hospital paediatric submission a few years ago; I think that was a national inquiry, but people met here. Clearly the people leading the provision about our paediatric services across the Territory will need to be critically involved in that, in issues of training and thinking then, together, about how something would be implemented.

Mr McCARTHY: For the *Hansard* record, that dog is from Perth. Does the dog want to put its name on the public record?

Professor Silburn: Yes - his name is Gus

Madam CHAIR: It is not a Territory dog.

On behalf of the committee thank you for coming today and sharing you professional views and expertise with us. We will send you a draft copy of the *Hansard* to look at and amend it if it is not quite correct or we did not interpret you properly. Thank you once again.

Professor CASS: Thank you for the opportunity to engage.

The committee suspended.

Madam CHAIR: Good morning. On behalf of the committee I welcome you to this public hearing into action to prevent foetal alcohol spectrum disorder. I welcome to the table to give evidence to the committee, Ms Priscilla Collins, Chief Executive Officer, Aboriginal Peak Organisations Northern Territory; Mr John Paterson, Chief Executive Officer, Aboriginal Peak Organisations Northern Territory. Thank you for appearing before the committee today and we appreciate you taking the time to speak with us and answer questions.

This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply. This is a public hearing and is being webcast through the Assembly's website. A transcript will be made for use of the committee and may be put on the committee's website. If at any time during the hearing you are concerned that what you say should not be made public you can ask the committee and we can go to closed session and take your evidence in private.

Could you state you name for the record and the capacity in which you appear today, then if you want to make an opening statement and pass comment and then answer questions from the committee members.

Mr PATERSON: Thank you Madam Chair, and good morning members. Let me firstly thank the committee for giving us the opportunity to provide evidence to this committee, which we see as a very important social committee embarking on our respective sectors as services providers. My name is John Paterson, the Chief Executive for the Aboriginal Medical Services Alliance Northern Territory; that is one hat. I am also part of a coalition of Aboriginal Peak Organisations of the Northern Territory which comprises the Northern Land Council, Central Land Council, NAAJA, the Central Australian Aboriginal Legal Service and AMSANT. Its chair and members will be presenting our joint submission. The first one I will present and deliver, and that will be APO NT. If I can, Madam Chair, refer to APO NT rather than having to say Aboriginal Peak Organisation ...

Madam CHAIR: Yes, that is fine.

Mr PATERSON: There are many acronyms. There is also AMSANT - if I can refer to AMSANT rather than saying the whole organisational name. I will present a little bit of APO NT and AMSANT jointly. We will be putting in submissions, both from APO NT and AMSANT, within the next few days – it is work in progress.

I will provide an opening statement on behalf of APO NT, including the AMSANT comments, and then my colleague, Ms Priscilla Collins, will provide additional statements that focus on issues relevant to the justice system in her capacity of Chief Executive of NAAJA. So, Madam Chair, if you are already to go?

A bit of a background on the drinking culture in the Northern Territory: at its simplest, FASD - if I can refer to foetal alcohol syndrome disorder as FASD as well? - is a range of conditions caused by alcohol consumption during pregnancy. APO NT and all our APO NT members have, for many years, been working to achieve coordinated action to address the devastating impacts of alcohol on Aboriginal people and their families in the Northern Territory.

The statistics on alcohol harm are shocking and unacceptable and also well known, so I will not repeat them here. It should be noted, however, that alcohol is not just an Aboriginal problem and I continually say that in all the media work that I do. We see it from our perspective as a whole of community, and you can just pick up the papers every weekend and find out and read stories that are happening all over the nation.

The average consumption of alcohol for non-Aboriginal people in the NT is reported at almost 14 litres per person per year, compared with the national average of less than 10 litres, while the mean for Aboriginal people in the NT is 16 litres.

With a thinly populated region occupying one sixth of the Australian land mass, the Northern Territory is one of the heaviest drinking regions in the world. APO NT in recent times has hosted two grog summits, one here in the Top End and the other one in Central Australia, focusing on alcohol policy and its impact on Aboriginal people in communities. The summits included delegates from across the Northern Territory, including leaders and Aboriginal representatives from Aboriginal organisations and communities along with service providers, medical professionals and peak bodies.

The summits provide an opportunity to consider the evidence and experience on what works and what does not work in relation to alcohol policy and approaches. Two of the presentations to the summits focused on FASD. At the Darwin summit, June Oscar, Emily Carter and Patrick Davies shared their experience in combating alcohol in their community at Fitzroy Crossing in Western Australia, which was suffering terrible alcohol related harm, including rising deaths and suicide.

As a result of community action and in the face of strong opposition they were able to introduce alcohol restrictions. This resulted in reduced hospital admissions and alcohol related violence and increased school attendance. Their community action attracted others to help, resulting in a partnership with the George Institute and Sydney University to conduct a study on the prevalence of FASD with the aim to identify the scale of the issues and how to respond.

The project identified and was driven by the community. A further project identified and driven by the community was the subject of a second presentation provided by one of AMSANT's member services, Anyinginyi health service, and I understand they are also putting a submission to the committee on this matter. On its pioneering efforts to develop a holistic community based response to FASD, Anyinginyi has provided a separate submission. These two examples demonstrate the kinds of community driven responses that governments should be supporting and investing in if we are to see effective outcomes.

The statistics and data in Australia on the prevalence of FASD are not well understood. The recent Commonwealth inquiry into FASD reported that among Indigenous Australians the incidence of FASD is estimated to be 2.76 and 4.7 per thousand births. However recent media reports suggested that half of the babies born in Fitzroy Crossing had disabilities from FASD.

What is generally known is that while the majority of Indigenous women do not drink alcohol, those who do consume at harmful or hazardous levels are at risk of having a FASD child. The committee should ensure the differences in this key data are addressed in this inquiry.

Diagnosis: there are no specific objective tests to diagnose FASD sufferers. This can lead to variable approaches to diagnosis and treatment, which risks compromising outcomes for affected individuals with regard to intervention, counselling and treatment. Failure to diagnose may be due to the lack of knowledge around the identification of FASD, an inaccurate diagnosis because symptoms resemble other conditions or perhaps the condition was recognised, but not followed up.

Undiagnosed sufferers will fail to access appropriate medical and social services. Inaccurate diagnosis can result in inappropriate treatment, which may be harmful. For example, medications for ADHD may be inappropriate for a person whose conditions stems from prenatal alcohol exposure. APO NT recommends a review of existing screening tests for FASD to inform the development and implementation of a uniform effected diagnostic tool. Data should also be collected uniformly to effectively diagnose and treat individuals who suffer from FASD.

Many Aboriginal women have experienced, or are experiencing, problematic alcohol abuse in their families as children or as adults with their partner's substance use, as well as violence or trauma in the context of family or intimate relationships, poverty and hardships of many kinds. Intergenerational and ongoing trauma is a significant underlying factor that can result in feelings of powerlessness, victimisation or maladaptive coping strategies, including alcohol and substance use to cope with psychological distress.

This illustrates the importance of the social determinants of alcohol abuse in advising strategies aimed at preventing FASD. Some of those preventions could result in much experience to draw on both internationally and locally - you heard from the earlier speakers about the international experience.

In Canada the network action team on FASD prevention articulated the 10 fundamental components to guide prevention of FASD. Policies aimed at preventing FASD should be:

1. Respectful
2. Relational
3. Self-determining and women centred
4. Harm reduction orientated
5. Trauma informed
6. Health promoting
7. Culturally safe
8. Be supportive of mothering
9. Use a disability lens.

APO NT also supports the recommendations on prevention in the Foundation for Alcohol Research and Education, FARE. The Australian FASD Action Plan 2013-16 includes conducting a public education campaign, implementing mandatory health warning labels on alcohol products, providing specialist support services to pregnant women and educating health professionals.

Experience shows the scope of FASD prevention must be broad and not just focused on alcohol. There are many contributing underlying factors and the role of alcohol must be considered in a broader community holistic context. For these reasons, APO NT strongly opposes any approach based on the criminalisation of alcohol use during pregnancy.

There is no evidence to support criminalisation as an effective or appropriate response. On the contrary, the evidence supports therapeutic and parental support approaches.

Best practice recognises the importance of four levels of prevention grounded in the support alcohol policy. These are:

1. Broad awareness building and health promotion efforts
2. Discussion of alcohol use and related risks with all women of child bearing years and their support networks
3. Specialised holistic support for pregnant women with alcohol and other health social problems
4. Postpartum support for new mothers and support for child assessment and development.

Health services have an important role. An effective way to reduce harm from alcohol consumption in pregnancy is through an integrated approach of comprehensive primary healthcare. I note three of AMSANT's member services, Congress, Anyinginyi and Danila Dilba, have provided solutions to this inquiry and I commend these to committee members.

Aboriginal community controlled health services provide a range of clinical and non-clinical services that are relevant to the prevention, early detection and management of children with FASD. These include screening for hazardous drinking and health checks, high-quality antenatal care and universal child surveillance.

APO NT recommends that the Northern Territory government provide additional positions in primary healthcare to provide clinical screening and intervention services, family support workers and increased outreach capacity.

There is a need for a population approach to screening for alcohol-related harm in primary healthcare rather than just focusing on pregnant women, particularly as damage is done before pregnancy is diagnosed. There is evidence of the effectiveness of screening and early intervention in primary healthcare.

Health service staff working with communities with, or at risk of, FASD require training, education and support, including understanding the impact of drinking during pregnancy and a range of other risk factors such as trauma, etcetera on child development, so that appropriate support and intervention can be provided to affected families.

In terms of education awareness APO NT recommends the Northern Territory government provide the necessary funds for education and training for clinical and other health service staff in having empowering conversations with women about alcohol before women are pregnant, when they are pregnant and postpartum. Antenatal and postnatal support: there is an important role for home visiting and peer mentoring programs for women and their partners, and children who are at the highest risk or continue to drink and have other life problems.

The Australian Nurse-Family Partnership program, based on the old model of nurse home visitation and case management of children from vulnerable families, provides structural support for pregnant women until the child is aged two. The program has been operating in the US for over 25 years and has been shown to reduce alcohol and other drugs use in the mother and child, improve outcomes of educational attainment and reduce rates of child neglect and juvenile offending. The Nurse-Family Partnership program has been piloted by selected Aboriginal community-controlled health services and funding to expand the program to additional sites has been provided by the federal government, which we welcome. The program should be funded for all willing Aboriginal community-controlled health services.

Parent and family support: all children with high needs due to factors such physical illness, disability, developmental delay and/or family dysfunction require case management within prior health care. Some Aboriginal community-controlled health services provide case management for children with high needs. However, many are not funded to provide multidisciplinary care of children with high needs. We recommend that all Aboriginal community-controlled health services be funded to provide case management for high risk children.

The Northern Territory government should support the ongoing delivery and expansion of community based programs, ideally through comprehensive primary healthcare services, such as nutritional, violence prevention, housing, alcohol and other drug programs that can be available to families and communities on an ongoing and voluntary basis. When appropriately resourced to deliver such a program, services such as community based health services with which families voluntarily engage can establish trusting relationships and have better and more cost effective client outcomes than services where clients are mandated to attend.

In the early childhood area, the best practice principles emphasise the need for good early childhood services for assessment of developmental difficulties and for appropriate family support and interventions to support healthy development. However there are risks in too narrowly targeting early childhood services to specific conditions. Better outcomes from investment would be achieved by building up services for children with functional deficits, whatever their cause, particularly given the high rate of developmental vulnerability in remote communities. This would require targeted intervention for children at high risk of developmental delay, as well as population based early childhood programs. There is already a developmental screening program, Healthy Under 5 Kids in place, although this needs to be better supported.

An example of an effective early childhood program is the Abecederian program, which is an out-of-home care model which demonstrates an enriched care approach for children with FASD. It has demonstrated long-term sustainable benefits, including education on social outcomes.

Finally, Madam Chair, on the need for a review of health policy in the NT, there is a need to better understand and respond to alcohol issues throughout the community as an effective FASD prevention. This relies on evidence-based policy and evidence-based alcohol prevention/intervention programs. This requires comprehensive measures encompassing supply, demand and harm reduction, including population-based strategies to reduce the risk of harmful use of alcohol.

APO NT has previously outlined what should be included in a comprehensive evidence-based approach to addressing alcohol harm and provided details to the committee in our written submission.

That is it, Madam Chair.

Madam CHAIR: Thank you.

Ms COLLINS: Just as an Aboriginal justice agency NAAJA's submission will focus on the interaction between Aboriginal people with FASD and the justice system. The first thing we really want to highlight is that punitive responses are not the answer. Criminalising alcohol use by pregnant women will deter them from seeking prenatal care, accessing addiction treatment or speaking openly about their substance use with healthcare providers at a fear of losing their child.

The NT also needs to have culturally safe therapeutic programs. One we want to highlight is the Family Partnership Program run by the Central Australian Aboriginal Congress in Alice Springs as an evidence-based home visiting program. It has achieved positive outcomes for Aboriginal women and their families. It provides ongoing education and support to women and their families from pregnancy until the child is two years old.

There is also a very low level of knowledge about FASD in the justice system. This includes lawyers, prosecutors, police, judges, magistrates and Corrections. FASD-affected defendants are more inclined to agree with propositions put to them. They may have poor understanding of the time and sequence, and may have increased difficulty following and being actively involved in court proceedings. FASD needs to be flagged at the earliest possible time. This is crucial. For example, in relation to how police interview a suspect and how lawyers and courts communicate with FASD-affected clients.

In Canada they are looking at a medic-alert type bracelet to be used by FASD-affected young people. This would mean that when police pick up a FASD-affected individual they will immediately be aware of their FASD status and able to consider this in the processes, such as cautioning and interviewing. In the NT we do not have medical professionals based at the magistrates court, as is the case of other jurisdictions. In Victoria they have a mental health court liaison service based at the Victorian Magistrates Court, and has been since 1994. Their role includes identification and assessment of people coming before the court who may suffer from mental illness and making linkages to an appropriate mental health facility in the community or prison system for treatment and support.

Research is needed to gain a clear picture of the number of FASD-affected people in correctional youth justice and child protection systems. In many cases FASD will be a mitigating factor in sentencing, but without diagnosis courts are not taking this into account. On the other hand, without a diagnosis there is a danger some characteristics of a FASD defendant could be wrongly interpreted as an aggravated factor to the offending.

Mandatory sentencing also has a proportionate and harmful effect on offenders with FASD. In the NT courts can avoid imposing a mandatory minimum sentence where exceptional circumstances exist. For example, in the absence of FASD diagnosis, courts do not have a sufficient evidence basis to find exceptional circumstance. Also in the NT many Aboriginal people are placed on orders that set them up to fail. Many face conditions that are unrealistic or excessively rigid. By way of context, 89% of parolees who breached their parole in 2011, resulting in their re-imprisonment, breached conditions of their parole as opposed to reoffending.

A creative innovation in the United States and Canada that seeks to address this issue is for bail conditions or probation orders to be provided to a FASD-affected defendant in picture form rather than written form. It is imperative FASD-affected prisoners, some of whom will not even understand why they are in prison or forgot over time, are properly supported while incarcerated.

In the NT we have the highest proportion of custodial sentences, the lowest proportion of non-custodial sentences and the highest proportion of prisoners serving short sentences. In this context it is crucial alternatives to incarceration be made available, especially for FASD-affected defendants.

Aboriginal legal and medical services in Canada are providing wrap-around services for FASD-affected young people and adults. At the moment NAAJA and Danila Dilba are considering a collaborative project to provide alternative options for clients whose offending is intrusively linked to their drug and alcohol issues. It would place them on a holistic therapeutic treatment plan, including counselling for mental health issues, AOD counselling, support to address social determinants of health, for example linking a person with housing, vocational employment agencies and assisting them to establish positive links with the community such as working with elders.

Magistrate Crawford in the Western Australia Children's Court noted that the Department of Children and Families rarely mentions FASD. She also notes lawyers acting for parents and children cannot rely upon the department to initiate the screening, assessment, diagnosis or planning for dealing with the needs of a FASD-affected child. In NAAJA's experience, this is also not taking place in the Northern Territory child protection system. This affects not just children involved in child protection, but also their parents. Thank you.

Mr WOOD: The issue of criminality cannot - Menzies School of Health informed me the other day, as well as yours - what I have issues with is, I suppose, and I do not know how other people think, but if a mother has been subject to all of the education, advice and given every opportunity to stop drinking alcohol when she is pregnant and has been counselled but she continues to drink, and you know that the evidence is that if she continues to drink the baby will be harmed when it is born or it is being harmed while it is inside the mother, do you think a court or a judge has the right to say that you must stop drinking?

Ms COLLINS: It is a tricky one because at the moment that does not happen. These young people do not have that support. So if that support if provided, if you put all that support in there …

Mr WOOD: I understand that. I am saying you put all that information in. This is a person that is pregnant, you have told her that if she keeps drinking she will harm the child and she continues to drink. Should there be some intervention, even from the court, to say, 'you must stop drinking because the child will be harmed and the evidence shows that will happen'?

Ms COLLINS: If all these systems are in place and those support networks are provided to that young person and they continue drinking, yes. At the end of the day something needs to happen to protect that child, but the first thing that needs to be done is to make sure that those services are available.

Mr WOOD: I am not disagreeing on that. Only if the person did not do what the court asked, what would be the consequences of that?

Ms COLLINS: You have got to look at the safety of the child. That is your priority so you know, at the end of the day, is has got to come down to what is best for that child and if there is a support network to be able to care for that child while that mother does get support or goes to court.

Mr WOOD: I suppose I was looking at the issue of what if the mother has been told that she must not drink by a judge or court and if she does not, how would you stop that mother drinking?

Ms COLLINS: That is a tricky question. It is a case by case basis.

Mr WOOD: It is, but I think it is important because we are saying that there are still a lot of people with foetal alcohol syndrome, and I am very much in favour of intervention before

and intervention afterwards, but what do you do when all of that information is given and the person does not take any notice of it? There are other reasons - they might be alcoholics, but that still does not help the baby, of course.

Mr McCARTHY: Can I just jump in there, Gerry? One thing I picked up from the presentations, which I really liked and they are great recommendations for government, is it not just about the mother, it is about the family package, the community package and the whole of population, which I have written in my notes. From a judicial point of view we should be focusing in on that collective as opposed to isolating the mother.

Mr WOOD: I am focusing on the baby as the other part of this equation which is just as important because we want to the baby to be born without that harm if possible.

Mr McCARTHY: But I think the question also zones in on the mother and what I am picking up in this committee is that is must be a holistic approach.

Madam CHAIR: Can I go back to some questions? When you said, Priscilla, that other states have a medical expert attached to the court who can then assess any person, whatever they are up for and say, 'Yes you cannot plead because you are no good' - did you say that some of the other states have a medical person and we do not, obviously?

Ms COLLINS: We do not. In Victoria they do.

Madam CHAIR: So Victoria has one, okay. Is that sort of like a full-time person who is attached to the courts permanently to assess if people are fit to plead or they have got mitigating circumstances like FASD, they are autistic or something maybe?

Ms COLLINS: Sorry, can I just refer to my Justice Manager?

Madam CHAIR: Just introduce yourself for the records.

Mr SHARP: My name is Jared Sharp, and I am a lawyer at the Northern Australian Aboriginal Justice Agency, my position is the Manager of Law and Justice Projects. In a previous life I worked as a criminal lawyer in Victoria and in that jurisdiction, if you have a client and you suspect that they may have any kind of mental health issue or disability, there is a mental health worker who is a clinician, based at that courthouse right then and there. It is so important for defendants and the justice system that there is an immediate response that while they are there at court you have got that window of opportunity to actually get them assessed. So that mental health worker can then do an assessment and provide a report to

the court about what that initial screening assessment shows. The court can, if it sees fit, order a further, more detailed assessment report.

Madam CHAIR: Most courts have interpreters for people where English is a second language. I was interested when you said a medical type person is attached to courts.

Mr SHARP: Yes, and for our service it is something we frequently see. For example, in the youth justice jurisdiction there is no one to assess any kind of mental health issue then and there at the court at it is desperately needed. So many young people are processed through the courts and it is only in the rare case the mental health issues are picked up and properly dealt with.

Madam CHAIR: There must be a stage in the justice system where a judge says, 'That person has to go away and be assessed because I do not think they are fit to plea'.

Mr SHARP: Fitness is a separate issue as to whether there is – that is a specific scenario where they are not able to say they are guilty or not guilty because of the nature of their mental impairment. However, in most circumstances young people or adults will be able to enter a plea. If they are FASD-affected, there is still a crucial consideration in the sentencing process and how the court should properly balance the competing sentencing factors in their case.

Should they apply a deterrent model against somebody who does not understand the consequences of the criminality of their behaviour, how can they understand – if they are not a vehicle for deterrence then it is pointless the court throwing the book at them and locking them up for a lengthy period.

Mr McCARTHY: I have a good mate best described as a bushman and a battler. His stepson is now 15 and diagnosed with foetal alcohol syndrome because of the in-utero situation, as well as his physical features and so forth. This guy has worked through everything, from the impact of the behaviour of this child on the siblings, the impact of the behaviour on the neighbours, the suspensions and expulsions from school and now he is dealing with the cops who are visiting the house. This has all happened over the last 10 years and he is asking for solutions and help. Your submission is based on this whole approach.

I like the idea about the medical alert bracelets. He is now desperate to get the message to the cops before this kid ends up in the justice system and probably end up in prison. These links in the chain are so real and they need this approach to be coordinated.

Mr PATERSON: To add to that, international evidence demonstrates and confirms these solutions have to be driven by community. The Fitzroy Crossing - how those two strong women dealt with barricades and huge pressure to tackle the alcohol industry and those who did not want certain restrictions implemented in their communities. They stood strong, had the backing of the community, got the majority of the community to agree with some of those strategies, and some of them were probably tough, but the story they told at those summits and the success they have had - we should all be looking at that and trying to replicate it in places where we have those problems.

These initiatives and programs need to be holistic, community driven and empower and enable those community groups to make the appropriate decisions. If any punitive-type measures need to be implemented they will certainly apply them. There are a number of women's councils around the country that are very strong and do not tolerate any sort of behaviour that is not acceptable to community. We have to empower and build that capacity in some of the communities where we have not only alcohol, but other issues as well. It needs to be holistic to be dealt with.

Madam CHAIR: Are there any programs for prisoners who are affected by foetal alcohol syndrome? Do you know if the Corrections system has any programs to help those people in their adjustment when they get out? Clearly there will be people in there who have got foetal alcohol syndrome; there is no doubt about that, men and women. Is there anything that you know - do you know what I am trying to ask? They have got it, they are going to get out; are there management programs to help a prisoner? What family do they have or do they have this condition or disorder - what is going to happen when you go out? I am just thinking there are all sorts of other things when prisoners are in gaol, teaching those skills, reading, writing and research. So I just wonder if there is a need for managing the portion of prisoners who will be released at whatever time, and if it is something we should be looking at.

Mr SHARP: In the prison context we are not aware of any programs that exist. In fact it is even worse in that with the ordinary programs that do exist, for example if you need violent offender counselling in the prison, it will sometimes be the case that if you have a mental health issue you will be excluded from participating in that program because it is seen that they are not able to cater for the needs of those specific offenders in that particular counselling environment. That is our experience, but we may be wrong, there may be other programs that exist.

Mr WOOD: The new prison will have a special section for mental health.

Madam CHAIR: It does have that?

Mr WOOD: The new one, yes.

Madam CHAIR: But whether it has programs to equip people with some knowledge so that they can …

Mr McCARTHY: That is a secure unit and that is to address the issue of a mental health affected person being in a traditional prison. You are right, Jared, and I think that the approach – well, I will not go there.

What the challenge is is the traditional white coat clinician in the programs. If you have a cognitive affected person and a person who has got extreme challenges processing and all those elements that need to be in place to basically comprehend and then assess and process the learning, then it is not going to work and this is where we need the changes. In your submission you have touched on that, in the judicial system and the correctional services system, so this is once again the holistic nature of a government intervention and policy development around that.

Mr HIGGINS: When you were talking before about there being no doctors who can identify these people at the courts, do the lawyers point those out to the magistrates or the judges? That is the first thing, then do the judges and magistrates take that into account when they are doing that? The other thing I picked up was when prisoners are in gaol, and we talk about programs, but they also get to the point when they do not even remember why they are in gaol, which to me indicates that the judges and magistrates have not taken that into account. The third thing I have a bit of worry with, but I think it is a good idea, is the bracelets, but where you draw the line with that. Do you just say this person has got FASD, ADHD and something else, like epilepsy? Where do you draw the line and how do you force them into – is that an optional thing or compulsory?

Mr SHARP: The third one with the medico bracelet – I read about that as a proposal, so to my knowledge it is not actually in place at the moment. It is something that in Canada they are thinking about doing, so I think the issues that you are raising would be things that they will need to think through.

Mr McCARTHY: That would be voluntary I presume, like epilepsy. My son is an epileptic; he wears the bracelet, so it is voluntary.

Mr SHARP: I think it goes to the point that Gerry was making; for that 15-year old boy it is crucial that the different services interacting with him have that information. That brings us to the first point that you were making about lawyers and the way that they are bringing it to the court's attention, and I think where they have that information they absolutely do, but the problem is we are in this information vacuum, not just in the Territory, but all over Australia. We are not getting that diagnostic information, whether you are a lawyer a police officer or a

child protection worker. You do not have access to the crucial information of whether the person you are dealing with is FASD affected. The lawyer might raise it before the court that it is suspected that this person is FASD affected. The court may in particular cases, order reports. In Western Australia they are ordering neuropsychological assessments of defendants to get to the heart of it. I am not aware if that is happening in the Territory and would be surprised if it is. It is only happening in a very small percentage of cases in WA, but that is the way we have to go so the courts have all that information.

The second point you were making about how judges are responding now - as best they can. They are constrained by the *Sentencing Act*. The literature would suggest the sentencing considerations for FASD-affected people need to be different. There should be less of an emphasis on punitive sentencing and deterrent sentencing, and more of an emphasis on community safety and rehabilitation and balancing those two things. When you have mandatory sentencing in place it skews that balance and means courts, unless they find exceptional circumstances, have to apply the mandatory minimum sentence. The big problem with mandatory sentencing at the moment is people are not diagnosed with FASD, they are being dealt with by courts, are not necessarily able to establish exceptional circumstances and are serving revolving door, short, sharp sentences in the prisons.

Mr HIGGINS: There is no mechanism in our legislation - having never been to gaol I do not understand a lot of these things. We have nothing in place if someone is locked up and the lawyer or judge did not pick up they have this condition but Corrections does. What is the step for those people? Do they have to suck it up or can that be the basis for an appeal?

Mr SHARP: Potentially that could be the basis of an appeal. It is obviously case by case. That person would need legal advice as to whether or not the process was fundamentally flawed because FASD had not been picked up earlier. Again, we have the problem in the Territoryof how will Corrections pick up a person is FASD-affected? The prisons, at the moment, would not be aware who is FASD-affected and Corrections would not have the tools at their disposal to diagnose it.

Madam CHAIR: It would be anecdotal, I suspect.

Mr WOOD: What do you do when you have people who might be affected by petrol sniffing? Both alcohol and petrol affect the brain, so are people affected by petrol sniffing picked up when they go through the court system?

Mr SHARP: Yes.

Mr WOOD: Is that easier to do than people with FASD?

Mr SHARP: To my knowledge it is in the sense there are more markers earlier. The person, because of their volatile substance addition, may have already been in an assessment facility, there might be a background to document and the police would probably have flagged it. In the statement of facts that goes to the court it will be pretty clear a person may well have been sniffing petrol. There are flags of that, and then the assessments can be made and the reports ordered and put before the court. The court can then tailor the sentence to meet the needs of that person.

Mr WOOD: Which is what you are trying to suggest for a FASD person?

Mr SHARP: Exactly.

Mr WOOD: It is a little more difficult to do.

Mr SHARP: Absolutely.

Mr McCARTHY: It is like a heroin addict or somebody committing an offence drunk, it all comes out in the process.

Mr PATERSON: Madam Chair, with your permission I call AMSANT's Public Health Medical Advisor, Dr Natasha Pavlin, who might be able to add more from a clinician's perspective.

Madam CHAIR: Can you state your name for the record?

Dr PAVLIN: Natasha Pavlin, Public Health Medical Officer with AMSANT in Darwin. The overlap between the health and legal situation is complex with all the things you are talking about. In AMSANT's submission they are talking about how well placed community health organisations are to know that. It is similar to what you are talking about with families. People do know about harmful behaviours their loved ones and friends and families are engaging in. There are always people who know, and health services that are well-engaged with communities know. I have been involved in situations with child protection because a pregnant woman was known to be doing harmful things. Because her family was involved they were worried about it, they involved child protection and then the health service, the doctor, and the health workers went round the communities trying to find her and engage with her to do harm reduction. That is what you are doing in all these scenarios, when you are looking at it from a health point of view rather than a legal point of view. You cannot wave a magic wand and fix it all, but you can try and limit the damage as best you can. I do

not think – you know when you asked before about people who have the best supports in the world, the best knowledge in the world, everything going for them and still choose to do something that is harmful to the baby inside them? I think they would end up being a relatively small number in that case. There are factors like addiction and things that are difficult to deal with, but with really good knowledge and community awareness and health service capacity, and if it is picked up early that person will – if you acknowledge, 'I cannot stop drinking. I want to use really good contraception. I do not want to cause harm to a baby.'; no one rationally wants that.

Similar to some of the other harm reduction things that are in place like with people who knowingly infect others with HIV, there are programs around Australia to deal with that. There is a very small number of people. It is extremely resource intensive and expensive to deal with those people and we do have programs for that. I do not think it would actually be a lot of people. If you were doing all the other things that we are suggesting that would be good.

Madam CHAIR: They do have it in Canada, but it is voluntary. The wonders of iPads; All I have got here is it is VON Canada and they are basically saying that – which raises another issue - it is about educating your child, educating community, and they say ask a child to wear a medic alert bracelet, so they must have a code. But it raises another question of – I presume all primary schools and probably high schools have a list. Bees Creek has it on the board in the teachers' room – all the children who have got allergies, like nut allergies or whatever and some of them have it around their neck in a card system, but I have never seen FASD listed on the board. It depends on the composition of the school as well as too, but that might be something we can ask education people, because they …

Mr WOOD: As long as the kids do not know, because they could say, 'So your mother drinks.'

Madam CHAIR: Well, it is usually a teacher thing.

Mr WOOD: Yes, I know, but you would want to make sure that the kids were not bullied or teased about it.

Madam CHAIR: Yes, sure.

Mr McCARTHY: That stuff is handled confidentially and it becomes part of the teacher's professional development. If you look at Anyinginyi Congress' public campaign with the puppets, I found that quite confronting, because the puppet actually tells a story: 'I am so and so, why I look like this is because I have got FASD. It meant mum drank, blah, blah, blah.' I

found that very confronting. But going back to the bracelets: it would be a good comment from the justice agencies; the dad I am talking about when the Housing Commission comes around and threatens eviction, he has got to go through the whole story of why he is sorry and why this kid is in trouble. When the police turn up he has got to go through the same story and the neighbours and so forth.

Is there the good old element of discretion? What he is looking for – police can exercise discretion. So if it is a minor offence, such as he interfered with somebody's car down the street, he got in the car and he was playing in the car - that is where I get it. That is the bracelet. That is where the police officer can make that discretionary judgment before it goes down the line, and dad is called and he goes to the police station. That is where I see that medic alert bracelet working.

I think it is a great pragmatic recommendation there.

Mr HIGGINS: I think it would have to be centrally controlled. There are a lot of different things; diabetics can often be diagnosed as being drunk or on drugs and you have got epileptics and all that sort of stuff. Diabetics have a card with a number on it, but police do not have access to the card. I think they have access to the diabetes ones and stuff like that, so you would need – they have a registration number on them as well –some sort of central register. We could introduce an NT card, a bit like the Australia Card or something, I suppose.

Madam CHAIR: That is something the committee could look at.

Mr McCARTHY: That is another committee.

Mr WOOD: Are you making that recommendation?

Mr HIGGINS: I was not being serious about that.

Madam CHAIR: Any other questions of the members? If not, thank you very much for coming. Thank you for your extra advice and help. As normal, you will get a copy of the *Hansard* so you can go through it and make sure it is all correct for what you want and, yes, by all means put in your submissions whenever you are ready. We are not hard and fast on timelines with that.

Mr PATERSON: Thank you, Madam Chair, members.

Madam CHAIR: Thank you very much.

The committee suspended.

Madam CHAIR: Hello Vicki, this is Kezia Purick the Chairperson of the committee, good morning. Here at the committee in Darwin, we have Gerry Wood, who is the member for Nelson, Gerry McCarthy, member for Barkly, Nicole Manison, member for Wanguri, Russell Keith is the Secretary of the committee and Gary Higgins is the member for Daly. On behalf of the committee welcome and thank you for agreeing to give evidence and to answer questions of any of the committee members.

This is a formal proceeding of the committee and protection of parliamentary privilege, with the obligation not to mislead the committee, applies. This is a public hearing and is being webcast through the Assembly's website. A transcript will be made for use by the committee and may be put on the committee's website. If you would like to speak about something that you do not want made public we can go into a closed session and take evidence.

Ms RUSSELL: I would not imagine so, but thank you for the option.

Madam CHAIR: Can you, for our record, state your name and your full title and organisation, please Vicki.

Ms RUSSELL: Absolutely. My name is Vicki Russell and I am CEO with National Organisation for Foetal Alcohol Spectrum Disorder in Australia (NOFASD).

Madam CHAIR: Thank you. Have you got an opening statement or some preliminary words that you wanted to say?

Ms RUSSELL: Just perhaps to update committee members on the work of NOFASD Australia might be worthwhile. We are a non-government organisation funded from funding out of the Department of Health, federal funding that is. We are the peak body, or the peak

non-government body representing the interests of individuals and families living with foetal alcohol spectrum disorder.

We have a range of activities across the prevention spectrum from raising public awareness, education and training and most importantly supporting, often parents, who contact us either via our comprehensive website or a 1300 number. We provide support nationally.

I am based in Tasmania, so our work role involves quite a lot of travel interstate and fundamentally we more often require a community development model to engage a community so that if I travel to the Northern Territory to do training I try to do quite a number of workshops across days and try, in lots of ways, to engage the community to pick up and action FASD wherever they are and whatever capacity or role they have. One of the things we are currently working on in the Northern Territory is setting up a face-to-face support meeting for parents and carers of children who are living with this condition, which is something we became aware of over time. There is huge gap in having that opportunity to speak to one another about different strategies in the care of children.

Madam CHAIR: Vicki, who do you work with in the Territory? Are there any particular groups? Is it the Department of Health?

Ms RUSSELL: No, the Foster Care Association generally. That is where our inroad has been, but that being said, that has connected us to other groups of people including service providers and Aboriginal communities. Generally speaking, when I have worked in the Northern Territory there has been a very broad mix of people in the audience.

Madam CHAIR: Okay.

Ms RUSSELL: It may well be a psychologist, childcare workers, alcohol and drug service workers, youth workers etcetera combined with interested parents and carers.

Ms MANISON: Vicki, given you are a national organisation, how do rates of FASD in the Territory compared to other jurisdictions?

Ms RUSSELL: That is the million dollar question. We do not really know. I am guessing when we talk about prevalence rates and look at discrete communities, currently, where we have some evidence of prevalence, it is an interesting scenario. I often think about the prevalence in the general community.

As one of my colleagues in the United States said, when we are looking at prevalence we are often accessing easy to access mums and children. They are children who are already, for want of a better word, perhaps under greater scrutiny. We do not really know, and I am very cautious about prevalence rates because until we know - until we have really good diagnostic and support services, I am not sure predicting prevalence in any community in Australia is something we ought to be doing. Even as we gather data from individual or select communities across Australia I do not know that we can easily translate that into other community settings.

All I can report on is the number of calls I receive from parents and carers in the Northern Territory is that their concerns are great and the services are not there for the families. They are often struggling by themselves and continually have to engage with service providers and tell their story over and over. I could go back through my data and tell you over a year how many carers I have contact with, but they are incredibly isolated.

I sent in my submission last week and we hear all the time rates of one in 100 live births may be affected by FASD. Recent prevalence studies in middle-America have said 3% to 5%, but we know not all children exposed to alcohol in-utero are affected. The vulnerability of the foetus to alcohol may be due to a whole range of things. What we do know, as I wrote about in my submission, is that there is lots of corroborative type evidence that tells us about patterns of drinking by girls and women, that pregnancies are unplanned and that very often in January I get a lot of calls from women across Australia who are so distraught because they have had their pregnancy confirmed, and they realise that they have been drinking since Christmas Eve, even though they have planned the pregnancy. These are articulate working employed women, well educated women.

I know that I am all over the show when you hear about prevalence, but I think it is such a complex issue that we basically need the research.

Ms MANISON: Just sticking to that theme then I suppose, looking at your submission and how you start speaking – you have written about diagnostic teams, and clearly, being able to diagnose it is going to give us a much better understanding of prevalence. How do you think we are going in the Territory when you look at how we go about diagnosing whether a child has FASD compared to other jurisdictions and what do you think needs to be done?

Ms RUSSELL: I would say not terrific, but probably not any better or worse than anywhere else in Australia. The thing that I would encourage the community to think about is that interdisciplinary teams do not mean the creation of something new. Those people are already working in the community, the people that would participate on that team – OTs, speech and language therapy, neuro psychs – they are people that are already employed. What the interdisciplinary team really is about is how to pull that information together to do

the best assessment for a child, adolescent or adult and to plan for what their needs are in the future.

It is probably an easier path than we might imagine. I know from conversations, for example with paediatricians in the Northern Territory that I have connected up with people like Professor Elliott and Doug Shelton on the Gold Coast, that they are eager enough to learn or get knowledge about the diagnostic process but they need the resources to get started. To me one of the main things that NOFASD Australia wants to do is get a coordinator in the Northern Territory to pull that together. It is not just the matter of the diagnosis, the diagnosis tells you what it is but it does not tell you what to do. The carers, the people who are going be caring for these individuals, often 24/7 for the rest of their life, need some help in the diagnostic process.

Madam CHAIR: Vicki, it is Kezia here, I worked in and around the mining industry for 16 years and they did a lot of research into trying to improve safety for obvious reasons. I recall one piece of work that was done up here with a particularly large company where generally in Australia we are a nation of risk takers. Do you think that a lot of women – it does not matter what background or what race –generally have that attitude, as we do across the board with a lot of things, that 'it will not happen to me'?

Ms RUSSELL: Absolutely. Professor Steve Allsop reminded me of the old well known philosophical term called othering, where everybody else has got a problem but me. It translates across a whole lot of different health and safety issues like drink driving or not wearing seatbelts. There is this thing of, 'Oh, well, my mother drank when she was pregnant with me and there is nothing wrong with me, or my friend drank and there is nothing wrong with her child'. So that calls for consideration of the spectrum of harms of foetal alcohol disorder, because we are so fixated on the face and the biomarkers, the physical indicators of foetal alcohol exposure, that we have not yet alerted the public to the more subtle forms that this condition can take, whether that is a learning disability or a behavioural problem. If you look at the statistics we are now seeing in this country about the numbers of children who need access to special education, for example. This population group we are talking about: is it inclusive to those other groups? That is a question I often think about. Where are these children?

Professor Sterling Clarren in Canada talks about the fact they have – off the top of my head - 27 diagnostics teams across Canada with estimates of thousands of affected children, but they have only seen hundreds for diagnosis. He asks where these children are. We think they probably are in those other population groups of children with disabilities, but we have not identified them or they have been misdiagnosed.

To go back to your question, yes we are a population that take risks, but we do not have all of the information. As you would be aware, information does not change behaviour and

attitude. We have a social and cultural problem much bigger than FASD called alcohol. I worry for these children because they are - many of them, particularly the children of high risk level drinkers - not only exposed to alcohol in the pre-birth period but are born into environments where they are further exposed.

If you really want to do something about prevention, we have to look at this issue as what are the harms of alcohol. That harm impacts across the life span and you would be aware, for example, of your population of Aboriginal men in prison. What do we know about them? What do we know about their literacy and numeracy capacities and their level of schooling, if they had access to education?

I worked in a youth detention centre for three-and-a-half years and can tell you the school leaving age and level of learning disabilities amongst that group is so high. Whether it is foetal alcohol exposure I do not know, I think some of it is post-birth trauma, but how we find these people is a huge question.

Mr WOOD: Vicki, it is Gerry Wood here. Talking about alcohol, one of your recommendations was that prevention of FASD must begin in early childhood as one of the times in life when alcohol should not be consumed; that is, do not consume alcohol while the brain is developing less than 25 years, when planning a pregnancy, during pregnancy, or while breast feeding or taking prescribed medications.

A lot of young people go binge drinking; it is one of the issues we have. Is it realistic to try to get governments to increase the drinking age? The debate has been around. At the moment you can drink once you are 18. In America I think you have to be 21. Do you see any possibility in that area if we look at the number of people ending up in our prisons because of FASD?

Ms RUSSELL: Yes, what I have read is there are strong indicators that if you increase the drinking age the uptake of alcohol is older in years - that follows some sort of parallel.

Mr WOOD: When you say older, what do you mean?

Ms RUSSELL: If the drinking age is 18 and their uptake age for alcohol is 14, if you move that to 21 you see a correlation with the uptake of alcohol perhaps not being until 16. If we can get two years where their brains are not exposed to alcohol, there has to be some positive benefits from that.

Mr WOOD: Have you had any feedback - I have heard this around before, but has the labelling of alcoholic beverages with warning signs gone any further or is it really effective?

Ms RUSSELL: I guess this is probably more of a personal comment than an organisational one: I fundamentally believe that we have got a right to know what is in any consumable and if it poses any risk. We have no qualms in labelling other food or removing it from the shelf in the shop or the bottle shop if it is toxic. With this one we are so hesitant, so it is that bigger question again about the social acceptability of alcohol. I was talking about othering; this liquid in a bottle is used by so many people so how could it be dangerous? Yet we know the effects from experience, from our own personal experience, of what alcohol does to the brain and yet the industry is so hesitant in accepting if that is the effect it has on an adult brain, what is the effect on the vulnerability of a foetus?

To me there is a definitive answer that as a product that is consumable, consumers have a right to know what is in that consumable product and that includes any risks.

Mr WOOD: We put warnings that there might be nuts in this particular product.

Ms RUSSELL: Yes, we are totally into that. It is like the pregnant woman who stops eating camembert cheese or shellfish because she knows there is a bacteria prevalent in those foodstuffs which could harm her foetus, harm the pregnancy, so she stops eating camembert cheese, shellfish and goodness knows what, but keeps drinking a chardonnay on a Friday night. I ask you, where is the rationale in that?

Mr WOOD: Good point.

Ms RUSSELL: To go back to your question before about point three, I think one of the disservices that perhaps we have done to young people is harm minimisation, because that takes the position that says that young people are going to drink, so let us teach them how to drink safely. What point three is saying is that as adults we have to step up and say very clearly there are times in life when you should not use alcohol and to me they are very clear. I think young people need guidance from us in words, in our actions and the way we role model drinking. I would be looking at campaigns that encouraged family celebrations that were alcohol free. This is not every time; I am not a wowser, I enjoy a drink. I have no problem with that, but I think in my own life experience that my grandchildren are present at an ordinary family occasion and there is wine on the table at most of the events that I attend. I do not know how it is for committee members, but it is so obvious and I do wonder at what subtle messages we are giving little children.

Mr McCARTHY: Vicki, Gerry McCarthy here. NOFASD as an organisation commenced in 1998 and you mention federal funding. What was happening in 1998 to create this?

Ms RUSSELL: For about 14 years, NOFASADE, as it was known then, functioned as a voluntary organisation so that all the work that was being done in supporting individuals and families was done without funding. About three years ago we lobbied heavily in Canberra and we got two rounds of interim funding which covered us for about seven months, and then we successfully applied for three-year funding, which for the first time enabled the employment of two full-time workers. That is all we have nationally; there is myself as CEO educator and trainer and we have just recently appointed a national educator to pick up some of that work, because this organisation is moving much more into a coordination role. For example, one of the things that I have set up this year is a FASD consortium of interested persons from around Australia. There are ten of us that meet by teleconference each month just to share information about what is happening

in states and territories. I have been in contact with two people in the Northern Territory who have been employed in Education as FASD coordinators, which is a fantastic outcome and, hopefully, they will join that consortium as well.

Mr McCARTHY: Vicki, we heard from a health professional earlier that there has been a definite shift in focus and resources by governments into early childhood growth and development. Can you see that? Is your advocacy organisation being supported better or do you see a good future in this field?

Ms RUSSELL: Who knows? I know for 14 years after NOFASD was established, we are still battling for the same things. The notes I wrote on the front of my copy of this submission say there are always consequences to any policy actions that are taken for individuals and families and we are still arguing for appropriate support services for our target group. Fourteen years later that has not changed. Despite every dollar that has been put into FASD by the federal government, most of it is research and that has its place, but we need to see something actioned on the ground. That is why I come back to my earlier point that NOFASD Australia needs a coordinator in the Northern Territory so that person can be responsible for education and training, support of families, advocacy in schools, connecting services, ensuring there is follow up, ensuring we are planning for five years down the track because children with FASD have, as I am sure you have heard, problems with memory and impaired functioning in day to day life, etcetera.

My background is in trauma counselling. I am horrified at the current state of play in Australia around child protection services, where children are used as a bartering chip in an adversarial process where they are returned to families who cannot care for them. It is not that they will not, not that they do not love their children, but if they are FASD-affected themselves they simply cannot care safely for their children. So many issues arise out of

foetal alcohol exposure, as I hope you are starting to glean from the submissions that you have been receiving.

I think the research is fine and the federal government - it is safe for them to go with research because they do not upset the alcohol industry. They are in a double bind there collecting revenue and whatnot through taxation on alcohol products, and you have the service industry associated with alcohol, tourism and it goes on and on. I totally understand the government's position in the middle of this, but if research is not applied in some way back in the community then what is the point of it.

We know this product is toxic. There is so much evidence out there. We are in the 40th year since FAS was formally identified at the University of Washington in 1973. Here we are, 40 years later, and we are still arguing over the minimal dose to cause harm during pregnancy. We are going around in circles and the plea is out there. It is really strong from families. They are exhausted. They are dealing with quite violent behaviour as these children age. I was talking only last week to a parent carer from Alice Springs who is a single parent. She has a 14-year old boy who is exceptionally violent. She is frightened of him. She does not know what to do. She does not know whether to return him to the department or look for an alternative placement for him, but she has had him since he was seven months old ....

Madam CHAIR: Vicki …

Ms RUSSELL: … and the school enrols him in five tutoring programs because they believe that it is a parenting issue. This boy has got full-blown FASD. So the federal government is playing it safely and trying to satisfy both sides of this conundrum, if you like.

Madam CHAIR: Vicki we might have to leave it there because we are about ten minutes over, and I have just asked the committee if they have got any more questions at this point in time and they have not. If we needed to come back to you would you be available?

Ms RUSSELL: Yes, I am on annual leave.

Madam CHAIR: I do not mean tomorrow I mean we have got about …

Ms RUSSELL: Until 9 June. So if you got Lauren – is it Lauren or Laura?

Madam CHAIR: No, no you are correct.

Ms RUSSELL: If she sends me an email I will make myself available, for sure.

Madam CHAIR: Vicki, we will send you a copy of the *Hansard* so you can just go through it to make sure it is all correct before we put it up publicly, and then if we need to we will come back to you and contact you via email, but thank you very much for talking with us today.

Ms RUSSELL: No problem. Thank you very much for listening.

Madam CHAIR: That was very good. Thank you Vicki, bye bye.

Ms RUSSELL: Bye, bye.

The committee suspended.

Madam CHAIR: Good morning.

Dr BREEN: Good morning, Doctor Breen here.

Madam CHAIR: Good morning Doctor Courtney Breen, this is Kezia Purick the Chair of the committee here in Darwin. Can you hear very well?

Dr BREEN: You are a bit faint, but yes I can hear okay.

Madam CHAIR: Okay, we had better talk up. There is Gerry Wood the member for Nelson, Gerry McCarthy is the member for Barkly, Nicole Manison is the member for Wanguri and there is myself, Russell Keith, who is the committee secretary and Gary Higgins, the member for Daly.

Dr BREEN: Hello.

Madam CHAIR: Courtney, we just need to ring Professor Burns as well to get her on the line.

Dr BREEN: Great.

Professor BURNS: Hello, Lucy Burns.

Madam CHAIR: Professor Burns, it is Kezia Purick here from the committee in Darwin.

Professor BURNS: Hello.

Madam CHAIR: Can you hear me okay?

Professor BURNS: I can hear you fine.

Madam CHAIR: Oh good. We have Courtney Breen on the line as well.

First of all, thank you for appearing before the committee. I appreciate you taking the time out. It is a formal proceeding of the committee and the protection of the parliamentary privilege applies and also not to mislead the committee. It is a public hearing. It is being broadcast on the Assembly's website and the transcript may be used by the committee to put on the committee's website. If there is any time that you feel that you want to have something not made public we can go into a closed session and take it in private. Just for the record, so that it is picked up by *Hansard*, could you state your name and the organisation, please?

Professor BURNS: It is Lucinda Burns from the National Drug and Alcohol Research Centre.

Dr BREEN: Courtney Breen from the National Drug and Alcohol Research Centre.

Madam CHAIR: Thank you very much. Do either of you want to make an opening statement to give us some preliminary information?

Professor Burns: I would like to make a statement, please. Foetal alcohol spectrum is most common in women who are dependent on alcohol. To prevent Foetal Alcohol Spectrum Disorder, it is imperative that effective education and treatment is given to women who are alcohol dependent, both prior to conception and during pregnancy. A common indicator, or the most common indicator of the presence of a foetus exposed to alcohol is the presence of a prior child to that mother who already has Foetal Alcohol Spectrum Disorder.

Campaigns should be developed to identify screen and treat at risk women and babies. There are pharmacotherapies available, and programs include things such as detoxification, adequate nutrition and support. Therefore procedures must be put in place for women who are drinking heavily, pregnant or not, in order to provide a backup to any screening that finds positive traits in these women.

Thank you.

Madam CHAIR: Questions?

Mr WOOD: Just a question to either of you. What policy reforms are most likely to contribute to a reduction in alcohol related harm in Australia, even from a broad prospective?

Dr BREEN: Population wise, looking at the price and availability of alcohol are probably big things to reduce harm at the population levels. It is known that there are more harms in areas where there is greater availability of alcohol and also price is something to look at if you are wanting to look at reducing harms.

Mr WOOD: Do you report back to the Commonwealth government with those sorts of recommendations and if so, is it a case that those recommendations do not get very far?

Dr BREEN: Different projects have looked at that and recommendations have been to look at availability. I cannot really comment with regards to how far they go within government.

Mr WOOD: Right. I was just wondering whether your national drug and alcohol research centre is funded by Commonwealth?

Dr BREEN: Yes, part funded and then grant funded as well.

Mr WOOD: I suppose I was just wondering if it is something that our committee can look at. If you are looking at FASD and you are saying that alcohol contributes to FASD and you are recommending certain policies that might help at least reduce the possibility of alcohol related harm, perhaps you are not being listened to; or are there other forces that may not agree with that, like the alcohol industry?

Professor BURNS: That is always in the background and then we work within that background as well. The work that we have been doing here in particular has focused on the identification of women and promoting services for women who are alcohol dependent and pregnant and alcohol dependent. That is the pointy end and that is where most of the disability in this group lies. It is not equally spread across the population. There has been within the media and I think within a lot of the research community, promotion of a population level approach, targeting all women, but that is not where the disability lies. The difficulty lies with women who are alcohol-dependent and usually have at least one other child with foetal alcohol spectrum disorder. So if it was serious, if this was to really look at how to reduce those problems, it would be to provide a new model of service that would ensure those women were treated, hopefully prior to having a baby, because you could in fact prevent that problem occurring at all.

Mr McCARTHY: Gerry McCarthy here. First of all, congratulations on the New South Wales State of Origin win last night.

Mr WOOD: That will be deleted from *Hansard*.

Mr McCARTHY: And associated with that it is just rather disappointing that they are running around with a massive alcohol advertisement on their jumper. That might be interesting research. In terms of your research, proportionately, how much is going into FASD?

Professor BURNS: I am sorry, can you repeat that?

Mr McCARTHY: In terms of your research nationally on drugs and alcohol, what proportion is focused on FASD or associated early childhood growth and development issues?

Professor BURNS: We have a program of work here that has myself, Courtney and some other people working on it, and I would say that it would take all of Courtney's work, 30% of my time and then, of course, that is just at this particular centre. There are other interventions, the Telethon Institute, the paediatrics surveillance unit and others that may have even more time dedicated to them. I would say that the interest in this has really grown

and the research has grown also over the past, perhaps five years, so there is much more attention now.

Mr McCARTHY: That confirms other evidence that has been submitted to the committee. So are you seeing that translated into more resources?

Professor BURNS: As Courtney mentioned we do have a project running here which is working on the area that we are going ahead with. There was a call by the NHMRC for FASD-related research but that seemed to have a very strong, and rightfully so, a very strong Indigenous angle. So while there has been an injection of funds, I would think there would need to be increased funding if you are really going to look at appropriately treating not just the child, which the focus has been on, but the mother, where there has been a very significant lack of understanding, even of the nature of addiction, and that it is a chronic relapsing disorder. The 'Just say no' campaigns simply do not work.

Mr McCARTHY: Thank you for that, and in terms of what the committee is hearing, that is a whole-of-community approach. Is your research focusing on any specific Indigenous communities, such as communities in north west New South Wales?

Professor BURNS: No. I mean it is not. Work that has been done by Mrs Elliot and people in Queensland has really looked at the Indigenous aspect there, but even within that I think there needs to be – it is fantastic work diagnosing children, but we really need to get behind why women are drinking that particular way and I think that is an area that has further need.

Dr BREEN: I would just like to add, as Lucy mentioned, women that have already had one child with FASD are more likely to have an additional child. So as Lucy said, treating the women, but also looking at promoting contraception and interventions that include contraception is probably another area to look at.

Mr McCARTHY: Yes, and from a national perspective and monitoring the media there seems to be very much a political interest in alcohol harm and harm minimisation in relation to the nightclub precincts and one punch legislation. Politically are you hearing from the politicians around FASD, and the need to develop new policy in that area?

Professor BURNS: I think that, unfortunately, the media portrayal of the mothers is of impulsive, self-indulgent women who should be vilified, where in fact that is where it comes back to the complete lack of understanding of the nature of alcohol addiction. Unfortunately, the media does not often take a very sympathetic approach to these women, and I have not seen much sympathy really. At the federal government level there has certainly been recent

recognition that this is a significant problem, and resources made available to manage it. At a community level, the campaign should also look at educating people; it is not always a matter of, 'I will stop drinking now'.

Ms MANISON: We have heard a range of different views this morning. It has probably been the first time we have really engaged on the issue of dealing with chronic alcoholism of mothers and making it a priority to treat them when it is identified as a risk in going forward with further pregnancies and whatnot. From your perspective, do you see focusing on general awareness campaigns around FASD, looking at prevention and early diagnostic detection or treatment of really high risk mothers and families as the greater priority? Where do you think resources need to be honed in and focused on by the policy makers and the people with the funding to do it?

Professor BURNS: I would say on the high risk women. I think it is a very easy solution to run a campaign that simply says, at the population level, we can give out a few pamphlets and run a nice campaign. It is a harder ask and journey to identify and treat these women within the context there may be dire circumstances around their drinking. I think we have to make a stab at it; we cannot just ignore it because it goes in the 'too hard' basket. What about you, Courtney?

Dr BREEN: The greatest burden is among those women that are high risk. They are the ones most likely to have a child affected by FASD. The population messages of just saying no or stopping drinking during pregnancy will not work for them. They need to be supported and the issues associated with the alcohol dependence, mental health issues and domestic violence need to be addressed.

It is harder to do, but that is where the greatest burden is.

Ms MANISON: In regard to healthcare professionals working with FAS and FASD, from your perspective where do you see key skill gaps at a national level at the moment?

Dr BREEN: The identification of women drinking in pregnancy - primary healthcare professionals need to have the skills to ask and we are currently working on a project to address that. Any health professional that comes into contact with pregnant women should have awareness of the effects of alcohol during pregnancy, be aware of the stigma associated with it and be trained how to appropriately ask and address alcohol use during pregnancy.

Professor BURNS: Also, because foetal alcohol spectrum disorder or foetal alcohol syndrome has generally been the remit of paediatricians and very child focused, and that has

not really - I think because of that, despite being highly trained and educated people, maternal addiction is lacking in their skill base, the nature of maternal addiction and treatment or even liaising with drug and alcohol experts, so that the mother can be cared for as well. I think often we focus on the child, and rightfully so, as the child is the one with the ongoing lifelong disability, but ignoring the mother just does not prevent anything. It just increases the likelihood that the second child or subsequent children will have foetal alcohol as well.

Ms MANISON: Have you had a chance to drill down specifically to the Northern Territory in your research, to have a look at whether FASD is more prevalent here than other jurisdictions?

Professor BURNS: No, we just really got – no, Carol Bowers' work, I think, is probably the most relevant there, but we have not done any measure of that.

Madam CHAIR: Thank you. No more questions?

Thank you, Dr Breen and Professor Burns. The committee does not have any more questions. We will send you both a copy of the *Hansard* in draft form for you to provide any amendments, and if we needed to come back to you at any stage would you be available?

Dr BREEN: Yes.

Professor BURNS: Yes.

The committee suspended.

Madam CHAIR: Good afternoon, on behalf of the committee I welcome you to this public hearing into action to prevent Foetal Alcohol Spectrum Disorder, and thank you for coming and taking the time to talk with us today, and perhaps answering some questions some of the committee members may have.

This is a formal proceeding of the committee and the protection of parliamentary privilege applies. It is a public hearing and it is being webcast through the Assembly's website. A transcript will be made for use of the committee and may be put on the committee's website.

If at any time during the hearing you feel that something should not be made public, we can go into a closed session and take evidence in private. For the record, could you state your name and capacity in which you are appearing today, please?

Mr THORN: Mr Michael Thorn, Chief Executive Officer of the Foundation for Alcohol Research and Education, and I am accompanied by my colleague, Ms Sarah Ward, who is a senior policy officer for the foundation. We are here as one of the organisations that has made a submission to the committee of inquiry.

Madam CHAIR: Thank you. We have Gerry Wood, member for Nelson, Gerry McCarthy, member for Barkly, Nicole Manison, member for Wanguri, myself, Kezia Purick as Chair, Russell Keith is the committee secretary and Gary Higgins is the member for Daly. Would you like to make some opening remarks or comments before we get started?

Mr THORN: I am happy to make an opening statement. Thank you and we welcome the opportunity to present both formal submissions and verbal submissions today and to take questions from the committee. We welcome that because not enough is being done to prevent an entirely preventable harm.

Regrettably, the dimensions and the complexity of the prevention challenge appears to have paralysed the system's ability to respond. We need to take a deep breath and get on with implementing a plan. We can no longer feel daunted by the tasks ahead. The challenge in terms of preventing Foetal Alcohol Spectrum Disorders is a classic 'how do you eat an elephant' challenge. The answer, of course, is one mouthful at a time.

FASD is referred to as the invisible disability. This is because the signs of FASD are often not visible and its impact is largely hidden from the community. Prevalence estimates for FASD place it at approximately 3000 births per year across Australia. However, this is only an estimate because we do not diagnose FASD; we do not record cases and do not even routinely ask women about their alcohol consumption during pregnancy.

In the Northern Territory we suspect the prevalence is much higher. Why? Because women in the Northern Territory consume alcohol at riskier levels than in the rest of Australia. Women aged 14 and over in the NT have the highest levels of risky alcohol consumption in Australia. Almost half consume at least five standard drinks on a single occasion, placing them at risk of short-term injuries and illness.

It is time for governments to take practical actions to address Foetal Alcohol Spectrum Disorders. We can no longer ignore the many gaps in prevention, diagnosis and management. Australia has no comprehensive prevention plans. We do not routinely ask women who are pregnant about their alcohol consumption; we do not even have a national diagnostic tool for FASD and we do not recognise the condition as a disability.

All of these factors contribute to FASD continuing to be the invisible disability. In our view, the role for the NT government is clear. As a primary provider in health, education and the criminal justice system, the government can make a significant impact on the prevention of FASD and make a significant difference to the lives of people with FASD and their families.

The NT government can undertake prevention campaigns; provide support to health professionals to encourage routine discussion of alcohol during pregnancy with women; test the FASD diagnostic instrument that was commissioned by the Commonwealth government more than two years ago; establish a diagnostic clinic and mobile diagnostic teams; establish a model of care to provide clear pathways for people with FASD; and they can also ensure that the education and criminal justice systems are adequately equipped to support people with FASD. It is important that the strategies adopted are evidence-based.

The government recently indicated that it was exploring the antenatal rights of the unborn child, including options such as prosecute or alternatively restrain women who are drinking through pregnancy from engaging in conduct which harms their unborn child.

Madam CHAIR: Mr Thorn, just to interrupt, was that the Commonwealth government that was looking at that?

Mr THORN: That is as I understand in the …

Madam CHAIR: In the House of Representatives report?

Mr WOOD: No, ours.

Madam CHAIR: Sorry, my apologies.

Mr THORN: This is not a policy response that we would support. It does nothing but stigmatise women and prevent them from seeking the services they require and flies in the face of all the available evidence of what works and what does not. It is also counter to

World Health Organisation guidelines for the identification and management of substance use and substance use disorder in pregnancy, which states that prevention and treatment interventions should be provided to pregnant and breastfeeding women in a way that will prevent stigmatisation, discrimination and marginalisation and promote family, community and social support, as well as social inclusion, by fostering strong links with available childcare, employment, education, housing and other services.

Most importantly, it will be vital that the Northern Territory government acts on the recommendations of this committee. There has been much talk at Commonwealth, state and territory government level but too little action. In August 2013, the former Australian government released their $20m Action Plan for FASD. The plan arose from a national inquiry into FASD. The plan has not been implemented and its status remains unclear. Despite all the talk nothing has happened on the ground. Nothing has changed for people affected by FASD, their parents and carers. Nothing has changed for generations of people who bear the consequences, the grief and the displacement.

I sincerely hope that this committee makes strong recommendations that government and the people of the Northern Territory cannot ignore. Remember, nearly 50% of women are consuming alcohol at the time of conception and nearly 20% continue to drink after pregnancy has been confirmed. This is the dimension of the challenge that we all face.

Thank you for allowing me to make those few introductory remarks.

Madam CHAIR: Questions? Gerry Wood first.

Mr WOOD: Good afternoon. My question might relate to some of the information we have had previously, in that there has been some discussion about more research and more research, but also others are saying that it is time that we acted rather than worried about more research. We know, basically, that a child will be affected by alcohol. Do you think that there is not enough happening or are you saying, basically, the government is a bit loathed to act when you mentioned that the Australia Foetal Alcohol Spectrum Disorder Action Plan has not been put into action yet?

Mr THORN: I think I empathise entirely with the sentiment of your remarks. From our perspective it is time for action. I think we know what to do. We just need to get on and do it and the longer we leave the problem the more harm that is created, and these are impairments and disabilities that are entirely preventable.

It seems to me that there is sort of a – people were overwhelmed in the face of what is a highly complex problem. It seemed to me that people do not seem to know where to begin.

In my view what we should be doing, if nothing else, is at least trying to get the message out and doing things that will actually prevent this. There are many other things that need to be done, including diagnosing people who have FASD and that is not going to happen overnight. We have a model diagnostic instrument. It needs to be field tested. We have been advocating for this to be undertaken now for nearly 18 months and nothing has happened. Funding has been offered and then it does not get implemented and I have to say we have been very disappointed at the Commonwealth level that that has not been acted on.

With the people who clearly have been affected there have been discussions about how they can access disability services. There has been a need to recognise these people in our education and criminal justice systems, and yet too little work has really been done to address that.

From our perspective what we are seeing is a system that seems to have been paralysed by the scale of the problem and an inability to break the problem down and staff to deal with aspects of the solution.

Mr WOOD: Do you think that perhaps we have made it complex for something that is fairly straightforward? From all the people I have heard we know that if you are pregnant and you drink alcohol there is a pretty good chance someone will have FASD. Is that not really getting to the guts of the matter and that is where we need to start, from that end? I am not saying we should not do other things as well. Should that program be national with some specific areas, like whether it is targeted at Aboriginal people, immigrants or people of non-English speaking background, but should it be really a national program rather than being pushed by different states?

Mr THORN: Absolutely, it has to be a national program and I agree with the implication in your question that that is where we should begin. We should be beginning with a prevention message. We do not know precisely how much alcohol causes these harms. We know that it does and that clinical trials on animals show that that is the case. We also know that the effect can be very idiosyncratic, that some people do not experience any problems and others do. Which is why the NHMRC advice, of course, is it is safest not to drink during pregnancy.

I think if nothing else there is a need for a national program that targets that objective and that is to reduce the number of women who are pregnant or thinking of becoming pregnant from consuming alcohol during that pregnancy.

Mr McCARTHY: Gerry McCarthy here, I am interested in the diagnostic instrument. Can you talk a bit about that please?

Ms WARD: In about 2011, the FASD collaboration, which is a range of researchers from across Australia, came together. They were funded by the Commonwealth Department of Health to develop an Australian diagnostic model. They undertook quite a lengthy process to do that and have submitted that model to the Department of Health and as Michael mentioned that model has not yet been released. There are two components to it being released, one is that the researchers want to field test the model to make sure that the diagnostic tool is appropriate and does effectively diagnose people when it is implemented. The second is that there is training that goes along with that diagnostic tool, so that when it is released to health professionals it is not just released as a diagnostic tool of, 'Here you are, go away and do it'; they need training and support to then be able to undertake the diagnosis. For many health professionals it will be a new diagnosis or a new diagnostic tool that they are working with.

The diagnostic tool itself – there are four international diagnostic tools that currently exist. One is a Canadian one and one is a Washington one, and this Australian tool really looked at all of those four models and developed them together into one model, rather than having different people using different models. It was the whole aim that we had a standardised tool across Australia.

Mr McCARTHY: Thank you, are there any Australian jurisdictions looking at this or interested, are they making contact?

Ms WARD: I think there are many Australian jurisdictions that are interested but because the Commonwealth government are the people that commission the work and they are the people that hold the work it has not got any further than that. I know the Western Australian government has a Model of Care for FASD and they are very interested in the diagnostic tool. Diagnosis is going on in Australia at the moment in a limited fashion and people who are diagnosing people with FASD are using a combination of the international tools that exist. So if we were able to implement the Australian diagnostic tool we would have national consistency. One of the things that we are recommending is a jurisdiction field test the diagnostic tool, and doing that work on behalf of the Commonwealth so that it can get out there and be used.

Mr McCARTHY: Yes, that is good to hear because I think the Northern Territory could be a very good example. So a recommendation from this committee, for instance, could be that there is a tool and that a partnership with the Commonwealth to deliver that training and implementation and research in the Northern Territory would be a good thing.

Mr THORN: I think that would be, and in our 2012 National Action Plan we recognised the timing problems in establishing the sorts of services that need to be established. Before

diagnostic clinics can be established we have to have an agreement on the tool and once you have got the tool you need to be able to train staff to be able to use this and it is going to take time. The more delays that we suffer in getting things like the diagnostic tool field tested, the longer it takes to deal with the problem of the young people or the kids who have been affected.

Mr McCARTHY: Yes, thank you for that. We are just starting to see a sequence of initiatives and that tool from what you have just explained seems to be a very important part of that chain. So thank you for sharing that.

Ms MANISON: Can I just move on a bit further than that, Gerry. It is Nicole Manison here. In your recommendations you do also speak about trialling the diagnostic tool by having a dedicated FASD diagnostic clinic in the Territory and you refer to examples where they do exist in Sydney and the Gold Coast. Can you just talk the committee through a bit about how those types of diagnostic clinics work, and how people end up getting referred to go to those clinics?

Mr THORN: I think it is important to answer that question and describe what the process is because a clinic is not a place where you go where there are lots of machines and where you plug a patient in. I will ask Sarah to explain a little bit about how the process of diagnosis takes place. It is important that people do understand what is actually being spoken of here, because once we get that tool signed off it is our view that we need to be looking at its application in a number of different environments.

FARE has been funding a clinic in Sydney at Westmead hospital. I think there is some work going on in Perth and you mentioned the Gold Coast too. These are all different environments and we need to be trialling that diagnostic process because we are dealing with different types, different cohorts of people who have been affected. So I think being able to work with the Northern Territory health services would be important because that is another peculiar facet. There is another different population group that we need to be able to get to. Sarah, you can just talk about what is actually entailed in running a diagnostic clinic.

Ms WARD: There are different methods for diagnosis. The diagnosis of FASD is a diagnosis of exclusion, so children are tested in terms of neurodevelopment and capability. They undergo psychological testing, physiotherapy testing and also have 3D photographs taken of their face to see any changes, the facial anomalies, the sort of differences from the standard deviations from normal, and all of these things together are then excluded from other various diagnoses, say autism, or Asperger's or ADHD, or all those other similar developmental disabilities, to come to a diagnosis of FASD. They also need the confirmed exposure of alcohol, so they need to have some information about whether the mother was drinking or not. That is particularly so for a diagnosis of Foetal Alcohol Syndrome, less so for the further diagnoses which fall under the FASD umbrella.

There are different ways in which a FASD diagnosis can be undertaken. At the Westmead clinic, my understanding is that Elizabeth Elliott is the key person. A child comes to her clinic that is located within the hospital; they see her and are then referred to a psychologist, they see that person and are then referred to a physiotherapist and they see that person and are then referred to someone else. Eventually all of those assessments are undertaken. That information comes back to Elizabeth and a diagnosis is made.

In contrast, the Lililwan Project, which was at Fitzroy Crossing in Western Australia, sent a team of people out to the Aboriginal communities and they undertook those assessments in one day. It was quite exhausting for the children in that they were put through eight hours' worth of tests, but they did not have those time limits, or those time lags between seeing one health professional, another health professional and another health professional.

The idea of best practice in undertaking FASD diagnosis is a multidisciplinary assessment, so that they are assessed by more than one person. There are those psychological assessments, physiotherapy assessments and those sorts of things.

As Michael mentioned, in FARE's FASD action plan, we put in four examples of different diagnostic clinics. One would be the Westmead model where a child comes into a hospital and sees all those health professionals. The second is existing child development services.

In Western Australia, at Princess Margaret Hospital, there is an existing child development service that already sees children that might have suspected autism or Asperger's etcetera, and they are adding Foetal Alcohol Spectrum Disorders into that cohort of children that they see, and that is the way that New Zealand has expanded their diagnostic clinics. The third model is the Lililwan model, where you have a team of health professionals that go into a region and they screen all of the children that they can, and the fourth model is that you have, again, a lot of those mobile clinics that go in and see children in a local area. They also train up the people who live in that local area, particularly in rural, remote areas, so that once that team leaves, the paediatricians and the physiotherapists that are only visiting, you retain that knowledge and that expertise within the community. That is something that when we were developing our plan came across really clearly, especially from Aboriginal and Torres Strait Islander people, the need to train up local people and have local knowledge about diagnosis and how you undertake diagnosis.

I think we are saying we need to increase our diagnostic capacity. There are different ways that we can do that and there are different models available to us, and not one way is particularly right; it depends on the local situation.

Ms MANISON: Sorry, we have got limited time with you, so I am just going to race down the list to a few other questions that I had. In relation to your recommendations 11 and 12, you have written about recommending that in the Territory work is done with the Department of Education to develop resources for training teachers and education professionals around understanding FASD and strategies to deal with it in the classroom. Also we had a fair bit of discussion earlier this morning around the criminal justice system and people with FASD eventually heading down the pathway and ending up there, and looking at training programs for judges, magistrates, correctional officers about managing and identifying FASD. Do you have any other examples of where these types of programs exist in Australia, or is this still fairly new ground?

Mr THORN: I think the truth of this is it is new ground and there really is not sufficient recognition of the problem to begin with let alone establishing the best way to actually manage and deal with those issues. Clearly there are different circumstances in the health system and the education system within the correction system, but I am heartened that there are, in the criminal justice system for instance, a number of judicial officers who have begun to understand or perhaps appreciate that FASD might be one of the underlying conditions that relates to the offending behaviour. From our perspective, what we hear from professionals is that while FASD is a lifetime disability, you actually can manage that disability to some extent, like many other disabilities, and I think that means that it is not a hopeless situation.

Sarah has got some examples of what happens in – it is the Queensland health system, isn't it? She will think about that for a moment and I will just finish off.

There are some examples. In Western Australia the child protection system has been doing some training of their staff to recognise FASD and from what I have seen is that has been very much welcomed by those professionals. In the WA justice system, Magistrate Cathy Crawford has taken this on as an issue within the magistracy, so she is somebody that is worth talking to, I think, about how they might be approaching that issue in the criminal justice system.

I think just to get a bit of a handle on the magnitude of it - Mark Kleiman , who is an American academic, has written about the failure of the system that sees so many people imprisoned. He has talked about the emergence of Foetal Alcohol Spectrum Disorders as one of the factors that has actually been driving the rates of offending in North America and in Canada in particular, where there has been good research. He is another one that I think is optimistic that this can be managed, if only people know what they are dealing with. So the issue of diagnosis becomes critical, so then you can actually manage the problem.

Perhaps Sarah might be able to help us out with some examples of how you can manage people within those systems, be it education, criminal justice or health.

Ms WARD: Yes, I was thinking internationally. I think this is really an area where especially parents and carers say, 'We do not need research,' because there are already examples internationally of education curriculums for schools and projects in Canada working in prisons and sentencing options in Canada and things like that. So in the US and in Canada they have developed educational curriculums for schools and for teachers on FASD. In Canada in the Yukon there was a judge who has looked at different sentencing options for people with FASD. It is difficult because there are mandatory sentencing conditions in Canada, as well as parole conditions and changing some of the language that is given in parole forms so that it is more sensitive for people that have FASD. There is a whole sort of system in place and recognition that people with FASD do end up more likely to be involved in the criminal justice system, and there has been a lot of work that has been going on in Canada and America and we can learn from that.

In Australia FARE funded some people in Queensland in the criminal justice system to look at what the needs are of lawyers and judges and magistrates. That found that all of them or pretty much all of them thought that FASD was an issue that was relevant to them, but they did not refer people to services because none existed or they were unsure where to refer them to. They could not refer them for a diagnosis, and they could not refer them for treatment because there was not anything available to them.

There is evidence, again in America and Canada, that shows that if you put in place early intervention programs when children are three or four, that you can mitigate some of the conditions that they might go on to develop. There are the primary disabilities which are predominantly associated with the brain damage that is caused from the alcohol exposure, but when those disabilities are misunderstood, when a child is struggling to read or to understand or understand cause and effect, rather than being told to straighten up and fly right, because that has no meaning to them, if a strategy was put in place to help them at that stage then that can help mitigate against them falling out of school, becoming truants, being excluded and going on to shoplifting and minimal crime and getting involved in the criminal justice system, which is so often the case that we see with a life trajectory with someone with FASD. There are people in America who are motivational speakers who are people who have FASD and they are very inspiring individuals, but they had that early intervention when they were very young, when they were four or five, and that is how they have gone on to change their life.

Mr WOOD: Can I just ask one question on that? I mentioned before to another speaker about how you read about the elasticity of the brain and you just spoke about some motivational speakers. Have they trained themselves to at least manage or even train the brain to override or replace some of those parts that may have been causing some of these problems? Do you know why they are where they are today?

Ms WARD: That is an interesting question. With brain plasticity we are not clinical people, but my understanding is that if you can intervene early there is some ability to change the brain plasticity. But with these motivational speakers, one is a man called Miles and he is a very eloquent speaker, but if he does not have someone with him all the time that tells him you have to eat lunch now, he just will not remember. He can speak very eloquently about his life and his experiences but he does not understand cause and effect. He does not understand that if he does not eat lunch, he will get hungry or if he does not eat dinner he will get hungry. He just does not compute that so he needs someone with him all the time to just remind him of those things and those are the strategies that he has put in place in order to live his life.

Lots of researchers in FASD talk about what is called the external brain, so you have someone with you who has a fully functioning brain and that can understand those things and be your advocate in certain situations where those people are unable to do it. They are inspiring but they still have deficits and they have strategies that they put in place in their lives to manage, basically. It is unlikely that he would manage his own money; he would have someone else doing that for him.

Madam CHAIR: Can I ask a question? I know you are not medical people, or are you?

Ms WARD: No.

Madam CHAIR: Is it the regular drinking at a high level that does the damage or can someone who is a binge drinker, who just drinks on weekends or a combination of everything - the fact that you are actually drinking alcohol, it does not matter how, you are just drinking a lot of it.

Ms WARD: Unfortunately, we do not know. What we do know is that higher amounts of alcohol and higher frequency of alcohol consumption are more likely to result in damage, but there is not a cut-off point that has been found. What has been found is that some small amounts of alcohol, say 2 to 2.5 standard drinks once or twice a week on an occasional basis have still been found to result in neurological problems and that basically means that effects are being found at less than a bottle of wine a week but there is not a cut-off point that we know of. The clinicians would be much better able to answer this, people like Professor Elliott. There is not a zero point where alcohol does not cause damage, we just have not found that level, but we do know that damage is more likely to occur with increasing amounts and increasing frequency of consumption.

Mr THORN: We are unlikely to ever know of course, because you could never do the sorts of trials that you need to do to be able to establish beyond doubt what that is.

Mr WOOD: I have one question; it probably relates to the issue of whether you can train the brain to overcome some of those difficulties, but you do mention in one of your recommendations about having treatment management plans. Are we still at a very early stage of being able to do something that we could show would have a marked effect on these people? In other words, for instance if you read some of those books on the plasticity of the brain where one person had a bullet through the brain during the war; he learnt to use the other side of the brain to overcome some of the problems he had had with damage to that side of the brain. I know nowadays they do have computer programs which people can use to try and keep their brain active and train the brain to do certain things that it could not do before. Do you know if there is any move in this area, because obviously brain damage is the reason that we have this problem?

Ms WARD: I think it is about the functioning of the brain particularly more so than the ability of the brain to work. It is about how the alcohol damages the brain, and it damages the brain by damaging the executive functioning, so things like cause and effect. People do not understand. The FASD researchers talk about someone reaching a certain age level, so they might have a cognitive awareness and an ability of an eight year old, but they will continue growing throughout their life, so obviously when they are 18, or they are 30, they are an adult but still have the mental functioning of that lower age group.

The researchers always talk about the lower age group. So if you expect that a teenager should be able to do certain things, a person with FASD will have a lower understanding of that and they might only ever reach, say, an eight-year old or a twelve-year old's understanding of the world and that will never change. That is as far as they can get. It is obviously different for each individual because alcohol affects each person differently, and so that is why it is so difficult and why you need management plans in place.

Management plans would look at specific deficits that that person has as well as specific strengths that that person has and put in place strategies for them, whether they need a speech therapist, or whether they need a physiotherapist to help them with walking, or whether they need hearing aids to help them with hearing and things like that, because alcohol can damage so many organs in the body, as well as the brain.

That is what those management plans would put in place and from the Lililwan project, each of the children that have been identified, they were putting in place those management plans for them. They are quite young children in that they were seven or eight, so it would be a lot to do with education strategies and things like that that they can put in place for them, but as far as I know that is occurring at the moment. It has not all been published or anything yet.

Mr WOOD: Thank you.

Mr McCARTHY: Gerry McCarthy again. I am interested in the recommendation that FARE has said not to use a legislative framework around detaining the woman in terms of addressing the issue of Foetal Alcohol Spectrum Disorder. We have also heard from justice agencies that also have a similar recommendation. I am interested in a national perspective; is this the common theme that any legislative framework around detaining a woman is not going to be a good outcome in solving this issue?

Mr THORN: I think there a couple of different aspects to it. The obvious issue around detaining people is the risk you run of people really hiding from help and care. That is what we do not want. If we have an ideal model and diagnose a child as early as possible we can then move towards putting in place a management plan that can try to mitigate the consequences of that disability as much as possible.

It is a fairly widely understood concept within the public health sector. The other issue that has been raised is really what the responsibility of those who are providing alcohol, for instance, might be. I think it goes this way that we would like people who are thinking about offering someone alcohol, be it a sale at a hotel or a sale at a bottle shop or even pouring a drink at home, to think about that person and that child, that baby that has been conceived. I do not think that we can put in place a regime that penalises people who might provide alcohol.

The sad reality is that some people who are dependent will drink and are likely to harm their child. I suppose there are odd occasions where that child protection people should intervene to do something about remedying that situation or mitigating that. This is not a new area, social workers have been having to deal with this for a long time and probably the best expertise is in the illicit drugs areas. I think that we get ourselves into dangerous territory if we start talking about penalties for publicans, for instance. What are we expecting a publican to do? Are we expecting a 20-year old who is working at a bottle shop, for instance, to ask all their customers about whether or not they are pregnant in order to discharge their legal responsibilities?

I just think it is highly impractical and would ultimately fall into disrepair as a public policy measure. There are two issues that are currently being bandied about: one is about whether or not the state should intervene to protect the unborn child, and the second is criminal sanctions, be they on the mother or on the server of the liquor. I think that in both cases that criminalising people is not the right approach.

In some news in the media today, for instance in Western Australia, child protection have intervened in a case of a young person who is morbidly obese. Now it seems to me that is a straight out child protection issue; an assessment has been made and the judgement call

made that we are going to intervene and that child is in a situation where their safety can be better guaranteed than leaving them in the home with a mother who clearly has problems.

Ms WARD: My point of view on the woman issue is that you want to help the woman as much as possible to stop her alcohol consumption and therefore you want to make it as easy as possible for that woman to seek help and support and treatment. Anything that helps make that situation easier is of benefit and anything that restricts and makes it harder will drive the problem underground, making the problem worse.

Mr THORN: We have funded some research in New South Wales where people have been looking at this issue of alcohol dependent woman and pregnancy and we should make sure that you get access to those published reports.

Mr WOOD: On that issue there you mentioned Western Australia. I was interested in hearing that on the news yesterday, and obviously they made a decision that the child was at risk of being further harmed if they did not take the child away. But if you have done everything possible in the form of trying to educate, putting in programs for a particular woman to stop drinking, where is the line drawn then between the government's responsibility to say, 'We do not want that unborn child harmed, therefore we will have to take you into some form of confinement until you have that child because you cannot stop drinking'?

That is the dilemma I see because you know that alcohol will cause FASD. You have done everything possible to prevent and educate that person not to drink, but if that person continues does the state have a role to play in protecting the child?

Mr THORN: I believe the state does have a role and that is a decision for the parliamentarians in this country, so Mr Wood, in the end that is going to be put back to you. My sense about it is that you have got to work your way through that process of working with these people who might have those dependency issues, and ultimately I think it will become clear where you have reached the end of the road and the state does need to intervene. The problem, of course, is that the damage may well already have been done and that is the challenge. I worry because of the numbers that I recited earlier that 50% of women are drinking at the time of conception; 20% continue to drink after pregnancy. That is an awful lot of people. There are more than 300 000 births in this country; that 20% figure that you are talking about comes to about 60 000 women who are potentially putting their child at risk as a consequence of their consumption of alcohol during pregnancy. They are really large numbers.

Ms WARD: I think the other thing as well is that we need to look at what else is going on in the woman's life, so for women that are alcohol dependent or who are very heavy drinkers

and they are pregnant it is rarely a single issue that is taking place in their life. They are often survivors of violence or they are current victims of violence, domestic violence. There was a study in America of 80 mothers who had had children with FASD; 95% of them had been sexually, physically or verbally abused in their lives and 72% of them were in current abusive relationships and felt unable to stop drinking because it was not safe for them to stop drinking. So it is usually a very complex issue.

In Canada there was a program called She Way which basically worked with women and they tried to identify them early in their pregnancy and then worked with them to put in place things such as housing and support and education and jobs. If they were in domestic violence relationships they tried to support them to get out of those domestic violence relationships and they put in place a whole range of support really early on in the pregnancy so that they could help the woman stop her drinking and they had remarkable reductions in alcohol consumption. Not all of the women did become completely alcohol-free, but the alcohol consumption did come down greatly and therefore the harm is mitigated to some degree. Again, I think we should look to what happened internationally and what we can learn from those programs. It is really about trying to put those supports in place early and trying to support those women, rather than necessarily confining them or locking them up. They might go on to have a subsequent pregnancy and it might be the same situation again and again.

Madam CHAIR: We are just a little bit over time so I do not think that there are any more questions. Thank you very much for your time, both of you, to Mike and also to Sarah, much appreciated and thank you for your submission. We will send you a copy of the *Hansard* so you can check it to make sure everything is accurate and then we will put it out to public, but if we need to come back to you, can we do so?

Mr THORN: Certainly may.

Madam CHAIR: Oh, that is lovely, thank you very much for your time today.

Mr THORN: Thank you very much for having us on and best wishes for your inquiry.

Madam CHAIR: Thanks very much, bye bye.

The committee suspended.

Madam CHAIR: Hello there, it is Kezia Purick here. Welcome, and thank you, Carol, for joining us.

Professor BOWER: Thank you.

Madam CHAIR: Are you based in WA?

Professor BOWER: I Beg your pardon?

Madam CHAIR: Are you based in WA?

Professor BOWER: I am in WA, yes. I am finding it a bit hard to hear actually, not because I am in WA probably.

Madam CHAIR: No, I just saw the Winthrop word, so I figured it was.

I am Kezia Purick, Chair of the committee. Thank you for appearing today.

Professor BOWER: Yes.

Madam CHAIR: I am just trying to get my notes.

Thank you for giving evidence, we appreciate you taking the time. This is a formal proceeding of the committee and the protection of parliamentary privilege applies. It is a public hearing and is being webcast through the Assembly's website. A transcript will be made for use of the committee and may be put on the committee's website. If there is anything that you want to talk about during the hearing that you do not want to be made public, we can go into a closed session and take the evidence in private.

For the record, could you state your name and the capacity in which you appear here today, please?

Professor BOWER: Yes. My name is Carol Bower and I am an epidemiologist at the Telethon Kids Institute in Perth in Western Australia.

Madam CHAIR: Okay, thank you. Do you have any opening comments that you wanted to make or opening statement?

Professor BOWER: Well, just briefly, that it is great that there is this select committee because this is a really important issue and it is important that information is collected in each state and territory to see what can be done about preventing Foetal Alcohol Spectrum Disorder, so thank you.

Madam CHAIR: So what kind of work does the Telethon Institute do in this regard, with FASD?

Professor BOWER: We have got a suite of projects. We have done work on the incidence and prevalence of foetal alcohol syndrome and Foetal Alcohol Spectrum Disorder. We have done work to find out about the knowledge, attitudes and practices of health professionals and justice professionals in relation to alcohol use in pregnancy and Foetal Alcohol Spectrum Disorder. We have done surveys of women to find out what they know, about their knowledge, attitudes and practices towards alcohol.

As a result of the surveys we did with health professionals we found that not all of them were providing information to pregnant women about the risks of alcohol in pregnancy and not all of them were actually even asking them about alcohol use in pregnancy, but they all really wanted information to assist them in doing that. In another project we developed education resources for health professionals. We have distributed those and evaluated those and found that they have been helpful in increasing the proportion of health professionals who routinely ask about alcohol use in pregnancy and provide advice, and also that the advice they are providing is in line with the current NHMRC guideline, that no alcohol in pregnancy is the safest choice.

In the justice system we have done similar surveys. They are obviously concerned about children coming before the court who might have FASD and it is not always diagnosed, but it would be helpful to know because the management through the system may be quite different. We are currently working with them to prepare some educational materials for justice professionals as well.

Then there is a lot more research, but perhaps relevant to the Northern Territory we have been involved with – but I am sure you are hearing about that separately – the Lililwan project in the Fitzroy Valley and now we have been invited collaborators with the Marulu

Prevention Strategy in the Fitzroy Valley. James Fitzpatrick, who is a paediatrician, works here at the institute and is very closely working on that project.

We have also developed messages for women about encouraging no alcohol use in pregnancy and they were developed by the Drug and Alcohol Office into a television advertisement that has been on on several occasions here, and that has been evaluated and been shown to be salient and very effective in changing women's intention or supporting women's intention to not drink alcohol in pregnancy.

We have done a whole lot of other stuff, looking at the effects of alcohol use in pregnancy on stillbirths. That is probably quite important because that work showed that women who were heavy users of alcohol - to the point where they had been admitted to hospital with an alcohol related diagnosis - the children of those women were more likely to have cerebral palsy, more likely to be intellectually disabled, more likely to have birth defects, more likely to be stillborn, more likely to have Sudden Infant Death Syndrome and more likely to have infant mortality due to other causes.

Mr WOOD: It is Gerry Wood here. I was going to ask you two questions. Just on what you said about the heavy drinkers: is that literature or study available in relation to stillbirths?

Professor BOWER: Yes, I can send you copies of those papers if you would like. Would that be helpful?

Madam CHAIR: Yes please, that would be good.

Mr WOOD: The other question was in regards to attitudes of people working in justice. We had a lawyer here today saying one of the problems is that people do not know how to recognise FASD and the problem is that people get put into prison that perhaps should not be there. That education material you are preparing: how far advanced is that?

Professor BOWER: Not very, we have only just got the grant to do that, so that is very much a work in progress.

Mr WOOD: Is it an issue in Western Australia that a lot of people do not really know much about FASD?

Professor BOWER: A lot of people in the justice system?

Mr WOOD: Say particularly when someone goes to court, magistrates and that, do they …

Professor BOWER: I think it is increasing. Three or four years ago one of our researchers was concerned about this and actually wrote to the Chief Justice; fortuitously they were just updating their bench book and they asked her to write something that could go into the bench book about Foetal Alcohol Spectrum Disorders. We did that and that is now going through another update, so we are providing additional information there.

The children's court magistrates here are very much on the case. They have been driving this work really. One of them worked in the Kimberley for a while and really felt that this was a really big issue, so they are very keen to be able to identify – you are quite right that actually getting a diagnosis is a problem and I guess that is another bit of work that we have been doing that I really should not have omitted, which is we have a Commonwealth contract to develop a diagnostic instrument for use in Australia. We have done that and we are now going to be getting some funding from the Commonwealth, we hope, to check the feasibility of that, develop some training programs and roll-out the diagnostic instrument so that it is available and with some support about how to use it and what to look for and so on for health professionals.

We hope we will gradually improve recognition of the condition. Of course the important thing then is what do you do once you have recognised it? I think there has been a reticence sometimes in making the diagnosis, because what are you going to do next? The services for these kids are not necessarily available, particularly in rural and remote settings, but we feel that you have to start somewhere and it is perhaps easier to advocate for services if you can actually identify the size of the problem. We are hoping that increasing the diagnosis will lead to provision of appropriate and sufficient services to make the lives of these kids and their families the best they can possibly be. Of course, prevention is really the goal for us all, prevention in the first instance.

Mr WOOD: Just go back one step: in relation to the courts does Western Australia have mandatory sentencing for violent offences?

Professor BOWER: Yes.

Mr WOOD: Can a judge make a decision that can override that based on special circumstances, such as if it was proven that someone had FASD?

Professor BOWER: That I do not know.

Mr WOOD: Ok, thank you for that.

Mr McCARTHY: Professor Bower, Gerry McCarthy here. I am interested across generations. Is the younger generation and naturally the generation they are producing, the natural population growth, more aware of FASD as opposed to Gen Y and the generation previous?

Professor BOWER: I think they may well be. The surveys we have done of women of child bearing age show they have all heard of it. I think they are not so clear about what the consequences of the diagnosis are, but most women have actually heard of foetal alcohol syndrome or Foetal Alcohol Spectrum Disorder and younger women are actually more likely not to drink in pregnancy than older women. Heather D'Antoine, who is with you now in the Northern Territory, did some work in WA among Aboriginal women and found that they were actually pretty knowledgeable about Foetal Alcohol Spectrum Disorder and very concerned about it, of course. I have to say that in WA a lot of the work that we have done has been led and the call for this research has come loud and clear from the Aboriginal population who are very concerned about what is largely an oral culture that is just being lost through grog.

Mr McCARTHY: Thank you for that. Is the research then starting to point to definitive socioeconomic status?

Professor BOWER: Sorry I missed the question, could you just repeat it, please?

Mr McCARTHY: Is the research now drawing links between, for instance lower socio-economic groups not having the knowledge and not making the right decisions, or is it still right across our society?

Professor BOWER: Yes. Some of the work that we did with the women was actually involved women of higher social groups who are the ones who were drinking in pregnancy. The effect on the foetus relates to the amount that is consumed and the timing of when it is consumed in pregnancy. It is not good at any time, but if it is consumed very early in pregnancy it has the greater effect on birth defects and so on, so it is the pattern of consumption, the amount that is consumed, but high consumption in association with other socioeconomic or nutritional aspects and almost certainly genetics determines whether any given child will be affected and to what extent.

It is hard at a public health level to say, 'Well it is only a problem in lower socioeconomic status or high socioeconomic status'. There is high alcohol consumption across the board, and I think the message needs to get out to them all, but there are particular high risk groups where you might want to focus the prevention message, or tailor the prevention message so

that it actually has meaning to particular groups. You would probably want a different format of the message for women in high social class than you would in women who are not in that category.

Mr McCARTHY: Thank you for that and that led to the next question I wanted to ask you. In terms of public health and education and awareness, you mentioned a television advertising campaign. Are the policy makers coming into your institute, for instance, and asking for advice around advertising and education and awareness?

Professor BOWER: Yes, and we are going to them as well. In Western Australia the department of health has developed a model of care for Foetal Alcohol Spectrum Disorder, which in fact grew out of some results that we presented to the Health department of a high rate of foetal alcohol syndrome using data from our birth defects register. Many of us in the institute have contributed to the development of the model of care and also into an implementation plan for that.

So we do try and keep our research relevant and to be able to ensure as best we can that it is available for a translation and to assist in that translation if at all possible; and to evaluate what is done as well. That is important.

So I think it is really important and it makes life easier if you have got good routine data to use to monitor whatever interventions you might put in place. The important things to be monitoring are alcohol use in pregnancy, in a good way, in a way that is real and reflects what is really happening, and the diagnosis of Foetal Alcohol Spectrum Disorder because of course, as I said, if you have got good information on how common it is you are in a much stronger position to be able to advocate for appropriate services for those children.

Mr McCARTHY: Sure. A comment in relation to road safety: we have seen some significant public education awareness programs using a multimedia approach and that has changed over the decades. Are you aware of any moves to give this information to these highly professional marketing companies to start to develop a more hard-hitting approach or an approach for the younger generations that could possibly be aired on our national media?

Professor BOWER: Yes and that is a really good point and I think it is not for us. They are very clever people and can target the messages so that they really hit home. The advertisement that we developed here in Western Australia was developed at a very basic level and then given to one of these companies who does develop advertisements and they have developed that up. It is available as wanted. I am pretty sure it is available on the web if you wanted to have a look at it. Also, I can send you a link to that if you would like to see it.

It is much more focused on non-Aboriginal women or it may well be relevant to them but there has also been – the Drug and Alcohol Office here developed an ad with Mary G. I do

not know if you have seen that one, but it is specifically for Aboriginal women and that is really good. I have also seen some from Barkly, near Tennant Creek I think. It is a really good ad about drinking and pregnancy. So there are some out there; what would be good is to have a much more comprehensive campaign to screen them and evaluate how well they do.

Mr McCARTHY: That is good, and in terms of this committee forming recommendations we have obviously got to look at the diagnosis and we have got to look at the support services and the whole-of-community approach.

Professor BOWER: Yes.

Mr McCARTHY: Governments should be in a space of really resourcing this advertising education and awareness campaign. Yes?

Professor BOWER: Yes. You need a Health workforce that backs that up as well. There is not much point in women getting the message saying do not drink in pregnancy and then they go to their doctor and they say, 'Oh no, it is okay, you know you are not drinking too much'. That needs to be supported. I think that is the message; there needs to be a consistent message. Everyone needs to be on message.

Mr McCARTHY: Well, great advice for a politician. There are a few of us sitting in the room professor. Thank you.

Ms MANISON: With your model of care that has been developed in Western Australia around FASD, how long has that been in place and has there been any formal evaluation of that yet?

Professor BOWER: No. It was developed 2012, or 2011, I think; anyway it does not matter. Last year I think was the year that the implementation plan was built around it and that was cross sectoral and involved child protection, education, the Drug and Alcohol Office, so the implementation plan has only just been signed off. We are now keen to see how it will be implemented. I think that it is available on the WA Department of Health website, both the original model of care and the implementation plan.

Ms MANISON: Thank you, and my apologies if I have missed this, but we have had a lot of discussion around diagnostic tools today and the importance of diagnosing FASD. Is there any particular model being implemented within Western Australia and is it universal right across the state?

Professor BOWER: No, everyone really has been holding out until the Commonwealth accepted or not, but they have now accepted the diagnostic instrument that we have developed. There are several diagnostic guidelines around the world and they have subtle differences but they are basically very similar, and the one that is now called the Australian Diagnostic Instrument is based on those so it really varies very slightly. It is really just much more suited, we hope, to the Australian context.

I might not have made it clear that we are hoping that this year we will be able to build around it some guidelines for its use and engage with the professional colleges, for example, to be able to roll out some training programs so that health professionals can learn how to use it and therefore be making diagnoses across the country using the same criteria. That is the aim, so towards the end of this year that should be starting to happen. There is nothing wrong with using any of the other criteria that are around, they are all okay, but our view and many people's views are that if you can have everyone using a single national instrument, then that is to the advantage. We can all learn the same way and produce the same sort of information.

Madam CHAIR: Professor Bower, thank you very much for talking with us today. We will send you a copy of the *Hansard* so you can correct or make sure the parts that you have spoken about are correct. If we need to come back to you in the later stages, would that be okay?

Professor BOWER: That is fine. I just want to clarify if you want me to send you some copies of the papers?

Madam CHAIR: Yes please, that would be great.

Professor BOWER: Did you want the copies or just the link to them?

Madam CHAIR: Just the link will be fine.

Mr McCARTHY: And the link to the TV advertisement, please, Professor.

Professor BOWER: Yes, okay. I can do that.

Mr WOOD: That will include the link to still births and excessive use of alcohol?

Professor BOWER: Yes, it might be simpler to send you a copy of the papers, but I will do both of those things.

Mr WOOD: Thank you.

Madam CHAIR: Thank you very much, Professor.

Professor BOWER: Thanks very much for inviting me.

The committee suspended.

Madam CHAIR: On behalf of the committee, welcome to you today. Thank you for coming, and we appreciate you taking your time. It is a formal proceeding of the committee and parliamentary privilege applies, as you probably know. This public hearing is webcast through the Assembly's website and the transcript will be made for use of the committee and may be put on to the committee's website. If at any time during the hearing you are concerned that what you might say should not be made public then we can go into a private session and take evidence in private.

For the *Hansard* record could you state your name and your capacity in appearing here, please?

Dr SKOV: My name is Steven Skov, and I am the Chief Health Officer of the Northern Territory.

Dr WRIGHT: My name is Jo Wright, and I am the Acting Executive Director for Strategy and Reform for the Department of Health.

Madam CHAIR: Thank you, would you like to make some opening comments or an opening statement of any kind?

Dr WRIGHT: First of all, thank you for the opportunity to address the committee. This is a very important issue. Both Steven and I have worked as remote health practitioners for many years in the Northern Territory, and that is an issue that we have had to deal with on many occasions in the past. FASD is an important issue for the mothers and the babies, for infants and children, for developing young children and teenagers and ongoing adulthood. It is a lifelong sentence for those who are affected by FASD.

Perhaps I will just make a couple of comments, and Steven might add to it, about the terms of reference of the committee, but prevalence is a big problem to establish in any jurisdiction. The work in the Northern Territory to try and establish prevalence is mentioned in the submission that we made, but suffice to say we do not believe that our knowledge about the prevalence of FASD is in any way reliable or reflective of the size of the problem that the community has to deal with.

The recent research that has been done in the Fitzroy Valley has been the first population approach to a detailed analysis of FASD and the instigator of that work, Dr James Fitzpatrick, recently described the prevalence in that area as alarmingly high. The data is soon to be published, but it has not been yet so he is coy about exactly what numbers they were coming up with. The nature of the injuries is very broad and so that is part of the reason why it is difficult to diagnose and reliably address. They range from still birth to obvious facial deformities and other physical injuries that occur for the infant. By far the most common problems associated with injuries due to alcohol for infants exposed in-uterus is very high levels of behavioural and mental health problems that arise, and also many of the higher functioning facets of brain performance that allow people to operate in a social environment are damaged as a result of alcohol exposure in-uterus.

So perhaps I might leave those introductory comments there and leave it to Steven to add any.

Dr SKOV: Just on the last point: with the spectrum aspect of it, with most people you just look at them and you could not really tell that they might be quite badly affected. One of the real difficulties is that the sorts of deficits that these people have in memory cognitive function, behaviour and those sort of things can also be caused by quite a broad range of other things that are unfortunately prevalent amongst the populations that are worst affected by Foetal Alcohol Spectrum Disorder. So one of the difficulties is saying alcohol is the cause of this particular person's problem, or is it the fact that they had nutritional deficiencies as an infant or when they were in-utero, or is it related to extremely difficult social circumstances and stresses of life which can have behavioural impacts? It is very difficult to determine whether alcohol is what is causing this particular person's problem which makes it difficult to measure at a population level and difficult to ascribe alcohol in relation to a particular person's problem.

That goes to one of the issues that our society is wrestling with at the moment, whether FASD should be declared as a 'disability'. So it is difficult to say that alcohol is actually the cause of this, but then you might say, 'Well no, alcohol is not at the cause for this person', but in fact it might be, and you just cannot determine it. Declaring it a disability would create potential problems on both sides of over-recognising and under-recognising. There are some particular issues in relation to the nature of this disorder which makes it hard to grapple with at a population level as well as in relation to individuals.

Having said that it is really important to try and diagnose people with these disabilities and link them into services, because at all levels of being affected it causes problems for people and they do need help and their families definitely do need help. The issue is to deal with diagnosis, and training, in a range of different settings, is also extremely important. There is training for healthcare providers to recognise it, but also training in schools and the criminal justice system.

There are a broad range of areas where people with Foetal Alcohol Spectrum Disorder are going to be overrepresented, and where they are going to have difficulties and where the system and the various professionals need to have some understanding of their situation to best be able to manage them.

I suppose I would like to say one of the things about it is that this is irreversible: once you have got it you have got it and that is it and all that you can possibly do is try to manage it a bit better; to help the person affected and their family cope a little bit better with the whole thing, but it is irreversible. So really you have got to be looking at some sort of prevention type of strategy if you really want to get to the heart of this. In relation to that I think that there are two broad areas that we would like you to consider: one is that, first of all, the alcohol consumption of pregnant women takes place within the alcoholic consumption of the whole society and it is extremely difficult to just pick on one particular group in the society and their alcohol consumption and hope to have a positive impact, when all the rest of society is continuing to drink with all the other influences that are still going on.

The evidence is quite clear about this, if you want to reduce alcohol related harms, the best way is to overall reduce alcohol consumption in the whole of the society. In relation to that, again, the evidence is quite clear. The most effective measures go to the price of alcohol, the availability of alcohol, as the two sort of best buys if you like. And secondly, there are interventions in terms of identifying people and offering them what we call brief interventions, some sort of counselling and support to get them to reflect upon their drinking. Broadly speaking the best measures go to supply and availability of alcohol and that has been demonstrated throughout the world. It has also been demonstrated in particular in relation to Aboriginal people within Australia in a number of different settings, including in the Northern Territory, on a number of occasions.

That is a whole of society understanding of it and if we are really going to get to the heart and address Foetal Alcohol Spectrum Disorder then we need to be thinking in that sort of way. Having said that, there are other things that I think we could be doing in terms of actually specific programs that are focused in this area. One of the most promising is in the early childhood development area. There is a concept known as early childhood visiting, which is something that developed in the United States. Essentially the concept is that there is support provided for young families and young families who are particularly having difficulties whether it is social economic difficulties or just struggling with life in general. If you can provide support to those young families to help them deal with life, then it has been proven that you can have benefits for those children, the children in those families, in terms of better school performance, less involvement with alcohol and other drugs, less involvement with the criminal justice system as they go through their life.

This is something that within the Territory a number of Aboriginal organisations are particularly keen on. Central Australian Aboriginal Congress is very keen on this and they are putting considerable resources into this area. Within the Health department we are quite interested in it as a concept and in relation to this it has potential benefits not only in helping families who might have children who are affected in this way at an early stage, but with the idea that if you can work with young families – because you might not prevent something in the child that is born now but the woman might have another two or three babies. If you are able to support that woman and that family in the first instance with her first child you might have a better chance stopping her drinking as much as she might have done for the first pregnancy, in subsequent pregnancies.

That is a concept of which there is quite good evidence to suggest that it might be worth thinking about. There is quite a lot of interest within the Northern Territory, both within government and non-government circles, about can we explore this. We think that there might be benefits in a range of different areas.

Dr WRIGHT: It is very difficult to get to the first pregnancy, in general, for a whole range of reasons. In the Northern Territory, not the least is that we have quite young women, teenagers, becoming pregnant on a regular basis. More than 20% of pregnancies in Indigenous women are less than 20 years of age.

The measures that actually promote sexual health education and contraception, if well developed, will also be effective in helping to reduce the harms associated with exposure to tobacco and alcohol during pregnancy, and so really ramped up measures along those lines are of great benefit. When combined with the enhanced community visiting program Steven was just talking about, they do provide the opportunity for interventions at both primary, as in the first baby, and subsequent babies level, because you can establish the relationship with the mother and the child with the visiting program and much better link them in for subsequent pregnancies.

Madam CHAIR: So within the Department of Health, because I think you reference some of the work, how do you collaborate with other government agencies like child protection, Aboriginal Health Associations, like AMSANT? First of all, how do you go about talking with the other agencies that are relevant and, second, have you, within the Department of Health, got persons or an office or a focus on this issue, given that it is a growing challenge? Is there anything within the department where you specifically say – because we heard this morning that there are two FASD coordinators in the Department of Education.

Dr WRIGHT: There has been some cross-agency work done initially by the Department of Health and Families and then more recently convened by the Department of Children and – what are they called?

Madam CHAIR: Families.

Dr WRIGHT: Children and Families.

Mr HIGGINS: We know what you mean.

Dr WRIGHT: There was a report written, which I believe included a strategy that was released in 2012. I would have to say there is not a lot of visible work happening between departments at the moment. There is plenty of work that happens at the level of clinicians and of services, but I do not think there is any strategic work happening between departments at the present time. There has been extensive work done with education and child protection and health over the years, but just at the moment I would have to say there is no specific agency.

There is no doubt that health has done some useful work in the past in particular areas, but as far as a generalised program goes there has not been one. The Strong Woman Strong Babies Strong Culture program was very successful at improving global birth outcomes for the women who were targeted in Indigenous communities, where those programs were run, but of course they were not run in any of the major centres and they also were not run in every community.

There have been other measures targeting the roll out of contraception and sexual health information to teenagers. Perhaps Steven can talk a little more about the ACEP program.

Dr SKOV: Well, the ACEP program is a federally funded program run through the Sexual Health and Blood Imported Viruses program area of the department. Its funding was due to

run out this year, but they got a lifeline of an extra 12 months of funding for that broad area which will probably be allowed to support it.

The essence of that program was that there were trainers that went into the community and worked through schools and via community members to train trainers within the community and then to deliver an intervention, which was essentially a life skills thing for adolescent people, providing them with information about a range of different things to do with sexual health and alcohol and drugs and that sort of thing. It also helped them talk through what some of the issues are for young people in terms of relationships and responsibility and understanding where they are going, particularly in relation to sexual health in the idea that they might be better informed and perhaps better equipped to negotiate their sexual lives a bit more safety than had been going on previously. As I am sure you can understand, for young folks that whole spread of alcohol and new independence and sexuality is all mixed in together, and if it goes bad it can be a pretty toxic mix for some people. The idea is to help the range of those different new issues for them in a way that will help them make healthier, more sensible choices.

Ms MANISON: I might just come back a bit to your opening statement and one of the purposes of this committee in our terms of reference is to try to establish the prevalence of FASD in the Northern Territory. I know you were very up-front in saying it is very difficult to establish at the moment and you are waiting to hear what the results of that Fitzroy Valley study will be. I did note in your submission that there was a fairly alarming figure that you took out of a Department of Children and Families survey in 2013 and I will just quote directly from the submission:

A recent NT passive survey commissioned by NTDCF examined the files of 230 children involved with the child protection system in the NT over 2011-12, in order to identify the proportion of children affected by prenatal alcohol exposure and to identify the prevalence of indicators of FASD within this cohort. The study found that the prenatal alcohol exposure was associated with those children entering care, with 1 in 5, or 21% of children, in the study having experienced prenatal alcohol exposure. For children on protection orders that figure rose to 2 in 5, 40%.

That is quite an alarming type of figure that we have got here just in a very small group, I appreciate. I suppose what I am really keen to find out is with a small sort of figure like that, but quite an alarming figure, what work were you trying to do to better enhance and get an understanding of how extensive the issue of FASD is, and what sort of work were you doing around trying to implement better diagnosis of the issue here in the Territory?

Dr WRIGHT: The submission actually goes into some detail about recommending against a specialist diagnostic process at this time; however, what is definite is that the clinical community in the Northern Territory, involving general paediatricians, psychologists and

some of the other allied health workers currently does not have the skills necessary to actually perform the complex assessments required to recognise and diagnose some of the FASD features. For instance, there are workshops that are planned to be run by some of the Fitzroy Valley people in the Top End and central Australia. While it is not something that is being actively done to date it would certainly be a recommendation from me that we continue to develop our existing workforce to improve their ability to diagnose and intervene for this group.

Ms MANISON: We have just had other organisations and professionals we have spoken to at the committee today, and there has been a bit of discussion about the new diagnostic tool that was developed after the House of Representatives committee work. For example, that last lady we just spoke to from Western Australia was talking about having that rolled out in WA or looking at having a diagnostic tool that she felt would be constructive to have in WA but also Australia wide. Do you think that is something that should be used in the Territory?

Dr WRIGHT: Yes we do, we have not seen the final form of that. There are two aspects. There is a diagnostic tool - actually there are quite a few - but there is the one that you are referring to that has recently been developed and then the College of Paediatricians has also developed some guidelines that have not yet been released. Some of the paediatricians in the Northern Territory have been involved on that working group, and we would certainly be expecting that to be rolled-out, but as I said not through a specialist unit. I am afraid to say, my impression - I am speaking completely anecdotally - with 25 years' experience in the Northern Territory is that alcohol consumption patterns in the Northern Territory are substantially different to the consumption patterns that exist in the rest of Australia. The way in which FASD manifests in the Northern Territory is also different from the way it manifests in the rest of Australia. You only have to talk to teachers who have worked in primary schools interstate and then worked in the primary schools here to hear their comments that a substantial number of the children behave in a different way to what they are used to. We do not fully understand the way in which FASD manifests itself in the Northern Territory, and so to a certain extent I think we need to do a lot of learning on the spot, rather than there being a tool that we can pick up, which probably had input from Sydney, Melbourne and Brisbane, and then apply it here and expect it to give us the full answer. I think we will need to, in some ways, reproduce some of the work that was done in the Fitzroy Valley to fully understand the extent and the size of the problem and perhaps also some of the interventions that are required to deal with it. So I think upskilling our current professional workforce will be a major part of our response.

Ms MANISON: Another question I had was in relation to the different agencies that come across working with pregnant women with alcohol issues, putting their child further at risk of FASD, when a child is born with FASD and the journey that they take from their early childhood development through to school and, unfortunately for some of them, or many people, over-representation in the criminal justice system. Clearly, there needs to be different work done by different agencies in the space of FASD in the Territory. Do you see health

being the logical agency to lead the way in getting everybody working together, rather than silos, to make sure that it is a very holistic approach and look at the issue and strategies to reduce the incidence of FASD?

Dr WRIGHT: I think that health has a leadership role in some of the components of those responses, but clearly once it actually starts to become an issue for perhaps teenagers and adults and beyond, largely the health response is pretty limited. It becomes much more a case of the supports that are required for those age groups, but certainly for prevention and for early diagnosis and early management and rehabilitation, health can certainly play a leadership role in that place.

Madam CHAIR: In your submission, page 423, it is mentioned that the NT government currently does not have a whole-of-government framework. Do you think we should have one, a whole-of-government framework which can then move to bring agencies and research agencies together? Should we have one?

Dr WRIGHT: I think this is an example where, on occasions, we have succeeded in getting working groups which have been able to examine the issue and make some suggestions and collaborations happen, and then for various reasons, like for instance the most recent one convened by the Department of Children and Families, it reaches a point where nothing much further is done. I do think that greater focus by government would assist in the whole response by the community to this.

Mr McCARTHY: First of all, thanks for your input. It is good having two doctors who have got extensive experience in the Territory and in the bush, I am presuming. The Northern Territory education department will present to the committee as well, and in their submission they have got a table where they have quantified the FASD numbers. In Alice Springs for instance, they say 27. With the complexities around diagnosis - and we have heard about the history - where would they get that number from?

Dr WRIGHT: Can I just ask, you mean they have listed them as individuals, 27 individuals?

Mr McCARTHY: Yes.

Dr WRIGHT: In discussing FASD it is important to realise that this condition was only recognised 40 years ago when it was initially described as foetal alcohol syndrome, because it was associated with physical abnormalities that made it possible to diagnose. I think about 15 or 20 years ago, perhaps a little bit longer, the broader spectrum was recognised and the term Foetal Alcohol Spectrum Disorder came to be applied. Foetal alcohol syndrome is a

recognisable number within the foetal alcohol spectrum disorder. We have looked at hospitalisation data for foetal alcohol syndrome patients over the 11.5 years from 2000 to 2012, and we have identified 26 cases only. Really, that exercise was not done necessarily to try and figure out how many foetal alcohol syndrome cases were actually there, because we do not actually believe that is the total. We have identified them as being born in the Northern Territory; 24 of them are Indigenous, 2 were non-Indigenous. We are confident, in looking at that data, that there is no source we can go to which will accurately tell us what the size of the problem is.

I am afraid that any figures in the Northern Territory are going to be speculative. I suspect that the education department are probably gathering data on the most severe and difficult children that they have under their care, but I expect that those numbers are a fraction of the total. They are most likely going to refer to people who have been diagnosed as foetal alcohol syndrome rather than Foetal Alcohol Spectrum Disorder, which is a much larger group of people.

Mr McCARTHY: As a former teacher I first came in contact with this in the early 70s. Then in the Northern Territory I have been able to see patterns from the 1980s through, and so I found that interesting that there was a quantified number there and I understand what you are saying and it basically relates to a lot of the other evidence that has been given. I am also interested in your concern with the diagnostic tool. We have had a submission to the committee to promote the national diagnostic tool, and so that is interesting evidence that we will take. Just comments as doctors who have worked in the bush and worked in the Territory: do we have a small enough community where clinicians can use that localised knowledge, particularly in remote communities from a strong tradition of oral histories, to be able to start the diagnostic process with real knowledge about alcohol consumption within the family, alcohol abuse, the mother and so forth? Is that a reality of where we could start?

Dr WRIGHT: The Strong Woman, Strong Babies, Strong Culture program definitely gave evidence that starting with the stories there could be positive outcomes for infants and children as a result of having those stories commenced at that level. I think the point about the diagnostic tool and its applicability is that almost certainly it will be of benefit to apply the diagnostic tool. My caution was just that it will not necessarily match the spectrum or range of conditions that are occurring in our infants and children as a result of exposure to alcohol in the womb, and that we will need to have a skilled and trained local workforce who can understand where the nationally produced diagnostic tool might need to be modified or adapted, in order to meet the requirements we have here.

Dr SKOV: It is certainly possible to better skill the workforce to recognise to understand this sort of thing. One of the issues though with any sort of approach to a problem like this – you can always talk to health staff and say, 'Oh, you have got a screen for this or you have got to look for that'. It is one thing to find a case of this; it is something else again to be able to do something about it. One of the issues that always comes back to bite people, if you are

going to actively seek out cases whatever it is, is that if you cannot actually then offer that person something, then you find yourself in an ethical situation. You called this person - 'You have got this but I cannot actually do anything for you'. From a health service perspective it is really super discouraging for health staff if they find themselves in that situation. They do not want to get in that situation. So you might have a good diagnostic tool, but health staff will not actually do the work to use it if they do not feel as though they can actually offer that person something.

So it is a good thing to talk about diagnostic tools and training staff, but at the same time we have got to make sure that if they do find cases of whatever it is that you are looking for, that we have got to be able to try and offer them something so that they can offer their patients something. Otherwise it is a fatal break in that system of trying to address an issue.

Mr McCARTHY: Anecdotally, there has been a perception that the health professionals have been reluctant to diagnose and you have just given me an instance why.

Dr SKOV: Well, I think the other aspect of that is what can I actually offer this person? The second aspect of it is that this is a highly stigmatised condition. Particularly in Aboriginal health over the last 30 years, it has been one that the Aboriginal community has been quite uneasy about, especially when there is any conversation about it more broadly than within the Aboriginal community and within the Aboriginal health service community. In Canada they had the same issue and essentially they were able to deal with it first internally within the Indigenous health sector, within Indigenous communities dealing with it themselves, and then once they became more comfortable with it people were able to be a bit more open about it. So that is an element of it as well, because of the stigma associated with the condition and all the baggage that goes with it.

Dr WRIGHT: Even if you do suspect that foetal alcohol syndrome may be an issue, without a history of the mother consuming alcohol during pregnancy and if they will not agree that they did, it is a difficult diagnosis to make and you are left saying that the abnormalities or the difficulties that you are identifying might be due to other factors which could be completely valid. So you are reluctant to make the accusation in the absence of any admission or evidence that the mother did actually consume harmful levels of alcohol, and then there is a variation of sensitivity to alcohol.

The foetus does not get a uniform response to a dose of alcohol. Some infants are very heavily exposed to alcohol during pregnancy and go on to be professors of astrophysics and things. Other children seem to be exposed at quite modest levels and be quite severely affected. There is genetics involved and timing, at what stage in the pregnancy, whether the alcohol is a continuous low dose, occasion binges, frequent binges. All has an impact on the effect and so if the mother says, 'No, I did not drink alcohol during pregnancy,' and if there is

not a grandmother standing behind her going, 'Yes, she did', then you are left with the inability to make the diagnosis.

Mr McCARTHY: Dealing with a family unit - I really like your ideas around the early childhood visiting concept of intervention, and that has come up today with a number of other witnesses. I think in the Territory - that is what my question was about - we do have a close enough society. I think we do have the witnesses who would come forward. It has the secondary effect of increasing the education and awareness. Essentially, we are trying to create this conversation, are we not?

Dr WRIGHT: Indeed.

Mr McCARTHY: Within the family groups and if we can solve, as you said, the first pregnancy, then the second and third will consequently work.

Dr WRIGHT: Yes.

Mr McCARTHY: And so in the tension between research and then intervention and these diagnostic tools, maybe the Territory has got a position where we can lead with a different approach?

Dr WRIGHT: I agree. I think that there is the possibility to definitely build on some of the programs that have been rolled-out and make them more general and really innovate. I mean there is no doubt that we do have major problems and it is a pity that there is no representatives from Central Australia, from Alice Springs here, but certainly in Tennant Creek and Central Australia the difficulties with alcohol that show up in the whole of our data are substantial and they are much higher than occur in the Top End. Our perception is that foetal alcohol syndrome and spectrum disorder is a bigger problem in Central Australia than it is in the Top End as well. We have got major issues with alcohol throughout our whole community, and this is just one of the features. If we can introduce some effective measures to limit alcohol related harms we will also prevent Foetal Alcohol Spectrum Disorder.

Mr McCARTHY: Having said that, I do believe in that. The developers of public policy, the politicians, basically work off statistics so essentially we will have to try and quantify this because it directly relates to resource allocations. In education and special needs support, the first cab off the rank if you look at it chronologically with the children's age, there is that need for that specific quantifying of this. We will not be able to get away from it unless you change the political system and I do not think that is going to be easy to change. I think there also is a lot of scope for innovative Territory ideas, which will essentially come from people like you.

Mr WOOD: Just going right back to the beginning: you mentioned about the damage to the brain being irreversible, and I have been asking a few of the speakers today about that and how there has been a lot of discussion going on for a long period and in more recent times, about the plasticity of the brain. Is the brain capable of taking over parts that have been damaged or actually do not work anymore? Can it be trained to take over functions that have gone?

Dr SKOV: Yes, the brain remains plastic and continues to grow and develop into the early twenties. Twenty or thirty years ago we did not understand that, that is true. Having said that though, once the damage is done in-utero then you do have damage that will not be changed. What you can do if you are able to intervene early enough in the right sorts of ways is teach that person how to train their memory better or you can train them in cognition or you can train them in behavioural techniques. You can, with active training, help people overcome the sort of deficit that they have got. It takes quite a considerable sort of effort and probably would take quite a focused effort in order to be able to help people overcome those sorts of things, and it also depends on the degree to which the damage has been done. If somebody is much more at the severe end of the spectrum you are always going to struggle to make that person functional, even with a lot of effort. With somebody who is relatively mildly affected, with good support and interventions in those sorts of areas early on, you can probably get them to the point where they can be quite reasonably functional and there is everything in between.

When I say it is irreversible, that is to make the point that if you really want to get at this you have stop it happening in the first place to have the best benefit, but it is not to say that if you have got somebody who is affected by this there is absolutely nothing you can do to help them because there is, and also to help their families.

Mr WOOD: Is there work happening in that region? We know that to some extent it is easier to have a prevention program but to have a repair program, you might put it, is equally important because these people could end up in gaol costing us lots of money; they are burden on society. I am not blaming them but that just happens to be the way it is, if they are ending up in crime and in gaol and causing problems at home. So is there work being done on trying to manage this issue afterwards?

Dr WRIGHT: Those children who are being identified with Foetal Alcohol Spectrum Disorder are currently entering the health system and receiving care from paediatricians and psychologists and other allied health therapists appropriate to their conditions. The problem is that the workforce is general in its nature rather than specialised, so although I am personally familiar with a number of children who have done well by very targeted interventions and usually support from the broader family, not necessarily the mother, but the broader family who have stepped in and taken responsibility. This has resulted in some of

these children doing quite well as they move through the system. I would not say that you would expect to see them going to university, but they have certainly been able to take on functioning roles.

The bigger issue of how to deal with the larger number of people who are probably currently not crossing diagnostic thresholds is one where we probably need to skill up the general workforce, the teaching workforce, the nursing and community health professions, the remote health staff as well as the paediatricians and the allied health, so that they are aware of how to intervene with people with this set of problems, whether or not they have got the diagnosis of FASD.

Dr SKOV: Can I just add to that, please? To do this is quite resource intensive, even to sort it out properly. If someone is grossly affected it is straightforward. If somebody is intermediate or at the lower end of something, to get to the bottom of it you need to be able to do reasonably sophisticated neurocognitive type testing, which not everybody can do, certainly not every sort of general doctor, nurse and health worker in remote communities. Then, if you are able to identify specific deficits it again often will require a particular sort of training to get the best for that person and it is quite resource intensive. As a general health system, we can do general sorts of things, provide general sorts of training and it will provide some benefit, but to really help an individual as much as you possibly can, it is very resource intensive.

Mr WOOD: Just one last question from me and I asked this before to someone else. Are people who are affected by FASD aware they have a problem? Can they help themselves or has the brain not got that ability? My mother would say, 'Do not lose your temper' and she would say you were capable of self-control. So have they got the ability of self-control over some of those issues that cause problems in their life?

Dr SKOV: Again it goes back to how badly a person might be affected, because one of the areas is impulse control that is particularly affected in this disorder. If someone is quite badly affected then they are probably really going to struggle. If somebody is down at the minor end of things, then they are much more likely to have some insight and support and education and training to be able to manage that impulse control stuff better. There is not a yes or no answer to that question, I do not think.

Mr WOOD: I lead on to say they end up in prison because they have done something, but how do I know that they did it, they knew they were doing it, in other words?

Madam CHAIR: That is the dilemma. We are just on time, so thank you for your time here today and thank you for your submission. If we need other information, can we come back to you?

Dr WRIGHT: Certainly.

Madam CHAIR: Thank you very much.

The committee suspended.

Madam CHAIR: Welcome, thank you for being here at this public hearing into action to prevent Foetal Alcohol Spectrum Disorder. We appreciate you taking your time to be here today.

This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee applies. It is a public hearing and it is being webcast through the Assembly's website. A transcript will be made for the use of the committee and may be put on the committee's website. If at any time you feel that you do not want comments to be made public we can go into a closed session and take your evidence privately.

Could you state your full name or your name and the capacity you are here for the *Hansard* record, please?

Ms CARNEY: Jodeen Carney, Chief Executive Officer, Department of Children and Families, and my colleague is Lee-Anne Jarret Sims, Senior Policy Officer, Prevention and Family Support.

Madam CHAIR: Thank you. Do you have any opening comments or statement?

Ms CARNEY: I do, thank you. Thank you for the opportunity to speak this afternoon on behalf of the Department of Children and Families. My colleague, Lee-Anne Jarret Sims, has extensive professional history in our family support and policy and program area and its links to FASD and FAS and its effects on children. I am sure she will be very happy to provide any detailed answers to questions that committee members would have.

I would like to say that as a child protection agency we and our clients would directly benefit from better prevention efforts. It is clear from our own research, which has been included in our submission to the committee, as well as national and international research, that children who are exposed to alcohol while in-utero and after birth, and those who are FASD affected, are disproportionally represented in the child protection system.

I understand that the committee will be speaking with Ms Prue Walker, who is the author of the research into prevalence of FASD in the Territory's child protection system. In 2008, while she was working for the then Department of Health and Families, she was awarded a Churchill Fellowship to study FASD during 2009. In 2011 Ms Walker commenced a project to better document the prevalence of FASD in the Territory's child protection system. Since leaving the department she continued her research project. Much of that is summarised in the department's submission to the committee. I should say, however, that Ms Walker's research, or the project, has not been finalised. I understand it is likely to be finalised in the next few months.

In any event, the research findings confirm what committee members would suspect, that child protection sees much of the impact of FASD in its interactions with families and children at risk and/or children who are in care. I will not go through the detail about the study itself because we have provided details in our submission, but I think it is important for us to briefly highlight some of the key findings which help illustrate the impact of FASD on our agency.

The study reviewed the cases of 230 children who were the subject of a child protection investigation or in out-of-home-care in 2011 and 2012. Significant numbers of children came from families with concerning alcohol use or misuse by both parents. Key findings included 57% of the children who were the subject of a child protection investigation, 86% of the children on protection orders were exposed to concerning alcohol use by one or both parents and 20% of the children were identified as prenatally alcohol exposed. Of those, 6% had confirmed FASD diagnosis, with a further 8% with suspected FAS diagnosis. That is comparable to the international estimates of children in child protection systems with FAS or FASD diagnoses.

The study also found that 10% of those 230 children or cases sampled experienced growth delay, prematurity, low birth weight; 10% experienced speech or language delay and 23% had behavioural problems.

That is a sad, but I suspect not surprising revelation in the Territory. It is unfortunate that we that there is no standardised diagnostic tool for FASD. Unfortunate for many reasons, one of them is that while the figures that I have quoted from the research are grim, it is likely that the figures are much higher in the Territory for those kids in our child protection system, who either have or are likely to have FASD or are affected by it.

In addition to, obviously, over consumption of alcohol, the risk of FAS and FASD are known to be increased by poor maternal nutrition, high rates of smoking, stress and trauma and exposure to violence. It is sadly perhaps not surprising that the study also found that all of the children who were sampled in our out-of-home care were originally from town camps and 80% of the children were originally from remote communities. The Department of Children and Families Walker study also found that 63% of parents reported concerning alcohol use, of which maternal alcohol use was most prevalent at 43%. Not only were a significant number of mothers drinking while pregnant, but half of the children in the study lived in families where long-term alcohol use or misuse was identified and that is sadly, as we know, a terrible reality that we all encounter in the Territory. DCF has introduced a number of initiatives to strengthen its responses to FASD in recognition of the specific vulnerabilities of infants. All reports to our central intake team are classified as priority one and undergo a specific assessment designed to identify the risks and needs of children aged two and under.

Training to DCF child protection practitioners about FASD includes understanding the needs of FASD affected children in the child protection context and risk assessment and case planning for families where FASD may be present. DCF has also developed and implemented the Tune into Little Ones resources kit, which provides comprehensive information on infant development, their needs and milestones across the domains of physical health, emotional wellbeing and family relationships. TILO, as we call it, also provides resource information on FASD and how to help young children who may be affected by FASD or have it.

We have brought a copy of a TILO resource kit, which we would like to provide, or table, to the committee so that committee members can have a look at what we consider a very practical attempt to assist our parents, showing them what benchmarks children should be at through their development. DCF has also developed a number of actions for the future, three of which include - as part of ongoing reforms to out-of-home care, we are reviewing current foster and kinship carer training to ensure carers have the required knowledge and skills to manage a range of conditions and behaviours such as FASD; we are developing more explicit policy guidance about investigation techniques, intervention types and referral mechanisms for children affected by FASD for DCF staff and family support services; and we are enhancing existing mechanisms and processes that caseworkers can use to understand a family's risks and needs to make decisions on supports and interventions, such as the family strengths and needs assessment.

Committee members, DCF is one of a number of agencies that families and children with FASD come into contact with. DCF on its own can provide, however, relatively limited responses to families. We are unable to effectively identify or respond to their addiction problems without assistance from drug and alcohol services, nor can we respond to the specific learning or behavioural needs of children diagnosed with FASD without advice from

health or education services. While integrated and coordinated service delivery is important to meet the complex needs of FASD-affected children and their families, a standardised and diagnostic tool for FASD and increased services and access to specialists for treatment are essential.

DCF is very keen to work with other agencies to develop protocols; to improve access to specialist services, to ensure, for instance, that children diagnosed with FASD can access the educational and learning support provided by the Department of Education's student support services program; that children and families affected by FASD can access appropriate disability support services; and that children who are taken into care where there is a history of maternal alcohol use and misuse, and who demonstrate developmental delay, undergo a paediatric assessment.

In conclusion, FASD is a complex health issue which is integrally linked to broader community debate and attitudes about alcohol. I have briefly outlined DCF's current and proposed actions to respond to children and families affected by FASD; however, I repeat that we are somewhat limited in what we can do. DCF is just one agency working with these highly vulnerable children and families. I know that you will be hearing from other witnesses about the management of alcohol, drinking while pregnant and the impact of FASD on children, families and communities. DCF looks forward to the recommendations of the committee and wishes committee members well in their deliberations.

Madam CHAIR: We had the Department of Health people in just before and they have commented in their submission that there is no-whole-of government approach, I think it was, which I think we know anecdotally. Do you think we should recommend a whole-of-government approach and obviously develop strategies and plans, and do you think the Department of Health or some other agency should be the lead agency or it should be a new office altogether?

Ms CARNEY: I think the relevant agencies are probably well equipped to combine to work together. They do in a number of other areas, so I am not sure that it necessitates the creation of a new office or semi-department or whatever. Certainly, there are high levels of goodwill, I know, at a bureaucratic level so that would be decidedly doable.

Ms MANISON: Unfortunately by the time a child gets to the attention of your agency, they have probably gone through a whole range of different health professions, you would expect, and government but also Aboriginal health organisations or non-government organisations as well, who would have seen the child, seen the mother, seen the family situation and would probably have a far greater understanding whether or not the child has been exposed to alcohol and it has got FASD. How does that information flow on to your agency? Is it generally easy for you to ascertain that information early on in the piece? What is the information sharing like or is it still lots of different organisations dealing with these highly

complex individuals in silos, rather than them working together at times? I just imagine it would be much easier for you to get in and work with the family if you have a good understanding of the history and the diagnosis from the instant that they come to the care and attention of your agency.

Ms CARNEY: Well, perhaps we will both answer. I think the sharing of information is there. It is always obviously harder in reality than it is in theory, but it is there. I think it comes back a problem of there not being a standardised definition. Anecdotally, a lot of people, either in our agency, others or in some NGO services - you would have heard this yourself, in people saying, 'Oh, that child has got FASD'. It may not be based on anything except instinctively knowing or an educated guess, but if we had a better starting point of a better diagnostic tool I think that probably would assist the information sharing. Lee-Anne might have some further information for you.

Ms JARRET SIMS: I think that would definitely help. I think part of it is consistent messaging too, and this is part of the problem. There is no safe level of alcohol consumption whilst pregnant.

Ms CARNEY: If we had a better diagnostic tool I think that probably would assist the information sharing, but Lee-Anne might have some further information for you.

Ms JARRET SIMS: I think that would definitely help, but I think part of it is consistent messaging too around what are –it is part of the problem that there is no safe level of alcohol consumption while pregnant, so making that a clear message. I think part of the issues around sharing information or understanding the risk factors are communities' different levels of acceptance of drinking for pregnant women and for not pregnant women. The norms of drinking on a remote community may be different from the norms elsewhere in terms of the level of drinking, the expectation and the access of alcohol, so definitely I think that a coordinated approach is required. Improved sharing of information is necessary, but as part of that getting a shared understanding or an agreed understanding of what are the messages that need to be communicated, both across clients but internally into the service providers.

Madam CHAIR: You said you were keen to develop protocols for interagency work. What kind of protocols were you talking about? I know what protocols are, so are you saying they are not there now?

Ms CARNEY: It is certainly a work in progress, and I will let Lee-Anne give you some more information, but it is the case that not everything in every government department, I have learnt, is as good as it should be. There needs to be very clear language between bureaucrats and departments about what it is you are actually trying to do and how can we make it happen. Having set that background, I will let Lee-Anne give you the mechanics, but

protocols are very useful. They can be effective road maps for where agencies want to get to in terms of working together and solving a specific problem.

Ms JARRET SIMS: It sort of systemises the approach to particular children. For example, children in out-of-home care, if there is a diagnosis or a concern that there may be FASD or a developmental delay, there is a standardised process for getting that child assessed within Health departments. That flows on to what are the best interventions and supports for that child? How do we support and encourage that carer to care for that child? And what are the relationships then and the supports for the education system as that child moves through the system? It is about linking all of those intervention points for that particular child.

Mr WOOD: In your submission you talk about the review of the *Care and Protection of Children Act*. Is that review finished? Where is that at, because obviously you have covered some areas that I have raised today, which is about the rights of the child versus the rights of the mother. I have said before if all the education and all the attempts to stop a mother drinking have not worked, has the state got a role to play in protecting the unborn child? We know if the mother keeps drinking the child is more at risk. I suppose it relates to your department because simply you are in the care and protection of children. Where has that review of the act gone?

Ms CARNEY: The act is variously reviewed and has been for some time, and I cannot see that changing in the near future. If I understand your question to be asking where, in relation to unborn children is the legislative responsibility of our department, then I can indicate to you that it will be part of a review probably by the end of the year. However, last year, in fact in 2012 I think it was, maybe 2012-13, there was widespread consultation about many aspects of the bill. You will recall it was followed on from the Board of Inquiry and considered the effect on unborn children and what the department could do about it.

Now, in this context in particular for instance, the department was receiving some notifications that there were drunk women, who were pregnant, acting irresponsibly. Now that created a difficulty for our department because the current legislation says that we can only have investigations in respect of investigations in respect of children, not unborn children. There was some consultation at that time and not surprisingly there were quite polarised views that came from that consultation.

There were some people who you would expect would say, 'We must protect the unborn child at all costs and therefore we want the statutory child protection agency to investigate any notifications of concern'. The other one was to what extent do you interfere with the rights of a woman to drink, albeit drink irresponsibly, while pregnant? The effect has been that we cannot investigate unborn children. There is a real limit, as I think there should be, on our ability to embark on investigations in respect of unborn children. So there will be

some changes that will make it procedurally neater for us to accept, formally, notifications that we currently accept. We will not investigate those matters. For an investigation we need a child, as opposed to an unborn child.

For the notifications that we receive in respect of unborn children, we open what is called a family support case and we work with NGOs, other service providers, to encourage those women voluntarily to receive the sorts of services that are on offer. I know that is a long-winded answer to your question, but I think it is the best answer I can give you.

Mr WOOD: I suppose what I am looking at is that I understand where you are coming from and it will be polarised. If all things are being done by the Health department and various women's groups and whatever to help a mother understand that drinking is going to affect the unborn child, and the mother keeps drinking, regardless of all the assistance and advice she has been given, the government knows from its own scientific knowledge that there is a very good chance that child will be affected by alcohol. When the child is born, it is affected by alcohol. Has the government got a duty to step in so that the child at least is not born with FASD or it has limited the damage, because the child will be born?

Ms CARNEY: Are you suggesting that the statutory child protection agency should remove that child at birth?

Mr WOOD: Well, you mentioned it. No, you did not say that, but you mentioned yourself that there is a possibility – and that will create another debate – but you mentioned in here how we already remove people who are affected by alcohol and put them into mandatory rehabilitation. You might say if this is the last resort, is it the role of the government to be the last resort if it needs to protect an unborn child which has got no legal protection? It will be born and it will be damaged, if the government does not step in and try and do something about it. I know it is complex. I have been wondering where government has a role in this.

Madam CHAIR: Does the state have a role to protect that unborn child, but they cannot protect the unborn child until they do something with the mother? I think that is what Gerry is trying to say.

Mr WOOD: Because they know it will be born damaged, that is what I am worried about.

Madam CHAIR: So they knowingly …

Mr WOOD: Allow it to happen.

Madam CHAIR: … allow it to happen.

Ms CARNEY: Well, it is something of a philosophical debate, I suppose, member for Nelson. I think we as a society need to be careful about the extent to which governments step in. Yes, the government, as you put it, will know …

Mr WOOD: I will call it a state, so it not just …

Ms CARNEY: … that child will be born very damaged as a result of its mother having consumed a large amount of alcohol when pregnant, but the mother and the mother's family and friends will also know, must know, surely know, and if they do not know then the government has an even greater responsibility to increase its education campaigns. We have all lived in the Territory for a while, we have all seen various alcohol education campaigns come and go. I guess all of us ask how successful have any of them been, but I think the people drinking have arguably a greater responsibility than governments.

Mr WOOD: Governments also have a role when someone drinks too much; they take them off the road, and say they are not to drive any more. The lady who has been picked up time and time again and taken to the sobering up shelter, we take her off the road and hopefully help her because - again I am always careful about the word 'criminalising'. I think you have seen government's intention is from a compassionate point of view and here the compassion is both for the mother and especially the unborn, which is the one that cannot speak. I do not personally have a problem, but I would imagine it is the last resort and that is the bit - I know as we have heard today it is only a tiny bit of the population, but we still have to deal with that.

Ms CARNEY: I guess another way of putting it is it is not a competition about who has got the most responsibility when it comes to tackling something like this. Certainly, we need some form of intervention for the greater good to ensure that we stem what seems to be the rise of kids, certainly from our point of view in our child protection system, with FASD. It is up to others to determine how that is done. We have said we referred to the alcohol mandatory treatment program in our submission. That may be something that, provided that there is a relevant trigger, might be the sensible intervention for women who are pregnant and drinking. But really it is a matter for others.

Madam CHAIR: On page five you state that an unborn child is legally not considered a person in the Northern Territory. Are there places where an unborn child is considered a person legally in Australia or overseas?

Ms JARRET SIMS: Not sure.

Madam CHAIR: I know when a mother has a miscarriage and the child is of a certain age it gets a birth or a death certificate.

Mr McCARTHY: 20 weeks.

Madam CHAIR: So is there any jurisdiction where the child is considered a legal person?

Ms CARNEY: I do not know. We could take that on notice.

Madam CHAIR: Okay.

Mr WOOD: That was the case in New South Wales, of course, where it has been brought back, because of the woman who lost her child when she was hit by a car. It has just been passed in New South Wales earlier this year, so that child unborn had some rights. I cannot give you the details. It was a fairly controversial debate, but the law was passed.

Ms CARNEY: Would you mind repeating the question so that we can ensure we have it right?

Madam CHAIR: Your submission says on page 5:

An unborn child is legally not considered a person in the Northern Territory.

So my question is: are there jurisdictions in Australia and overseas where an unborn child is considered to be a person?

Madam CHAIR: I know it is probably a legal question with all that ethical, religious thing as well, but it is just the way the statement is written. It is not legal here in the Territory which raises the question: is it legal somewhere? The next question I was going to ask – you mentioned in your comments:

The department has no legal authority to compel the mother to accept assistance.

So my question would be: do you think the committee should consider where the department does get legal authority to compel the mother to get health or medical

assistance, and I think that was part of your question? Do you think the department should have that authority?

Ms CARNEY: To compel …

Madam CHAIR: The mother to get assistance.

Ms CARNEY: It is not really for our department to compel people to get assistance. We act on the notifications that we receive. There is, if you like, a filtering process, filters through after various assessments, and it gets to a point where they are either screened out, screened in, substantiated and so on, so I am not sure really how that would fit.

Madam CHAIR: I guess it is probably the mandatory line which I am not really pursuing.

Mr McCARTHY: As a point of reference, there was a debate in the Legislative Assembly around the issuing of a birth certificate through Births, Deaths and Marriages and a date of 20 weeks was defined in that debate. The parents in question were asking for the issuing of a recognition of the child's birth pre 20 weeks. That was an interesting debate here in the House.

Thank you for appearing before the committee and it was a great opening statement too, may I say, because you have really put a lot of qualitative data around the debate that we have been having today. It seems that we are really struggling around definition and diagnosis, and those areas and the qualitative data that I picked up in the opening statements certainly pointed to an alcohol saturated environment. There is a very high risk that there will be foetal alcohol syndrome and Foetal Alcohol Spectrum Disorder, so it identifies that broad spectrum. There was almost a hint of estimates there, Jodeen, and I thought, you on the other side of the bench, any chance of a political come back?

Ms CARNEY: Never go back, member for Barkly, never go back.

Mr McCARTHY: You certainly look good on that side of the bench.

Ms CARNEY: Send me a curly one.

Mr WOOD: What is it like on the other side?

Ms CARNEY: It is very interesting actually.

Mr McCARTHY: No, no, we will strike that from the *Hansard* record.

Ms CARNEY: Not quite the adrenalin rush from over there but very interesting.

Mr McCARTHY: I think that is really important information for the committee when you process it. Now I am especially interested in this production. I have only briefly scanned it, but if I had had it 40 years ago I might have had a distinction in my child psychology assignments, you know. It goes from some very simple concepts and language to some very high level language. For *Hansard* I will just read out a little bit in terms of the Tune into Little Ones extra concerns and how to help. In the section on hygiene, helping families with their little ones hygiene and physical care, it says

Make sure that there is a clean space for the little one to play and sleep.

The third dot point says:

Find out if there are any dogs or other pets in the house that can impact on the child's safety or hygiene.

So it goes from that level to health and development, immunisation and information around development checks at four weeks and six to eight weeks and just a quick scan – great.

So having the opportunity to influence government and policy and resources, what are your guys' plans to actually get this into your clients' arena, start that education process and deconstruct this simple language and high level language and - you have got it from me - turn it into an interactive experience with the family?

Ms CARNEY: Since you raised my former career, member for Barkly, I am almost tempted to say, 'thank you, Dorothy', because what we have done with that was that it was done – a lot of people contributed to that and it was in existence prior to me just getting to DCF. What was clear though was that give or take a couple of exceptions, it was pretty much stuck in Darwin Plaza. One of the key advocates, Meron Looney from our department who has had a lot to do with this – we had a chat and she has now been moved for six months to another area of DCF called remote services. Not surprisingly remote services has staff that travel all over the Territory and part of Merrin's task is to tell all and sundry in all of our different units in remote services all about Tune into Little Ones.

So she has been there for a couple of months. She has pretty much been requested by me to disseminate that far and wide, because in an agency like ours - to a large extent it sounds flippant - it is probably a good way of putting it: we really catch the kids at the other end and anything we can do at that preventative stage, or early intervention stage, is not only very useful, but provides our workforce with a bit of spring in their step. It is a good thing for a workforce and a statutory child protection agency to do, to go to front end stuff. That is a good example.

Ms JARRETT SIMS: Can I just add that the resource is developed primarily for DCF workers across the DCF workforce and also to family support workers? There were a number of training sessions, for want of better words, across the Territory to introduce the kit and to support workers in how to use it. It is not a kit designed to sit down with a family and go 'Okay, you have got this problem, this problem, this problem'. It is to resource the workers so that when they are working with a family they can reflect on what they are seeing and hearing and use that as part of their assessment, their supports or whatever the next stage is with that workforce.

Ms CARNEY: It also invites working with other agencies out in the bush, and as you know, it is everything from the local copper, the local teacher and so on. It is at that level as well and our remote workforce is very diverse. Remote area Aboriginal protection workers, child safety wellbeing workers, are embedded, if you like, in remote communities, so it becomes an invaluable resource for them as they spread the word.

Mr McCARTHY: Can I ask, was it an interagency collective to develop this resource?

Ms JARRET SIMS: It was developed primarily in DCF but in consultation with a range of other organisations externally, Aboriginal organisations, Department of Education. It was widely consulted in its development.

Mr McCARTHY: Well, you are certainly setting the pace there because a lot of discussion this morning came out about the silo effect and how really to address FASD and FAS in this interagency collaboration. I just say, as a personal point, do not underestimate the strength of this material sitting down and working with dysfunctional families. It is great to skill your workers up, but my point about interactive experience is that we have got to make sure that we do not end up with a poster on a clinic wall. I just have quickly scanned this stuff and this presents a really good opportunity, so congratulations on the material, but now it is about how you work it in the field. We have heard one idea: staff professional development. This has some real opportunities in an interagency, as you said.

Madam CHAIR: We are 15 minutes behind, so we had better wind it up. Thank you for your time today. Thank you for your professional contribution and expertise. We will send a copy of the *Hansard* for you to correct if there are any mistakes. Thank you very much.

The committee suspended.

Madam CHAIR: Welcome. Thank you for being here. I welcome you to the table to give evidence to the committee and appreciate you taking the time to be here.

This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee applies. It is a public hearing and it is being webcast through the Assembly's website. A transcript will be made for the use of the committee and may be put on the committee's website. If at any time during the hearing you are concerned that what you might say should not be made public, ask the committee and we can go into a closed session and take evidence in private.

For the record, could you state your name and the capacity in which you appear.

Mr DAVIES: Thank you, Madam Chair, Mr Ken Davies, Chief Executive, Department of Education.

Ms BAYLIS: Vicki Baylis, Executive Director School Support Services, Department of Education.

Madam CHAIR: Do you have an opening statement or just some preliminary comments you want to make?

Mr DAVIES: We have some preliminary comments. Following on from the CEO of Children and Families, we sent a submission up, Madam Chair. Do you have it?

Madam CHAIR: Yes, we do.

Mr DAVIES: We did not hear the number of children Jodeen was talking about, but from our perspective the agency started to see this as an issue and has started working to get on the front foot in relation to foetal alcohol syndrome spectrum disorders. I brought Vicki with me today to explain what we are doing in resource development and the work we have been doing in Tennant Creek just to make sure, when children come into the system with a diagnosis, we are managing and handling those children as effectively as we can in an education environment.

It is fair to say the numbers - when you look at our numbers with 27 children diagnosed - the diagnosis remains a challenge for us and we are convinced there are many children in our system …

Madam CHAIR: Many more?

Mr DAVIES: … in classrooms who are not diagnosed with people making assumptions around, but the diagnosis would certainly assist us. Children at the lower end of the FAS spectrum present the greatest challenge to our system because …

Madam CHAIR: Meaning those not so seriously affected?

Mr DAVIES: Yes. You can easily identify the seriously affected kids. Some are in our special schools so they have disabilities that come with it as well, but for those children in classrooms - classrooms are highly stimulating environments full of activity and action and for a child with foetal alcohol spectrum - an environment rich, active and very intensive is not necessarily the best environment for those kids in relation to their own learning.

For us the numbers diagnosed at this stage are small - 27 across the Territory. We think there are many more undiagnosed. Any child coming in with a disability is a challenge for the system. We want to make sure we are on the front foot around supporting the children and, of course, their families to get the best possible outcomes.

We welcome the opportunity to talk to you today about what we are doing in working with external providers and other government agencies to get on the front foot as we deal with something that happens in the womb but inevitably comes into our schooling system - children at risk.

Madam CHAIR: You end up with the end product.

Mr DAVIES: Yes. That is all I wanted to say in opening. We have provided a statement, and I might ask Vicki to explain how we have resourced and are supporting professional development.

Madam CHAIR: Before you do that, who tells you or the school that the child is FASD diagnosed? How does that get into the system?

Ms BAYLIS: It would normally come through a clinical diagnosis that is medical.

Madam CHAIR: How do they tell you? Who tells you?

Ms BAYLIS: We would often ask the family to seek a diagnosis. Some families have already received a diagnosis because other agencies or the family themselves have addressed the concern before they hit the schooling sector. In the schooling sector where we have young people presenting – particularly at the extreme end it is often in combination with the family and the Health department where we ask for a paediatrician to do an assessment. As I am sure you have heard, being able to access that support and service, particularly in our very remote communities, is a challenge at any point in time. It is also a lengthy process for a family and school to go through. That is why our numbers shared are only those with a formal diagnosis. Many of the doctors are reluctant, especially when students may be at the lower end, to attribute a diagnosis of foetal alcohol spectrum disorder.

In listening to Jodeen around the consistency of what are we talking about, what is the message we are trying to provide and how that help all of us would be a very useful outcome.

In response to this area which we know is underrepresented in the official data we keep on students, we are observing the behaviours presenting in schools. As a department we have established a psychologist position in Alice Springs to work in collaboration with a consultant as part of my team. –The consultant is Territory wide and she works on two particular projects. One is the FASD, and the second is pregnant and parenting, and we see some synergies in that.

This small group has been working with some of the NGOs, as well as some of the nationally recognised and internationally recognised resources, to adapt material for the Northern Territory schooling sector. Anyinginyi is one of the groups to receive a grant for this financial year to work with us because they have a whole lot of material particularly designed on FASD. We have also accessed material from Canada, which is a resource. The team also work within the schooling sector, and have been working with the Telethon material from

WA and some of the Kimberley material as well. There is a vast number of resources out there and we need to make it particularly pertinent and relevant to Territory schools.

It is not just our remote schools who have young people presenting with these behaviours; we have kids in urban settings presenting with behaviours that limit their capacity to engage in their learning that we could subscribe to this type of syndrome.

The challenge for teachers is these kids can be very linguistically capable. They sound like they should know a whole lot more; they are quite articulate young people. They will argue black and blue on the rights and wrongs and the justice of the world. While they are able to do that their social emotional maturity, their impulse control, their self-regulatory behaviour, their mathematical conceptual ability, along with the ability to stay on task and engage in learning is often delayed.

As Ken was saying, classrooms that are highly visually stimulatory are environments for example, artificial lighting – can overstimulate these kids. We need to help schools think about what they would change not to diminish the learning environment for all students, but to control that learning environment and make it explicit, make it very clear, systemised, routine, less self-direction for some of these young people and get them into a learning frame that is structured much more than a student who is a self-directed learner would.

Ms MANISON: This may be a very broad question granted we know the spectrum can be quite broad when dealing with children with FASD, but if a child is in a mainstream school in the Northern Territory, what other type of additional supports would they require in a classroom to help them have the best chance of being successful and pursuing an education? Is it a case where there needs to be individual learning planned for the child dependent on how extensive their issues are, or is it that you just need to have teachers and teacher aides appropriately trained to give extra support as required? What interventions does the Education department put in place in schools to support children with additional needs?

Ms BAYLIS: Given we do not have a diagnosis process and a consistent view around this, mostly it is around what these young people would present with at the lower end - not the kids with the high level needs who have multiple adjustments - they will present as kids that are not achieving at level or presenting with behaviour issues predominantly. The question you ask is around - depending on the presenting behaviour the child will have an educational adjustment plan or an individual learning plan, or it might be an individual behaviour plan that helps structure and scaffold. For kids in the mid-range, there may be additional assistant teacher time that comes in or special education support time that comes in. In some schools there will be groups of kids that come together for specific structured learning. That is a very small group structured, focused - it is not the whole class. Again, it depends on the number of kids, the type of presenting behaviour, whether it is around, 'I

have not managed to grasp these concepts in mathematics', or 'I am just a naughty kid and I can't stay in the seat'. That might be what it looks like and how it presents. The strategies you use as a teacher or as the support staff that work in that class is the work we need to do more of so it does not only get categorised as a behaviour problem - this child is naughty and we will suspend them or whatever it happens to be. It needs to be managed around a learning process and we need to be quite clear. These kids can learn, they are able to achieve; however, it is the type of approach you need to structure and scaffold and the sequencing of it so it is quite specific, routine, repetitive and expected from everybody who interacts with them. Me having a different approach to any of you or Ken is confusing.

Ms MANISON: What struck me today, as one of the big issues the committee has had, has been trying to pinpoint the extent of FAS and FASD. It has been really difficult to ascertain.

Ms BAYLIS: As a department we would have the same issue.

Ms MANISON: Clearly, you would welcome having better diagnostic tools in place so we can better ascertain the extent of the issue. It will make your life, as a department, much easier to allocate resources appropriately would you say?

Ms BAYLIS: It would be consistent around the types of work and helping teachers know the approaches they can take. It is not always around a resource issue; it is understanding the learner and what type of adjustment you need to make as a teacher so you can best cater for that child. Sometimes as a teacher you can do this within the resources you have.I just have to know this is what I have to do.

Mr DAVIES: Through the Chair, member for Wanguri, I think the issue is the earlier the system knows what is going on with the child the more capable we are of dealing with it. The earlier we can start the work - whether it is in preschool or transition - the better. An early diagnosis, or some consistency around diagnosis - you would expect, just on the sheer numbers and the issues, we would have more than 27 children identified. I was quite surprised with that number.

If you go to Acacia Hill special school and walk around with the principal, she will say that child has this disability but in fact is greatly affected because of foetal alcohol syndrome. It is drawing that line and working out how you get the diagnosis so you can get in early. Otherwise we are applying a lens that will be with some specialist support but at the school level - the schools will have to draw their own conclusions. As Vicki said, you have a skill set within your school which lets you customise a program and have an education-ready program for that child, but the diagnosis would help greatly.

Madam CHAIR: Are those 27 students primary school?

Ms BAYLIS: No, they are across the age cohort.

Madam CHAIR: It is high school as well?

Mr DAVIES: Yes, and non-government as well.

Madam CHAIR: Of both sets?

Ms BAYLIS: Yes, because we keep data on all schooling sectors.

Madam CHAIR: I did not go to it, but at the seminar at the university a mother gave a case study of her child. He was quite well-behaved in primary school, but as soon as the boy hit puberty he ran off the tracks. How do we know - obviously the answer is we do not know - there are not children in the primary school sector and their disorder is dormant and when they hit puberty it comes out?

Ms BAYLIS: We do not.

Mr McCARTHY: My first one is a parochial question for Ken. In quantifying your data by region, where is the Barkly region?

Ms BAYLIS: We do not have the diagnosis.

Mr McCARTHY: Does that suggest these statistics are out of regions that have special schools?

Mr DAVIES: No, these are children we have records of that have had an external diagnosis - a specific diagnosis around foetal alcohol syndrome. There will be a record of children in the Barkly region who have disabilities and they could well be in there, but the diagnosis will not have been specifically FAS.

Mr McCARTHY: It is a good talk about behaviour management.

Mr DAVIES: Sorry, it is possible they are picked up in the Alice Springs data. It is treated as the southern region, but we could check that, member of Barkly.

Ms BAYLIS: Those are Alice Springs only.

Mr McCARTHY: I thought it reflected special school enrolments.

Ms BAYLIS: No, they are both special school and mainstream schooling. Getting a formal diagnosis is a rare thing we see in a schooling sector. We may have other children with a disability and the diagnosis may be an intellectual impairment or a physical disability which may have come about because of this, but it is not the diagnosis we are provided with by the paediatrician or the psychologist.

Mr McCARTHY: It is good for the committee to hear about behaviour management, support, and the needs, and what I define as behavioural and emotional special needs, which is not necessarily diagnosed but you can see the scope. What is coming out in the investigation is the numbers around this and how we address it as a government and a society.

Some of the demographics being looked at suggest by 2017-18 up to 8000 Aboriginal children could present, at the age of five, into our formal school system. Some say 30% could be foetal alcohol-affected, and the committee is learning about this really broad spectrum. What planning is going on for that? That is an anecdotal demographic, but let us use a local example. Go to the AFL football on a Saturday in Tennant Creek and watch the kids under five run on to kick the football around quarter time and half time, and extrapolate that across the Territory and 8000 is probably a realistic figure.

Mr DAVIES: Member for Barkly, the data we look at is the Australian Early Childhood Development Index data. We also have a program called Families as First Teachers where we work with families, mothers in particular, and young children, and we have a partnership with the Menzies School of Health Research. I have not heard those numbers being quoted, but it is true that in the recent review of Indigenous education it was quite clear that index showed a large number of children are deficient on more than one element of that scale in the Early Childhood Development Index. If you have more than one you deficit in a range of areas - calculated around wellbeing, including social, emotional and physical wellbeing and you will experience substantial challenges at school.

Whether that is all related specifically to alcohol or not, it is fair to say that report makes it pretty clear there are substantial challenges coming through with young Aboriginal children,

particularly from very remote locations, coming into our system because they are behind in the early development index. How much of that is attributed to alcohol it does not specify.

Mr McCARTHY: As a general rule of thumb, when we are talking about the possibility of that high support needs cohort - generally we could all agree the higher support needs of the mainstream and what our urban schools are dealing with – is there a focus on addressing these needs? Is this in our planning and will it pick up the FASD and foetal alcohol syndrome issues as well?

Mr DAVIES: We will have to, around that review, put in place some specific responses around student wellbeing and getting some system coherence around that. In relation to the work we are doing specifically around foetal alcohol syndrome, we started work in 2011 specifically, but it is fair to say it is really recent. We have been focusing on managing the behaviours not necessarily the diagnosis and specifics around dealing with specific disorders that are coming through. They have been, in the past, left to special schools and special units. We are now starting to realise these kids are presenting in mainstream classrooms and have been treating them - going to Vicki's point - as a behaviour challenge, not necessarily their condition being a consequence of what has happened in the womb.

Mr McCARTHY: I also picked up refreshing ideas about what I define as alternative pathways so the mainstream learners can continue their learning and the class does not focus on 90% crowd control and 10% learning. What are the infrastructure implications around that? It is refreshing to hear that and you are definitely on the right track.

Mr DAVIES: Vicki, it goes back to that personnel infrastructure. You might like to point out a couple of the resources and show the committee as well.

Ms BAYLIS: The infrastructure stuff for us is more around what we add to the classroom. It is about the visuals on those sorts of things and being mindful we do not have - if you walk into some early childhood classrooms they are brilliant places so full and rich, and there are millions of things you could look at and engage with, but for these kids that is not necessarily always the best learning environment. It is about being mindful of the group you are teaching this year and how you are setting up the learning space, or how you engage that young person into that learning space so they are not overwhelmed. It is often not about how many rooms we have or those types of things; it is what we do in that room as a classroom teacher and a support teacher that makes the difference. They are the important parts.

It is about being able to, in a space, move into a smaller area, or it is about having the access with the students that is close and personal so they are focusing very deliberately on the person who is providing the instruction so you are not at the back of the room giving instructions and expecting the child to be paying attention because there are many

distractors between you and them. It is that type of thing that we can manage around an already existing resource and just being mindful of it.

The types of resources available - this is Anyinginyi's package we are working with. I am happy to share them with you but I cannot leave them. If you like, I am happy to get copies of them. They are both brilliant resources. One is more focused on the education component and how we work with classrooms, with teachers and with schools about looking at what they do to design the learning. Anyinginyi's is a more broadly focused education package about what is FASD, what does it mean to the brain, what does it mean and how do we work with families who are experiencing this? It is not just the child involved in this; there is likely to be other trauma that presents with that family group and the siblings so we need to be mindful of, in the education system, that it is likely to be more than one issue we are confronted with.

Mr DAVIES: In relation to the infrastructure issue, member for Barkly there is the architecture around how we manage this so we have somebody north-south working on it, which we did not have before. As you know, there is a range of special units and specialist places children can go to when they are diagnosed with high needs and high level disabilities.

In a system context, the responsiveness of a wave coming through early diagnosis would help us greatly in system architecture and our connection with agencies - like the previous agency that appeared - getting in early and making sure the behaviours manifesting have a grounding and are not just sheeted home to an individual who may or may not be behaving appropriately - there is some sort of diagnosis around it. The system architecture so the school system can respond is really important for us. If we have the early diagnosis then we can go in with the specialist support and help we need, otherwise we are making assumptions and developing that generic response that may sheet some of the behaviours to something like FAS.

Mr McCARTHY: I like the Families as First Teachers program. What is reflected there is off campus infrastructure. Some already exists within the towns, regions and the communities, but some will be required?

Mr DAVIES: Yes. The Families as First Teachers program largely has a remote focus. We are working with the Australian government to bring it into town camps. That is clearly a place there is lot of alcohol or access to alcohol in the regional centres. That is still part of where we have to go, and that goes to the response around the Indigenous education review and some of the things that happen outside the school fence we think we can do better around coordination and working with our other colleague agencies.

We will check the data around the Barkly, but it may well be that, member for Barkly, there is nobody at the local level in the medical profession prepared to make that diagnosis.

Mr WOOD: I ask about education, because it is the Department of Education. I know the Department of Education gets loaded with different things people want done, but in relation to secondary schools is there a consistent program, especially for teenage girls, relating to the issue we are talking about today which highlights the dangers? I know a lot of those girls, especially around Christmas time, head into town for the party and I suppose they drink a fair bit and sometimes get up to more than drinking. Is that type of education program part of the school curriculum? From the primary school level, is there an opportunity to promote it from the mother's point of view? We heard today if a mother has had a foetal alcohol disorder syndrome child it is likely the next one will be.

Mr DAVIES: Yes.

Mr WOOD: Is there an opportunity, when the mother comes to school with the child, to piggyback on some education for the mother when she turns up at the school or through the school newsletter? Not directly, but using the primary school a means of more education.

Ms BAYLIS: Can I answer the second one first? Yes, it is part of the formal curriculum around sex education that secondary schools are meant to provide. In our very remotes we have had a strong, positive working relationship with the Department of Health around adolescent sexual health education done in partnership with Health and community so we are addressing how community wants that discussion to be progressed. That has been largely funded through Health. That is up for review and it is one of the things we are in discussion with Health about - what we will do to redesign, within the resources available, that particular program.

In some communities the discussion is one where the community wants it to be gender separated. There are quite specific things they want to own and other things they expect us to teach, and that is all being clearly negotiated in community. Other communities are quite clear that they see this as their primary business and there is an agreement on what we will educate about because it is part of the curriculum. That particular program is then presented, depending on the capability and competence of local members within the workforce of our schools, within the clinics and within Health and the roving team with Health had been quite active in schools in working with our teachers as well.

That was a very strong program with very strong links and very clear education for boys and girls. We include the boys in this education around drinking as well, because we need them to understand because often that pressure is around, 'You need to come with me because this is what we are doing,' and that understanding for them that this is not

appropriate and the pressure and expectation of being 'my partner' does not mean that will be good for the baby.

That work has happened. As I said, it is about to shift slightly in the way we have delivered it previously and we are in conversation at the moment about how that will look.

Mr WOOD: In primary schools?

Ms BAYLIS: The primary schools around promoting - it is not something we have done formally and it is an opportunity. It is a conversation. Because we do not have that consistent diagnosis, consistent language and consistent way of doing things, where I have seen it happen has been through the families and schools together - conversations that have often been facilitated with the school through an NGO. That partnership is very strong, but it is not a universal every family in the school participates. That has been a very useful program which has been supported and has built that conversation. However, it is not something we have systematically done through newsletter or through an approach mainly because we do not have a consistent understanding set of languages and diagnosis at this point.

Mr WOOD: Gerry was talking earlier about silos and trying to spread the word around. A lot of discussion today has been about early intervention. FASD will cost the department a lot of money, if I want to be cruelly economic about it. As much as it is very much a human issue as well, and to some extent it is an early intervention from your perspective, but if we can try to use your facilities to be part of a process of trying to relay the important message that alcohol is no good when you are having a baby then maybe we can save some other kids.

Mr DAVIES: Given we are coming in on the end where we are trying to deal with the issues presenting to us, we would be very interested in participating on something on the other end which is about prevention in some sort of systematised way.

Mr WOOD: Even if it was just …

Mr DAVIES: As the member for Barkly said, if it was through the Families as First Teachers program - there are ways you could layer it in. Schools will play their bit here. If the committee was to come through with some recommendations that had some focus around us doing that we will get behind what you think is appropriate and take advice.

Madam CHAIR: I am conscious of the time because of the next witness. We have until about 4 pm before we lose her window of opportunity as she is on a video conference. Gary, if you have one question?

Mr HIGGINS: The family first issue has come up at Wadeye before. Wadeye has a Catholic school, and I will come back to that. Another issue that came up today was what information is being passed from department to department. The Health department was not willing to give the Catholics information with regard to newborn children. That problem had to be solved. From talking about all this stuff and strategies and everything, will there be some communication between not just government agencies but also across the schools because these kids move from one to the other? It is a concern I have.

Mr DAVIES: I will let Vicki answer that. In the curriculum area and these development areas we are all in this together, member for Daly, but I will let Vicki explain.

Ms BAYLIS: I will let Ken answer the Wadeye FAFT one for you, but if I come back to the sharing of data and the programmatic approach, my area is all schools, government, non-government schools together, and we work very closely on a whole range of issues from the curriculum as well as students support. While the Catholics will have specific project officers and work they do, we are connecting, very regularly, at both the officer level and at my level as well so we understand what is going on and we beg, borrow and steal each other's good ideas. Because we are a very small jurisdiction that sharing is a part of what we do within education. Health does share and has a precedent of sharing information with Education, but it predominantly starts with babies when they are born around hearing.

There is a capacity for us to build on that so our support team and the hearing team - because all newborn are checked for hearing. If there is any suspicion or any understanding we might have a child that is deaf or with a significant hearing impairment, immediately our team are also part of the small hearing team or a part of that conversation with families. There is a capacity for us to build on pre-existing work if that is one of the recommendations that comes.

Mr DAVIES: Member for Daly, with the Wadeye situation and the sharing of data, there is no doubt that if you operate at the Chief Executive level people will say, 'You should be doing that', but once you get down into agencies sometimes there are protocols around privacy and that sort of thing where barriers occur. I cannot speak specifically for the Health department, but where we have education providers and people who need access to our data we run a very careful process around it, but it is pretty much there for everyone's use. From our perspective, we need to be sharing and need to have better data sets because we all run records on children and the Health department has the earliest record. It is at what point it connects into the education system. The beauty of the Families as First Teachers program is it allows for those connections to happen very early.

As Vicki is saying, we have existing protocols. If there was a recommendation that identification at a health clinic - that foetal alcohol syndrome was identified as a possible issue early, even if it was not a full diagnosis - if that could be flagged with us in the same way the hearing health issues are then that would be a good start.

Madam CHAIR: Thank you. We had better wind it up.

Mr DAVIES: I will leave it at that.

Madam CHAIR: Thank you. We might ask you back or have more questions we want to put. Thank you for your time today and your professional advice and expertise.

Mr DAVIES: Thank you, Chair. If it is okay with you, I might do a little more work to look at the Barkly situation and find out what data we have in our system around the Barkly region - just to do a double check.

Madam CHAIR: Much appreciated. Thank you very much.

The committee suspended.

Madam CHAIR: Professor Elizabeth Elliott, I am sorry we are a little behind schedule. There have been many questions from some of the committee members, so thank you for bearing with us.

Professor ELLIOTT: That is all right. Can you hear me clearly?

Madam CHAIR: Yes, we certainly can thank you, professor. My name is Kezia Purick, Chair, and the committee members are on my right Gerry Wood, member for Nelson; Gerry McCarthy, member for Barkly; Nicole Manison, member for Wanguri, an urban area; and Gary Higgins, member for Daly; and the committee secretary, Russell Keith.

Professor ELLIOTT: Are you able to zoom in on yourselves?

Madam CHAIR: Can you not see us?

Professor ELLIOTT: As long as you can hear me. I may need to ask you to repeat a few things.

Madam CHAIR: Thank you, that is okay. Thank you for coming before the committee and we appreciate your time today and your patience. It is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee applies. It is a public hearing and is being webcast through the Assembly's website. A transcript will be made for use of the committee and may be put on the committee's website. If there is anything during your hearing or presentation you feel should not be public we can go into a closed session and make it private.

For the *Hansard* record, could you state your full name and the capacity in which you appear today?

Professor ELLIOTT: Professor Elizabeth Elliott. I am a professor of Paediatrics and Child Heath at the University of Sydney and a Consultant Paediatrician at the Sydney Children's Hospital Network at Westmead in Sydney and a National Health and Medical Research Council of Australia Practitioner Fellow.

Madam CHAIR: Thank you very much. Do you have any opening comments or statement that you wish to make.

Professor ELLIOTT: I applaud the initiative to have an inquiry into foetal alcohol spectrum disorder in the Northern Territory because, as I am sure you are aware, there are likely to be pockets of communities where there is high alcohol use and high rates of foetal alcohol spectrum disorders. Having had the federal inquiry, it is very good we are getting some follow-up at the state level.

Madam CHAIR: Do you know if the states have undertaken separate inquiries?

Professor ELLIOTT: I understood there was an inquiry in Western Australia, although whether that was specific to foetal alcohol spectrum disorders or educational disadvantage. I am not sure.

Madam CHAIR: Thank you, any questions?

Ms MANISON: I keep coming back to this point and am sure other members of the committee are sick of hearing me talk about this, but one of the aims of this committee is to grasp to what extent FASD exists in the Territory. We have had great difficulties with that, but it is clear that nationally it is a difficulty. From what I can see a lot of the work you have done has been around diagnosis of FASD, is that correct?

Professor ELLIOTT: That is correct. I run a clinic in Sydney for the diagnosis of foetal alcohol spectrum disorders and was also the senior paediatrician involved in the Lililwan Project, a prevalence study we were invited to do in the Fitzroy Valley at the invitation of the Aboriginal communities.

Ms MANISON: Would you be able to tell us about that experience and the work you have done around diagnosis? Do you think the Australian diagnostic tool being developed through the House of Representatives inquiry into FASD should be rolled out across Australia? You are also working with the diagnosis clinic in the hospital in Sydney? Can you tell us how it is working given it is fairly early days with that as well?

Professor ELLIOTT: I will start with the screening and diagnostic tool. Foetal alcohol spectrum disorders is a spectrum of disorders as the name implies, and when we are dealing with a biological model we have arbitrarily categorised foetal alcohol spectrum disorders into several different groups: foetal alcohol syndrome and partial foetal alcohol syndrome, which are characterised by physical abnormalities as well as learning and developmental problems, and then neurodevelopmental problems, which occur in children with alcohol exposure but without the physical features.

In the development of the diagnostic and screening tool we tried to identify what tools are being used to determine which category children fit in to. As you may be aware, there are several different criteria which are published in various guidelines. First, there are guidelines from the Centre for Disease Control, second there is the Institute of Medicine in the US, third there is Susan Astley's 4-Digit Diagnostic Code in Washington and, finally, the Canadian guidelines.

I am a bit biased reporting on the diagnostic screening tool because Carol Bower and I are the two chief investigators on that study. We decided to evaluate what was being used internationally and pick what we felt was best suited for Australia. It had to be practical and useful to clinicians and provide good, reliable information. We have decided to go with the Canadian diagnostic criteria which are published in their guidelines, although we also use tools from Susan Astley's 4-Digit Diagnostic Code.

It has been indicated that we will get funding to start implementing the screening and diagnostic tool, and it will be valuable to have something consistent and standardised across Australia. It will help increase the capacity of health professionals to recognise and diagnose these disorders.

The next question was about my practice in Sydney. Unfortunately, I only have pilot funding for a clinic in Sydney from the Foundation for Alcohol Research and Education. I see patients as a single practitioner, a paediatrician, and do developmental and physical assessments on those patients. Then I rely on assessments from speech therapists, psychologists, etcetera, and then put the results together and make a diagnosis and write the appropriate report.

In contrast to that, in the Fitzroy Valley we convened a multidisciplinary team of health and allied health professionals and worked together over an eight-month period in Fitzroy Crossing and the surrounding 45 very remote communities. That indicated to me that, as we know with any complex chronic disorder, it is much more efficient, effective and supportive for clinicians if there is a trained diagnostic team who can work together and, at the same time. It facilitates communication and saves time and cost. It is very supportive for people, particularly working in remote settings, where otherwise they might be by themselves. It is efficient in that, having put together and discussed everyone's findings, we are able to make a diagnosis anddevelop a management plan. In that particular study, we fed back immediately to parents and carers, teachers and health professionals and then provided the information to go into the electronic medical records.

From the Northern Territory's point of view, if you are looking at a diagnostic capacity, it would be very valuable to have a team of people who could work together, who were trained together and who could visit communities and efficiently examine children and come to a joint conclusion about a FASD diagnosis, or not, and an appropriate management plan.

I think they are the three questions you asked.

Ms MANISON: Yes, sorry, it was a long question, but thank you.

Madam CHAIR: When you talk about the diagnostic team, is that a team under the management of the Department of Health, or is it something that sits itself which has Department of Health professional medical experts, etcetera? I am trying to work out how it would work?

Professor ELLIOTT: The Lililwan Project was initially funded by a philanthropist, subsequently by FaHCSIA and the Department of Health and Ageing and subsequently an NHMRC grant. We paid for the training, travel, accommodation and everything else that went with that team. It would be a cost saving to government to run paediatric services in remote areas using those types of teams. If you have an occupational therapist coming in one week, a physiotherapist the next week and a paediatrician the next week it is extremely difficult to communicate properly – and they are all overloaded.

Furthermore, it is very difficult in remote settings to keep medical staff because of the problems of isolation. It is a very supportive way to work as well as an efficient way.

Mr WOOD: I am not sure if you can answer my question, but alcohol is a teratogen. Is that a chemical or a reaction alcohol causes? What is it?

Professor ELLIOTT: It is a toxin. The chemicals within alcohol are toxic to the developing embryo and foetus, and that is what the word teratogen means. We know it can have a range of effects: structural birth defects such as in the heart, the kidneys, the joints, the lungs, ears and eyes, but it can also damage the brain. It is the brain damage that subsequently leads to learning, behavioural, mental health and other problems.

Mr WOOD: Without it can alcohol be alcohol, or is it an intrinsic part of alcohol? Can you have teratogen free alcohol or is that what makes alcohol?

Professor ELLIOTT: No, alcohol has an inherent toxic component. If you and I drink alcohol we know it damages our liver, damages our brain and substantially increases our risk of a whole range of cancers. It is a toxic substance, but it is particularly toxic to the vulnerable developing foetus because there is rapid cell multiplication and development of structures at a very critical time. In us it kills existing cells, but in the foetus it can interfere with the development of the structures and function of organs.

Mr WOOD: Thanks.

Mr McCARTHY: We have terms of reference and are a committee reporting back to the Northern Territory government, which wants to progress work in this area. Through the committee process we have heard lots about early intervention and that prevention is better than a cure model. I ask for your opinion because you worked in the Fitzroy Valley so you have an understanding of the Territory and its massive geographic area, small population base, limited resources and all the dynamics around regional and remote communities.

Would it be fair to say a recommendation to government for intervention into children affected by alcohol could be a generic approach over the next five years to look at our agencies - our child protection, our health and our education - and try to create systems that will intervene into the behaviours and issues these children will present with? We are a long way from Westmead and the south eastern states that have the services to coordinate service delivery. I am looking for something that will be an interim solution to start the Northern Territory heading down this road.

Professor ELLIOTT: You are right in saying prevention should be what we are aiming for in the future. Once a child has organic brain injury you can modify their outcomes but not prevent adverse outcomes, so that is the first thing. The second thing is there is some degree of urgency in this. Our Aboriginal colleagues from around the country will say, 'Alcohol is decimating our communities and we are particularly worried we are losing the next generation to alcohol', so prevention is a major issue.

With regard to the issue of service delivery, as I implied in my previous answer I work in a big tertiary children's hospital but my capacity for diagnosis and management for this disorder there is actually less than we were able to achieve in a very remote setting in the Fitzroy Valley.

You can recommend to your government that it looks at training up multidisciplinary teams who not only would have the capacity to diagnose foetal alcohol spectrum disorder or any other neurodevelopmental problem, but will also deal with health issues. When we were in the Fitzroy Valley we would opportunistically treat pneumonia, lacerations, abrasions, skin disorders, asthma or whatever we came across. The multidisciplinary approach is valuable, and if you have an opportunity to recommend something it should be that a child health team work together and provide services throughout the Territory – it is both supportive to them, efficient and I am sure cost effective, and they would not just be looking at foetal alcohol spectrum disorders, they would be looking at a whole range of other developmental and health problems. That is the way I would be going.

The other issue is that we have done a prevalence study by looking at every single child in two age groups in the Fitzroy Valley. That was nearly four days of assessment per child and sounds a huge amount if you are proposing that in the future. I am not suggesting you need to see every single child in your setting, but perhaps when you have the screening tools available, the opportunity would be to screen kids in schools at the early primary age and identify kids in whom the teachers and the parents felt there were significant problems and then get your team to do a thorough evaluation on those kids. Whatever their problems are, and whatever the cause of their problems, it will be cost-saving to health, education and disability services etcetera in the future if they can be identified early and offered opportunities for remedial education and health services etcetera.

Mr McCARTHY: Thank you.

Madam CHAIR: Professor, when the child is born, assuming the mother said she did not drink but she did - forget the mother for now - how early after the child is born does a professional medical expert like yourself say, 'Yes, I think this child has foetal alcohol syndrome or it is on the spectrum' There might be the physical things, but let us assume there is not. Is it only when they get to about three or four years you start to think something is not quite right?

Professor ELLIOTT: Yes, you are identifying the difficulty of the stage at which the diagnosis can be made. If you have a mother you know drank a significant amount of alcohol during the pregnancy, that child can be monitored for developmental outcomes. You can do developmental screens in young children and look for delays in their motor milestones etcetera. t The children with no physical features are much more difficult to diagnose until later when they can be tested.

Obviously some red flag signs can occur in children with and without foetal alcohol syndrome like prematurity, low birth weight, small head circumference, irritability after birth and the facial features which can be recognised at birth or soon after. Quite a number of children who have the neurodevelopmental problems without the facial features do have other minor physical anomalies. It is a complex answer, but the key thing is to be alert. Are there any red flags that might suggest a follow-up? If you have the history of alcohol exposure then that child needs to be properly assessed and followed up.

That comes back to the issue that all our GPs and primary health care workers need to be asking about alcohol use and identifying alcohol use before women become pregnant ideally, because it is often too late once pregnancy is identified. Often people have been drinking for that first six or seven weeks before they realise they are pregnant.

Madam CHAIR: Perhaps one final question, we have heard today a case study of a mother whose child was pretty normal, went to school, grew up but as soon as the boy hit puberty his behaviour changed dramatically which was related to the drinking of the mother. Is there much research done, has any research been done, or is it just a dormant issue that we have not really come across or dealt with much in society that it might not present in primary school, but as soon as the child hits high school and puberty suddenly it all bursts out?

Professor ELLIOTT: It is highly unlikely that someone at the age of say 14 will have their first problem due to alcohol exposure in-utero. It is far more likely earlier problems have been unrecognized or attributed to something else, or that alcohol exposure has not been recognised. For example, we know there are lots of kids with ADHD, kids with oppositional

defiant behaviour, kids with conduct disorder, a whole range of learning difficulties and quite often the question has never been asked. What was the exposure in-utero? Did the mother have a problem with alcohol? Often when you go back you find yes, that mother did have a problem with alcohol use, alcohol dependency or alcohol-related injuries or other incidents which have not been identified.

Kids sometimes get worse with age. If you have a learning difficulty you are likely, as you get older, to fall further from the norm of your age-related classmates. We know children with learning problems often develop problems in adolescence because of the lack of self-esteem and the lack of ability to achieve and become employed etcetera. That is quite often when the mental health problems – anxiety, depression – manifest, when they are compounded by drug and alcohol use in that child, and when they come in contact with the justice system. They are dealing not only with adolescence, but adolescence is occurring in a child who has some limited capacity.

Ms MANISON: Going back to the diagnostic tool you were referring to that you have used in the work you have been doing, do you see that as appropriate for both an urban and remote setting as well as an Indigenous and non-Indigenous setting?

Professor ELLIOTT: Obviously the diagnostic tests used by different clinicians will vary according to the age of the child. For example, you can only do an IQ test at a certain age, and if you are doing developmental screening only certain tests are applicable at certain ages according to the developmental capacity of the child. The tests used will differ according to the age of the child and it may be necessary to modify the test used according to the setting. For example, we were very careful in the Fitzroy Valley to choose tests that would be recognised by the Education department because different states have different tests they recognise.

In addition to that, we were interested and concerned about the potential for biasing our results by using a test that was English based. For example, for the IQ testing we used a non-verbal IQ test so as not to bias the child who might have English as a second language. There are variations in tests but the principle is the same. In other words, for neurodevelopmental disorder associated with alcohol, you have to have dysfunction or impairment in at least three domains of central nervous system function. What tests you use to evaluate those domains will vary according to the setting and the age of the child.

Madam CHAIR: Professor, thank you for your time today and your patience with us running a little behind schedule. It was very enlightening. We will send a copy of the *Hansard* draft to you to make sure everything is correct. If need be, can we come back to you at a later stage?

Professor ELLIOTT: Yes, I am available. I do not know when that would be?

Madam CHAIR: We do not know either. If we need to come back we will contact your office to see if we can talk to you.

Professor ELLIOTT: I am always available on the phone. I would say one other thing before I go. It is likely the high rates of alcohol use we found in our cohort in the Fitzroy Valley, which were over 50% during pregnancy at high risk levels, are likely to be indicative of what you may have in some communities - not all but some - in the Northern Territory. Understandably, we are finding high rates of neurodevelopmental and other problems in those kids. We have our data submitted for publication at the moment and would be very happy to share more detail of that if you are interested. That would obviously need to remain confidential until it is accepted for publication, but I think it is likely what we found in the Fitzroy Valley would be similar to what exists in the Northern Territory, Western New South Wales and Queensland communities where there have been high rates of alcohol use over many decades in remote settings.

Madam CHAIR: That would be good if you could. Yes, we would handle it confidentially. That would be much appreciated. Thank you very much, professor.

The committee suspended
