



LEGISLATIVE ASSEMBLY OF THE NORTHERN TERRITORY

12th Assembly

Select Committee on Foetal Alcohol Spectrum Disorder

Public Hearing Transcript

12.30 pm, Friday, 7 November 2014

Nhulunbuy Town Hall, Nhulunbuy

Members: The Hon Kezia Purick, MLA, Chair, Member for Goyder
Mr Gerry McCarthy, MLA, Member for Barkly
Mr Gerry Wood, MLA, Member for Nelson

Witnesses: The following people attended the Public Forum:
Ms Jennifer Peers, Darwin community Legal Service
Ms Tara Canobie, Nhulunbuy High School
Ms Sarah Mitchell, Nhulunbuy Electorate Office
Ms Lynne Walker, MLA, Member for Nhulunbuy
Ms Tracy Groom, DOE Arnhem Regional Education Officer (FaFT)
Ms Zoe O'Hara, DOE Yirrkala School (FaFT)
Katie Pemberton, Gove District Hospital
Ms Melissa Mills, Child and Family Health (TEHS)
Ms Johanne Carroll, Community Child and Safety Wellbeing Team
Mr Corey Bousen, Arafura Times

[Editor's Note: Sound inaudible between 12:47:00 and 12:52:57]

PUBLIC FORUM

A WITNESS: Can I ask what you have found? Is this the last port of call? The other areas would not have restrictions on alcohol.

Madam CHAIR: They all vary. Police are outside bottle shops in Tennant Creek and Alice Springs. The people, NGOs and health people in Alice Springs, whilst they disagree with the policy they admitted there has been a reduction in supply which then had a reduction statistically on issues of going to hospital, domestic violence, police call outs and so forth. There are restrictions in various ways in different shapes and forms, but they are not consistent.

Mr McCARTHY: It has to (inaudible) at various levels. It is from a community perspective, an Indigenous perspective right through the higher level medical perspective. In a general synopsis, we have found over many decades the issue of foetal alcohol syndrome and foetal alcohol spectrum disorder have not really been dealt, aggregated and determined by governments as an issue in our society and how we deal with it.

That directly relates to the education sector, which has not had support for special needs children and has been dealing with this on a spectrum of disorders - management support, cognitive impairment.

The medical professionals are lobbying that they need a diagnostic tool so they want investment in science and to be able to create diagnostic tools. The Aboriginal health services tell us they need serious intervention into maternal health and early childhood because this is one of the spectrum issues impacting on growth and development. The community is talking about alcohol misuse, social elements and how we deal with those.

There are different inputs and the Northern Territory government has to make decisions around that. The Commonwealth has allocated resources recently - \$9.2m - and it has to be decided where that investment will be best placed. We have areas interested in developing responses to foetal alcohol syndrome and foetal alcohol spectrum disorder.

We heard from the medical professionals foetal alcohol syndrome is diagnosed through facial deformities and very specific issues around the child. When we talk about foetal alcohol spectrum disorder, that is the broader spectrum of disorders often ...

A WITNESS: A low percentage have facial changes?

Mr McCARTHY: ... related to the autistic spectrum. This is a personal summary. What I get from the medical professionals is that it is such a wide spectrum of disorders and there are so many challenges in normal growth and development around children; they are not too worried about zoning in on foetal alcohol-affected children, they are dealing with the broader spectrum. When you talk to the schoolies - I was a teacher for over 30 years - I was fortunate because I come from a family that had been talking about this stuff in the 1960s. When I first taught in north western New South Wales I was introduced to foetal alcohol syndrome, so I have had a long interest in this.

In our education system, because it has not been diagnosed and appropriate strategies and resources applied over generations, the education system is very much behind the game. I will make a political comment; what we heard at the hearing in the Northern Territory makes me think they are now very concerned they do not have the human resources, the physical resources or the capability to deal with this, and it reflects what government is worried about. Government believes these numbers are on the rise and that is why it initiated this investigation.

Madam CHAIR: The Department of Education CEO said there were only nine known FASD kids in the Darwin school system.

A WITNESS: Who is diagnosing it?

Madam CHAIR: That is part of the issue. They are the students they know from diagnosis, which is from doctors, paediatricians and however they do it. When you asked what else we have found out, there is high probability a lot of children have been diagnosed with something which is not that, it is FASD.

A WITNESS: I have suggested this through the education of particular students, but to come up with a diagnosis is extremely difficult, particularly because we are working with Indigenous families. If a family has a diagnosis of autism, that takes a lot of parent driving going to doctors, going to paediatricians and doing all this extra stuff. It is very difficult working with community to get that same level of diagnosis. It is the same in autism. I work alongside autism and there are very few cases of Indigenous autism, but I do not believe it does not exist; it is harder to diagnose.

Madam CHAIR: That is a challenge for the medical profession and the school system.

Mr McCARTHY: Then it leads to Corrections. Some of the best research globally is coming out of Canada and North America. Their research relates to the Indigenous people of those areas, and they are finding this tragedy from in utero to early childhood to adolescents coming in contact with the justice system - they feel a lot of people in gaol relate to foetal alcohol-affected people. That has a direct link to our Corrections system and the concerns government has around that as well.

A WITNESS: Has any work been done on genetic links? Obviously, if you have somebody whose genetic makeup is affected by alcohol in utero, will the next generation be landed with it as well, even if mum does not drink?

Mr McCARTHY: The medical professionals talk about it as substance abuse that has an immediate impact in utero on the child's cognitive and physical developments.

A WITNESS: That cannot be passed on to the next generation?

Mr McCARTHY: I have not interpreted that in any of the sessions.

A WITNESS: It is not being asked. I contacted a few forums and have asked if it is possible because if the core of the embryo is being damaged - that has an effect on the rest of the body because it does not just affect the brain, it affects physical aspects as well. Why can those damaged genes not be custom to the next generation?

Mr McCARTHY: The medical professionals have been dealing with it as an effect on all the wiring – they talk about it as impairment in all those aspects of the brain function and development. They do not talk about it as impacting on the genetics ...

Mr WOOD: (inaudible) different parts of the brain (inaudible) genetic change because they do not have any cognitive ability to work out not to drink. (inaudible) Gerry said why a lot of people are in prison, and they probably do not know why they are in prison.

We had an example in Alice Springs where police or Corrections said someone could walk down the mall and smash a window and a policeman says, 'You're in trouble; you smashed a window'. The person is let out. The next week he smashes another window. He cannot see the problem because the problem was smashing the first window, not the second window. The second window was another window. That person does not believe he has done anything wrong because he is not smashing the same window.

Madam CHAIR: Strong, no consequences, and also, from the medical people, there is not a great fear. Little children can be bitten by dogs, and that happens here, but because they do not fear the dog they do not know the consequences. For example, if you tease the dog and pull its tail it might turn around and bite you. There is no acknowledgement that could happen. B will follow because you did A.

Mr McCARTHY: For me, FASD is preventable. That is what everybody says. I am not concerned about the genetic (inaudible) it is completely preventable.

Madam CHAIR: It cannot be cured. There is no cure.

Mr WOOD: If there is early prevention, as we heard in Alice Springs, how do you do it? How you get early intervention in the first few weeks after the baby is born? I do not know. There is hope, if early intervention occurs – there are programs (inaudible) Dr Boffa, that the earlier the intervention the more chance you have of making the impact of FASD less. If you leave it, especially into puberty age, you can make some changes but it is much harder.

A WITNESS: It is cognitive training - this is teaching (inaudible) autism type.

Mr McCARTHY: A very common theme that has emerged is it is not only intervention into good maternal health, but also very intensive investment into early child growth and development through centres, programs and professionals. The Aboriginal health organisations said if a child is impaired in utero and consequently suffers poor nutrition and all the other issues, including that trauma, it is continual setback after setback. Their clear advice to government is that is where the investment should be.

A WITNESS: Can I ask, tongue in cheek, if you will take on that advice and allocate funds?

Madam CHAIR: What happens - yes. We look at the final report, which is in draft form now, which has all the evidence and data. That report will be presented and debated in parliament. It will have a series of recommendations. From memory, one of the recommendations – I have seen the preliminary draft - is like the quit smoking campaign everyone knows about - children know about it, sporting champions push it - they have to work out a strategy to develop a similar program. Where it starts I do not know.

The report is presented to parliament, is debated and then goes back to government. Government will accept some of the recommendations. One of the report's recommendations will be - I hope it is okay but the committee has not signed off on it – for a floor price where if there is higher alcohol content you pay more.

A WITNESS: Yes, so there is a minimum price for a certain amount of alcohol. Right now, if you buy very cheap – a bottle of wine and non-standard drinks costs a few dollars and it is an easy way to get intensely drunk. If the person (inaudible) alcohol so rather than once (inaudible) if you raise the minimum price it is harder for people to consume huge amounts of alcohol.

Madam CHAIR: It costs more money therefore they buy less. They burn up their money quicker - people who consume amounts.

Mr McCARTHY: (inaudible)

A WITNESS: It is a bandaid.

Mr McCARTHY: Therefore, it has resulted in the education sector not having the resources to deal with special needs children. Governments have been ignoring this, and now we have reached the stage – I give credit to the Northern Territory government for putting together this committee to get some accurate research around it. Governments are really looking at the economic issues around this in our society, and when they are talking numbers they are talking - this is the very broad foetal alcohol-affected child, the classic child affected in utero that progresses through the system – about the \$2m child. This is taxpayer resources to manage that child through all their deficits.

A WITNESS: Not to the end of their life. It would be a hell a lot more than that.

Mr McCARTHY: This results in them ending up in the justice system and in prison. That adds another layer. The comment is good, and the cynical answer is now governments are really worried about the impact on budgets and they have to do something about this. Let us hope so.

Mr WOOD: It will probably have to be more than just the Territory. A lot of work has been done at Fitzroy Crossing. If you get the background briefing on Radio National, a report was done on Fitzroy Crossing which will give you a good indication. I think the University of Sydney or New South Wales, plus another group, have conducted long studies and been looking at the tools required to assess whether someone has FASD.

If you want an advertising program it has to be national. We do not have anti-smoking campaigns just for the Territory. When you look at current advertising for not drinking while pregnant, it is a tiny pregnant woman on the bottom of the bottle. It depends whether it is international wine or ...

A WITNESS: There is the TV one, and that is great advertising.

Mr WOOD: I think that is Imparja.

A WITNESS: Yes.

Mr WOOD: You do not see it in Darwin or around Australia.

Madam CHAIR: It is not in Darwin.

A WITNESS: Are you serious? (inaudible)

Mr WOOD: (inaudible) into the Territory. I am not saying (inaudible) the majority of people live in Darwin.

Mr McCARTHY: (inaudible) in Tennant Creek; Imparja television is a sponsor and that is why it runs. That is why it is restricted. It would be nice if Channel Nine in Darwin picked it up too.

Mr WOOD: I think (inaudible), but the Territory cannot (inaudible) differentiate whether (inaudible). The Senate has conducted an inquiry, if you want to look up the website. It was a decent inquiry and there were a lot of medical issues if people want to learn about FASD and its effects. We also do not want to be repeating other things - we have a report, they have a report - lots of reports. Somewhere along the line we need to make sure there is a logical national approach into this. There are some specific approaches, particularly in the Territory. I think a lot of this is Australia-wide as well.

A WITNESS: Before coming here today I asked a couple of colleagues what their thoughts were. I am a child health nurse locally for the Nhulunbuy population - not the remote - and nobody had FASD on their radar at all. We did some research and diagnosis and there is only foetal alcohol syndrome as an option to search. FASD – you cannot search it for a diagnosis. There were three diagnosed cases regionally. I think Lucas from Miwatj mentioned two and there is one other. It is really well under our radar to the point nobody knows if it is an issue or not because it is so underdiagnosed.

Ms PEMBERTON: I am a midwife and have only been in this region 18 months. I work at the hospital so I do not really have a great deal of insight into the community and what happens. Certainly, when antenatal, all women were asked about their alcohol intake and very few women spoke.

A WITNESS: There is a sense of shame for those mothers to admit how much they have been drinking.

Ms PEMBERTON: You sometimes see pregnant women here falling over, and our women have no shame about smoking. They are all downstairs smoking - I should not say all of them. If you are looking for someone they will be downstairs either still pregnant or have only just had their baby and will want to go down to smoke. In caring for the women here, this is my first exposure to Indigenous birth. Some of the women I have cared for do not seem to equate what they do in their pregnancy with what will happen to the baby later on. They seem to think the baby has come out, he is pink, he is screaming, he is happy and everything is okay. Despite everything they have done in their pregnancy and all the education they would have had about smoking, drinking and eating well, if the baby comes out pink and well then the baby is fine. They do not look at the long-term implications, which is obviously what this ...

Madam CHAIR: There is obviously a lack of knowledge and information. Do you think that is because they have left school early and/or the information is not delivered through the schools systems or community program?

Ms PEMBERTON: I do not know. A lot of our women - their numeracy and literacy skills are not good at all. I am not sure what happens in the community because that is where the bulk of our women come from. They usually come in to Nhulunbuy at about 36 to 37 weeks (inaudible) sit down. They come in and if they are well then they become boarders so they can come and go from the unit as they please, and they wait for the labour and the birth. I am not sure about what happens in the communities. Unfortunately, Lesley Franklin, one of the community midwives, is away at the moment.

A WITNESS: I think alcohol per se - the communities are dry; there is not a great deal of alcohol consumed. My partner works for the homelands medical service - they do not have any births, but of the pregnant women they have had very few drink.

A WITNESS: My husband has explained that for - we are talking Yolngu - they do not see sex as how a baby is conceived. Sex has nothing to do with conception of the child. It has to do with their mother country and the body itself is just a vessel for the child to pass through from country. That is why being born on country - that child was born here and that is where the child has come from. That is their cultural view. We have a different view where mother and child are joined, but theirs is not that way. It has to do with the country.

A WITNESS: Yes, we have been doing adolescent sexual education program in Yirrkala School, which takes you from preschool through to Year 12. The girls are often completely stunned at the idea you can get pregnant when you start to menstruate. They just do not get the connection ...

A WITNESS: They do not get the connection.

A WITNESS: We show them - we have jigsaw puzzles, we have all sorts of great things. We do it through games and make it fun so they want to come, and they do. They are desperate to learn, but they are really not sure about this. We tell them, 'Go and talk to your grandmother, your mother', but they do not want to talk to them about this kind of thing. They will tell them, as you just said, 'That is your tree, that is where you come from'. That is where you were born.

A WITNESS: You do not come from the body.

A WITNESS: Yes, that is right.

A WITNESS: Only teenage girls are being told that. As they start to become young women the grandmothers are telling them stories about where they came from. Then, these girls are coming to our classes and are a bit stunned, to say the least, when they find out.

A WITNESS: Correct me if I am wrong, but a young girl died out there recently from toxic shock.

A WITNESS: It was not toxic shock?

A WITNESS: No, there were a number of things. That was one of the things that went round as gossip. From what I can understand, the coroner has not finally reported yet.

A WITNESS: But it was not something she could take to her - it was the younger women, younger girls, who were looking after her in regard to her periods and everything, wasn't it?

A WITNESS: No ...

A WITNESS: I would rather not talk about it.

A WITNESS: That is fine. But it also sets up that, where the younger women are not talking. On this level, what we are talking about is they listen to their mothers and grandmothers. What they are getting is the song stories, which are not what we are talking about.

Mr McCARTHY: And all the protocols. It has been very interesting, right across the Territory. I have been trying to pepper in questions. As a male, that has not been very comfortable. I have been surprised to hear, and it was evident in witnesses today, because I was particularly interested whether Yolngu had anything different to what I have lived with for the last four years.

It was interesting there are two parallels. There is, of course, traditional conception beliefs. However, even women here today said 'but', then quoted the CORE education program and applied protocols to dealing with that. So, it is a good new story for government to know that, of course, all the cultural values have to be valued and maintained, yet Indigenous people have been telling us across the Territory, 'But you can do education and awareness throughout traditional systems, in non-Indigenous society, to teach people about these very important issues'. That is coming up pretty clear. I do not know – am I right?

Mr WOOD: That is very much about ...

A WITNESS: I just want to support what Joanne is saying because I also run that same program, the Y-Chat program. It is a slightly different environment because I work in the town school, but I support the Yolngu students within that mainstream environment.

I approach parents before I do this to discuss that this is what I am going to do: it is going to be a girls' class, it is going to talk about this and this. Most of the guardians I work with are grandparents, and these women are so relieved and so happy that I am going to have those conversations with those girls ...

A WITNESS: They do not want to do it.

A WITNESS: I say we go quite in-depth and explicit with everything, and they say, 'Yes, yes, yes!' We always have that separate men's and women's business, but even for a woman most of the Yolngu families

do not feel comfortable talking around the stuff that ladies, old ladies particularly, recognise needs to be talked about. They do not have the skills, the ability or cultural inhibitions that stop that from happening, but they know that it is happening. They really like the fact that I am going to sit down with these girls and talk about this. We also run Core of Life which involves a great deal - we have the FASD baby doll along with that. We have two babies, a healthy baby and a FASD baby, but we do not do that until Year 10. There would be some relevance in linking what we do with the adolescent stuff along with the Core of Life because sometimes by Year 10 a lot of Indigenous youth we are working with are really not engaging at school.

A WITNESS: We usually (inaudible) the Core of Life up here next week.

A WITNESS: Week 7.

Madam CHAIR: When you referenced teenagers or young girls being quite alarmed where this came from, is it the same for young men – a sexual act with a partner will produce a child.

A WITNESS: We are not allowed to - you have ASEP for girls - adolescence sex education program - and ASEP for boys. We are not allowed to see ...

Madam CHAIR: We need to ask the boys ...

A WITNESS: Yes. I have met with some of the male facilitators. One thing I was fascinated with is contraception is not in the male ASEP. It does not appear as a category. We have developed our own in working with some of the – the facilitators worked with senior men to talk about what is appropriate for the guys to learn about. You will see the young lads regularly doing this.

Madam CHAIR: Checking if she has a ...

A WITNESS: Yes, and if she has, 'We run' and that is the attitude. We are trying to break that attitude as well.

Mr WOOD: That was raised by the Anglicare person also. (inaudible) responsibility, respect and the right to say no. Everyone says you are an easy target, but that is not what this is really about, unfortunately.

A WITNESS: No, that is right. We get the police to help us with that and to lay it on the line. 'If you do this when she says no that is sexual assault, that is rape and you could be imprisoned. These are the consequences, so let us think of other ways we can handle this.' Chubba, the policeman, is fantastic with the lads and they are all a bit shell-shocked afterwards, which is good and does them no harm. Erica talks to the girls and does a great job explaining they can say no. We then talk about different ways we can save face but get ourselves out of that difficulty.

Mr WOOD: Getting back to drinking alcohol when pregnant, is the program that you through Core of Life you (inaudible)? I presume (inaudible)

A WITNESS: Yes.

Mr WOOD: (inaudible) Core of Life (inaudible) education people (inaudible) ...

A WITNESS: There is (inaudible), which is now the ASEP program. That was designed by women in Alice Springs and it has been accepted by the Northern Territory government, but I think funding for that is about to come to an end as well. That is essential because it teaches community women, non-community women like myself - all of those.

Mr WOOD: (inaudible)

A WITNESS: ASEP - adolescence sexual education program.

Mr WOOD: (inaudible)

A WITNESS: They are trained. Tanda and Jess train the trainers then support us. I had my training two-and-a-half years ago, but I still see them probably every six months. When I am developing the next set of training I give them a ring, they tell me about the new things going on, any new legislation, and new

interesting ways of describing something. They are really good. We would like to keep them please, and Core of Life is phenomenal. It really is good.

Mr WOOD: The (inaudible) about sex education is it is not all about that. Jason, from alcohol and other drugs said you cannot just - with FASD, because of the alcohol and all the other uses that come with it so (inaudible). It has to be a holistic approach making sure that has to be an emphasis, but do not just emphasise that while someone is bashing up their wife (inaudible)

A WITNESS: In both these programs there is input about what travels down that tube. So, if you take the food in, it will then go along that tube and it will go into that baby's belly. It will then develop that baby. If you are having trouble breathing because of all that smoking, then how will that little one's lungs develop? There is an awful lot of connection. You are asking the girls, 'If you eat healthy food what is that baby going to get inside your belly?' 'Oh, well, it is going to get healthy'. So, it is healthy food, nutrition, rest, alcohol, cigarettes, drugs, domestic violence, stress – we explain all those things impact on the baby, both inside you and when it is born.

Mr McCARTHY: Do you do sexually transmitted diseases?

A WITNESS: Absolutely. Yes, definitely.

Madam CHAIR: Is there high baby numbers in the region?

A WITNESS: No.

A WITNESS: The (inaudible) is very poor.

A WITNESS: Having said that, Milingimbi just got results – 10 teenage pregnancies in the school.

Madam CHAIR: In the school? Nhulunbuy High School?

A WITNESS: No, Milingimbi.

Madam CHAIR: Oh, Milingimbi. Because you are a feeder for (inaudible) said they come from (inaudible) ...

A WITNESS: Our Indigenous births are about the same, but our Balanda births have dropped off since ...

Madam CHAIR: Is this a (inaudible)?

A WITNESS: All of the girls I work with at the high school have an implant. It ranges from girls of 12 years old through to about 16 years old. That is done through the clinic either in community or Miwatj clinic and families - nothing to do with us at school. This is only what I am seeing - pretty much when the girl gets to puberty the family takes them to clinic and gets an implant.

Madam CHAIR: You have to get permission, I think, someone told us.

A WITNESS: The family has to (inaudible).

A WITNESS: The family. The grandmothers are happy to take the girls because they then see that as one more baby I do not have to look after. But the girls, unfortunately, see that almost like a cloak of protection and forget about sexually transmitted diseases. So, yes ...

A WITNESS: We do a lot of talking about that.

A WITNESS: We do a lot of that, yes.

A WITNESS: I am not sure of the truth in it, but the story on Milingimbi is that a lot of the young lads are digging those out of the girls' arms.

A WITNESS: I have heard, very much through communities ...

A WITNESS: Yes, I have also heard of them breaking, or snapping them.

A WITNESS: A boy wants to own a girl so they actually take it out themselves to make her pregnant. But that is only been rumour that I have heard.

Madam CHAIR: You have heard it, you have heard it, and you have heard it?

A WITNESS: Yes.

A WITNESS: Yes.

Madam CHAIR: So, it is not hearsay?

A WITNESS: I have heard it.

A WITNESS: The girls almost seem to be quite proud. Sometimes, they will come in, 'Look'. And they comment on it several times on that first day or two that it is a bit tender and sore. It is almost like they see it as a bit of an initiation-type process; 'now I have this implant ...

A WITNESS: It is, apparently, just as effective on your inner thigh. The girls are offered that choice, but they choose to take it ...

A WITNESS interjecting.

A WITNESS: ... because it would not be seen on the inner thigh.

Madam CHAIR: As long as it is done (inaudible) ...

A WITNESS: They will not know, someone touch – going down there.

A WITNESS: That is a symbol of growing up.

A WITNESS: If they wanted to keep it private, and all that, then they have that opportunity.

A WITNESS: One thing I have found just from speaking to some of the local women I work with in the community, they said - and this is just what they tell me - everyone in the community knows that drinking alcohol when pregnant is bad, and they just choose to ignore it. Then, I wonder is it because the education is not sinking in for them, or what their issue is. This is speaking to grandmothers and young mothers as well. Because we have talked about the issue with some of the families, they said, 'Everyone here knows' ...

Madam CHAIR: So, they have that information (inaudible).

A WITNESS: ... so I wonder if the information is going around, at least in these circles they operate in, but they are not actually - I do not know if they are not absorbing it properly or getting the message right or they just think - the same with people who know about STDs and still choose to do it without protection - 'Oh, it is a risk. It is not guaranteed'.

A WITNESS interjecting.

A WITNESS: Yes. I just thought that was an interesting thing to ...

A WITNESS: It is not an immediate reaction either. You are drunk and have sex and continue to drink and you do not see the immediate result. One man said about smoking, he knows it kills him but just had a cigarette and is still here. It is not as if he lit up, smoked the cigarette and bang dead. So, that is true.

Madam CHAIR: You find people in their 80s who have smoked all their life and it has not killed them. That is a big struggle for health to deal with.

Mr WOOD: That is the 1%.

A WITNESS: I have one client in particular who has chronic lung problems, chronic heart problems, is diabetic, had a stroke but carries a packet of cigarettes around. She knows it is bad for her.

Mr McCARTHY: A perception emerged through our research where people were saying, 'It is okay because I'm not a heavy drinker'. The medical professionals tell us no, total abstinence. There was a link

to a planned child as opposed to a child who was not planned, and linked to the first trimester being really important as well. It is an interesting point because there a lot of different knowledge sets showed there was confusion in this area and we need to define ...

A WITNESS: There is not one strong message across the board.

Madam CHAIR: There was a conference - and someone referenced it for us - in Queensland about FASD and a woman presenter - a white lady - had one glass of wine and it must had been in the first trimester and the child is FASD. I do not know the name of the woman or the conference.

Mr WOOD: Was it Menzies School of Health?

Madam CHAIR: Menzies School of Health, yes.

A WITNESS: A girl goes to a party, meets somebody, maybe goes to a party the week after, she could be a week pregnant and the poor baby.

Madam CHAIR: That is the challenge for health professionals and the community, by the time the woman knows she is pregnant (inaudible)

A WITNESS: It is too late.

Mr WOOD: (inaudible) that Senate inquiry to give you a breakdown trimester by trimester. The issue the government has (inaudible) causes some discussion - what is the role of government. If a woman is told to stop drinking and she keeps drinking, and she has a court order to say she should stop drinking and she keeps drinking, does the government have a role to intervene? We discussed this a little today – if someone could be removed - you have mandatory alcohol rehabilitation (inaudible) but if you have a process where people can be sent to camp - we were talking to the Yolngu ladies today; there is the possibility of having those people go to outstations so the community takes responsibility for these people rather than government.

Perhaps the government has to take some responsibility where there is no cultural connection, but what do you do when someone refuses to stop drinking because there is a result? There was a case on the radio on the thirteenth, I think. It was on news radio, the 24-hour BBC radio news channel - I have the page where a woman was charged with (inaudible). It gets into very difficult areas, and I am not saying they are not difficult, but I like the idea of a community taking responsibility for that person, taking them to the appropriate place and looking after them. That is a difficult area. If someone is drinking do you intervene because (inaudible)? Economically, it will cost a lot, as well as for the families to look after.

A WITNESS: It is not fair on that child.

Mr WOOD: That is right, and that is the difficulty. The more education we can get now, hopefully, will reduce FASD to nil. We have cases where people do not care - (inaudible) FASD, and if you look at the Fitzroy Crossing numbers, it is something like 50% or higher because of drinking during pregnancy. It is scary because that is only one community. So (inaudible) we are not getting any (inaudible). I am just saying there are a lot of issues (inaudible) for discussion

A WITNESS: Have you talked to Prue Walker?

Madam CHAIR: Yes. The other issue we raised with people today that came up - it does not happen here but in Tennant Creek it does, voluntarily by the hotel. If they see a woman who is obviously pregnant they will not serve her. That will not stop them drinking somewhere else.

A WITNESS: No.

Madam CHAIR: That is why all drink ...

A WITNESS: And that gives them research.

Madam CHAIR: Yes. They obviously - why they did it down there; lots of things all have to line up.

A WITNESS: In Hawaii - my family is in Hawaii - there are signs in the coffee shop that say 'We will not serve coffee to pregnant women', because of the effects of caffeine on pregnancy. There are signs. I was blown away when I saw one that said, 'We will not serve coffee to a pregnant woman'.

Mr WOOD: Someone said today, the wife goes along - he was very male. He said, 'I was watching telly and I sent my wife down to get a couple of beers for me and she was not allowed to be served'. He was being jovial in the sense he said, 'Is it a bit harsh on the person ...

Madam CHAIR: No, in Tennant Creek the woman was going in to drink with mates. It was not takeaway necessarily.

Mr WOOD: Yes, that is right.

A WITNESS: Even if I go - say we go out to dinner with my husband, I will go to the bar and buy him a beer. I am pregnant. Does the person behind the bar then have to watch me to see if I sit at a table and I am drinking a beer? Or if it is, say, a Coke and rum or something - you do not know if there is rum in that glass. I personally agree it would be great not to serve them the drink if you can clearly see they are drinking it. It is inconvenient if I need to go and buy a drink for my hubby or my mates, and I am pregnant.

Madam CHAIR: It must just be in Tennant Creek then, but ...

A WITNESS: It is also that you never want to say to somebody, 'Are you pregnant?' ...

WITNESSES interjecting.

A WITNESS: ... and we have all been caught out.

WITNESSES interjecting

Mr McCARTHY: (inaudible) on the belief system in Central Australia around the conception story. A woman does not identify as being pregnant - that is another aspect. In the Tennant Creek example, Anyinginyi Congress has an expert on staff there who attracted resources and a lot of attention to develop a FASD program. That is the advertisement you see on television. With the puppets they have done a lot of work around it.

The town and the region - we just assumed the leadership position. That put a bit of pressure on the alcohol accord to step up as well. They started to display the FASD posters produced by Congress in bottle shops, and through the responsible sale of alcohol they started to ask questions around this. Be aware in a legal sense they will totally (inaudible) issues were discussed.

It was a Tennant Creek thing and we all get on well together. We are able to continue to work that through. Should somebody from outside of that town community have come in and made an anti-discrimination case against that, they would probably have won.

A WITNESS: Yes. That is a great idea, putting FASD posters and things in bottle shops and bars, so that it is reminding people. But if you can clearly see they are drinking, it is not part of your RSA training to not give it to a pregnant person. There is that line between - are they drinking it or are they drinking it? It is a really hard thing to police.

Mr WOOD: There are also dangers today, especially in the Territory with any Indigenous issue. We (inaudible) does not have anything to do with us. Some of the reports we have is that it does. (inaudible) ...

A WITNESS: That is a very good ...

Mr WOOD: ... how do you deal with that? It seems for us that sometimes it is easier if people relate to a group of people - they are Yolngu or Tennant Creek people. But when (inaudible). So how do you approach it from a different aspect or different points of view - whether it is the North Shore of Sydney or somewhere they do not have a problem.

Mr McCARTHY: Can I ask you what your personal knowledge about FASD and around affected children in utero is? Where you aware of it? Who taught you about it? Where did you pick up your knowledge?

Ms PEERS: There has been quite a bit of training here. I have been to two workshops over the last two years. I

Mr McCARTHY: Do you work in the health sector.

Ms PEERS: I am the disability advocate for the Darwin Community Legal Service.

A WITNESS: I am in high school and I have had no training. I would love to have had some training.

A WITNESS: Unfortunately it was cancelled.

A WITNESS: Another one has just been done. I did one (inaudible) last week.

A WITNESS: I have been here for 18 years and have worked with kids. The first case to me was the facial deformity - like this is what it is. You naturally go to find out more about the learner. My journey has been basically hands-on. I know of kids I strongly believe - without the diagnosis, however, they have no physical signs, but these kids cannot learn, they cannot concentrate and they cannot sit still. There is something going on. I have also noticed a lack of empathy. I am seeing - I do not know if it is the individual cases or whether it is one of those things, but I think ...

Madam CHAIR: Empathy for the child?

A WITNESS: That child has a lack of empathy for others around him.

Madam CHAIR: I see.

A WITNESS: That would lead on to justice, criminal behaviour and everything like that. That is something I have noticed observing the kids I have worked with. Those kids can be mean to other kids - cruel.

Madam CHAIR: (inaudible)

A WITNESS: Currently the program advisor for Families as First Teachers in the Arnhem region - I have worked in early childhood for 15 years in the Territory. I have certainly worked with children I suspect were, but you are catching these children in preschool; you know something is going on with this child but no one can put a finger on exactly what it is. These kids start in preschool and something is going on, they go for diagnosis by good doctors and specialists and still nothing is coming back. This is constant through their school years.

Madam CHAIR: By then you are starting to (inaudible)

A WITNESS: Then it is too late. Whereas, if you can identify these kids before preschool – if you could capture them when they first enter the school system you stand a ...

[Editor's Note: Audio lost from 13.43.10 to 13.48.57]

A WITNESS: Sorry, when they are older. My son came to me when he was 10, and he is typical FASD - the smooth upper lip, his ears and everything about him. He is now 13. Even though I am on the other side of the world, I am (inaudible) constantly speaking to him. He just does not have – yes, he works. He goes to work and if he does not go to work he does not get paid - 'Why not? Why was I not paid?' The whole thing – he does not pay the rent, and just daily living is over his head. Yet, there is no support for him, none whatsoever. When he was at school he had a special needs tutor, we did an awful lot of work and he did really well at school once we got the right diagnosis. But then, once he left school, there was nothing.

A WITNESS: One of the things that happened in 2012, because they had an annexe here for kids or students with disabilities, once they reached a certain age they were out - there was nothing else. So, I tried to do some stats. Through the three schools, being the Christian school, the primary school and Yirrkala School, there were 81 children with mild to severe disabilities. Nhulunbuy Primary School is apparently the highest funded primary school in the Northern Territory ...

Madam CHAIR: What disabilities?

A WITNESS: For disability students. That was not going into what their disability was, it was just to try to get some figures to put out there. Those figures were sent to the federal minister – what is her name?

A WITNESS: Jenny Macklin.

A WITNESS: Jenny Macklin's office. They did not want to know about it. No one wants to know about it until something happens.

Madam CHAIR: Are you in the school or medical ...

A WITNESS: No, I am Lynne's electorate officer.

Madam CHAIR: Oh, yes, that is right. Oh, yes, a real difficult job.

Ms WALKER: She is in a great job.

Madam CHAIR: Do you think, on the experiences - could be as an Aboriginal family, an Aboriginal mother or even a white mother - that the woman will not admit that her child is FASD because she has a shame job? So, therefore (inaudible).

A WITNESS: As a professional, if you are wanting to engage with that mother you are not going to start that conversation at all. You have to work on what the problems are now and getting forward. Going back is possibly going to sabotage any efforts.

A WITNESS: Also, in working with parents, when they first hear that maybe something is not quite right, you have to understand that parents go through a real grieving process before they are there to accept that. Personally, I know it is difficult. It is incredibly difficult ...

Madam CHAIR: It is what (inaudible).

A WITNESS: ... and with a lot of parents it takes a long time to be there and be ready to hear those things.

Madam CHAIR: Would it be different for an Aboriginal mum?

A WITNESS: I do not think so.

A WITNESS: I do not know.

Ms WALKER: They are still mothers.

A WITNESS: Every mum wants their baby to be ...

A WITNESS: Yes.

A WITNESS: They have a different way of caring for their children.

Ms WALKER: But they still love their children.

Madam CHAIR: Oh, I am not – I was not ...

A WITNESS: I know they love their children. Their way of parenting, which I am sure you are all aware of, is very different to the way we ...

Mr WOOD: Let them go.

A WITNESS: The other thing with that is parents do not have to have their children diagnosed. A lot are in denial. For example, at my site, I run the FAFT program at Yirrkala. We have a little girl with suspected Down syndrome and are trying to find out whether she does or not. The family has no obligations to have any sort of testing or even acknowledge it, which I followed up with two different health organisations. I followed up with the school. I followed it up with a lot of things just trying to find out,

because if she does I would like to have support in place for her. But apparently the family does not even have to find out or acknowledge it.

There are probably other families out there. I used to teach at the preschool here with Tracy. There would be families that just did not want to go there yet because they are probably going through their grieving process and do not want to acknowledge it. They said, 'I am not going to do any testing for another year or two years', and they keep putting it off because they do not want to hear it.

A WITNESS: Can I ask from you because I have not been able to get a diagnosis. Is it funded?

A WITNESS: No.

A WITNESS: Yes, that is what I understood. So, even though we get a diagnosis we still do not have funding within education ...

A WITNESS: That is just a diagnosis in Australia ...

Madam CHAIR interjecting.

A WITNESS: It is not.

A WITNESS: That is something, in education these kids do need. You can see they need, but without a diagnosis - they need more support.

Mr McCARTHY: You take the cross ...

Ms WALKER: Recommendation N 1.

Mr McCARTHY: If you take the crossover (inaudible) all the behaviours that tick all the boxes, it will determine the level of special needs funding.

A WITNESS: Yes, absolutely.

A WITNESS: It will be very ...

A WITNESS: But also to get that funding ...

Mr McCARTHY: This is the thing (inaudible) about it, we do not know what caused all those things.

A WITNESS: To get that funding, they do not want to put FASD beside it.

Mr McCARTHY: That is right.

A WITNESS: You can put ...

Mr McCARTHY: (inaudible) because we have been sharing the stories here, then I can share with you as well. You know the matrix I am talking about. You lay it over that kid's file, and the boxes all get ticked as it relates to special needs funding. Now government really has to ask the question: what is the diagnosis?

A WITNESS: The need is there because it is very difficult to figure out. If you have FASD you have probably got a bit of neglect, you have possibly got some mental health issues in the family ...

A WITNESS interjecting.

Mr WOOD: Certainly the group from Sydney University or the University of New South Wales (inaudible) they are doing block work - that is a major project - and trying to get the tools.

A WITNESS: Even now, trying to watch them trying to diagnose between ADHD and FASD, often it is splitting hairs. Sometimes, you are thinking you will get some funding, and you will not get any if they have ADHD, so how about - they do not do that ...

A WITNESS: But it is splitting hairs and it really is looking at quite subjective criteria for coming up with a diagnosis.

A WITNESS: The needs are the same.

A WITNESS: The needs are still there. The needs are apparent, and they are not in dispute.

A WITNESS: I am not sure if you said it before about the early intervention. The earlier you get in with individual strategies, the more success you are likely to have. Well, there are some children who are going through school and parents are looking for answers, but the doctors or medical professionals just are not willing to make those calls until children are a certain age. They cannot diagnose dyslexia until they are here, they cannot diagnose this because - do you know what I mean?

Madam CHAIR: Yes, I do.

A WITNESS: We need a tool that allows us to try to get these children diagnosed early so that (inaudible) ...

Mr WOOD: How do you ask a woman who just had a baby ...

Madam CHAIR: We need to talk to you.

Mr WOOD: We need to get early intervention. Someone was telling me you were drinking while you were pregnant – FASD (inaudible). If you can take them (inaudible) because some doctor said, 'You have to get them there (inaudible)'. (Inaudible) you can stick them (inaudible).

Mr McCARTHY: Is it Zoe?

Ms O'HARA: Yes.

Mr McCARTHY: Would you like to put on public record that government really needs to strengthen and enhance the Families as First Teachers program?

WITNESSES interjecting.

Mr McCARTHY: I will say it for you.

Mr WOOD: I know you are all teachers and you are all qualified in some form, but before all of that, did you know that drinking could cause harm to a baby?

WITNESSES: Yes.

Mr WOOD: How did you know that? That is the bit I was getting at. Who told you?

A WITNESS: I was told about 28 years ago.

Madam CHAIR: By whom? Your mum?

A WITNESS: No, I am not really sure. I was planning to have a child ...

Mr WOOD: By a gynaecologist?

WITNESSES interjecting.

A WITNESS: Just by a gynaecologist, yes.

A WITNESS: It is common knowledge.

A WITNESS: It is the same - maybe not as out there - as smoking, but it was ...

Ms MILLS: I recall recently sitting down with a friend who was pregnant. She was 20 something when she said she was pregnant. She was smoking and had a drink in front of her. She is a nurse, she has access to good information; 'Melissa, what would be best? Should I give up smoking or drinking?'

WITNESSES interjecting.

Ms MILLS: Foolishly I said, 'Well, drinking can cause brain damage, smoking might not. So maybe give up the drinking'. I heard her on the phone, 'Melissa said I should keep smoking'.

WITNESSES interjecting.

Ms MILLS: That was a relatively recent conversation with a relatively well-educated person.

Madam CHAIR: You cannot just assume that because the person is educated, has finished high school and got a tertiary degree, they actually know something.

Thank you, ladies and gentleman. We have to wind it up. As you can see, they are cleaning up around us. Thank you so much for all of that feedback. It has been really good. We will get a transcript to you as soon as we can so you can have a look at it.

A WITNESS: How long has that committee been going?

Madam CHAIR: About six or seven months now. It is a select committee, so once the job is done it disbands.

Mr WOOD: (inaudible)

Madam CHAIR: Yes, we just fit in with everyone's schedule. It is a select committee so once it is done, it is done. But there may be something that comes out of the report that says we need to, because in the parliament there is (inaudible). It might be that we make a recommendation that it becomes a sessional committee. So, (inaudible)

The public forum concluded.
