LEGISLATIVE ASSEMBLY OF THE NORTHERN TERRITORY

12th Assembly

Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder

Public Hearing Transcript

8.30 am, Friday, 1 August 2014

Andy McNeill Room, Alice Springs Town Council

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

The Hon. Bess Price, MLA, Member for Stuart

Mr Gary Higgins, MLA, Member for Daly

Mr Gerry McCarthy, MLA, Member for Barkly

Ms Nicole Manison, MLA, Member for Wanguri

Mr Gerry Wood, MLA, Member for Nelson

Witnesses: People's Alcohol Action Coalition

Mr Russell Goldflam, Member

Mr Bob Durnan, Member

Chamber of Commerce

Ms Kay Eade, Executive Officer

Public Health Association

Dr Rosalie Schultz

Central Australian Health Services

Dr Jennifer Delima, Specialist Alcohol and other Drugs

Central Australian Aboriginal Legal Aid Service (CAALAS)

Mr Mark O'Reilly, Principal Legal Officer

Tangentyere Council

Mr Blair McFarland, Operations Manager of the Central Australian Youth Link-Up Service

Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council

Ms Liza Balmer, Deputy Coordinator

Alice Springs Correctional Centre

Ms Lynda Jarvis, Manager, Prisoner Services

Ms Suzanne Wilks, Chief Prison Officer

Central Australian Aboriginal Congress

Ms Donna Ah Chee, Chief Executive Officer

Dr John Boffa, Chief Medical Officer, Public Health

Dr Boffa tabled papers regarding the regarding statistics on alcohol consumption in Alice Springs.

Central Australian Aboriginal Alcohol Programmes Unit

Ms Sabine Wedemeyer, Alcohol Mandatory Treatment Manager

Foster parents

Mr Danny Curtis

Ms Michelle Nuske

PEOPLE'S ALCOHOL ACTION COALITION

Madam CHAIR: Good morning. Welcome to the public hearing into action to prevent foetal alcohol spectrum disorder. I welcome to the table to give evidence Russell Goldflam and Bob Durnan from the People's Alcohol Action Coalition. Thank you for coming before the committee. I appreciate you taking the time to talk to us today.

This is a formal proceeding of the committee and the protection of parliamentary privilege and an obligation not to mislead the committee will apply. 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 may say should not be made public, you may ask the committee to go to a closed session and we will take your evidence in private.

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

Mr GOLDFLAM: Russell Goldflam, a member of the People's Alcohol Action Coalition.

Mr DURNAN: Bob Durnan, member of the People's Alcohol Action Coalition.

Madam CHAIR: Do you have any opening statements you would like to make, or comments?

Mr GOLDFLAM: Yes, I would like to make an opening statement. First, we acknowledge the Arrernte custodians of this land and, in particular, we acknowledge with sadness the many members of the Arrernte community whose lives have been cut down by grog.

I came here and immediately started working in Alice Springs town camps in 1981. In my mid-20s, I was naïvely optimistic enough to believe the appalling conditions I saw on my first day in Alice Springs when I went to Hidden Valley Town Camp would not be conditions that would continue to exist for terribly much longer. We all knew we were in the vanguard of the movement which would end impoverishment, racism, discrimination, and misery. Well, we were wrong.

It took me about 15 years living and working here to notice that this was not just a problem, but an inter-generational problem. When I started to see kids, the same age as the kids I had seen when I first came up here, who are now the children of those kids, it was around

that time I became involved in what subsequently became PAAC when it was formed in the mid-1990s. It was about that time I realised that if we did not do anything about grog, none of the other things we were working towards were going to be able to be effective. So, I decided at that point to commit myself to working on this issue, apart from my professional life, and make that my priority because, otherwise, it seemed to me I was going to be banging my head against a brick wall.

Now, another 20 years on from then, I still feel the same way. Tragically, we still do not have a handle on grog, although we have been able to successfully reduce the amount of alcohol drunk in Central Australia quite significantly, and the harms are, I think, going down. There is some small progress being made.

I should also say that when I first was working up here in the 1980s, that is when I first had the opportunity to work with Bess Price, who I deeply respect and have always respected.

We live in the Northern Territory. One of the best things about this place is it is a small community, so I know half of the members of this committee personally, which is not something you would be able to say in many jurisdictions. It is that sense of community which inspires me to keep working in these very difficult areas.

When I first heard about FASD a few years ago, it was described to me as the 'million dollar baby problem' because it costs a million bucks to deal with the appalling consequences of a child who is diagnosed with FASD.

I now realise that was wrong. I read the submission to this inquiry by the National Drug Research Institute at Curtin University. They report the most recent material from the United States is that it cost the community about $3.5m per child.

Six years ago, I acted …

Madam CHAIR: Would that be for the lifetime of the child?

Mr GOLDFLAM: Yes, as I understand it. It was just a brief. I have not read the original study that NDRI refers to. This is not just expensive. This problem has the potential to cripple our economy.

Six years ago, I acted for a young man from a town camp in Alice Springs who had savagely killed with a machete another man, and all but killed a second man. He is now doing life in prison with a 20-year non-parole period. We had him assessed by a psychologist, and it

came back that he had some sort of intellectual disability, but nobody could really put a finger on what it was that had caused that. Both his parents were drinkers. They are both now dead. I have no doubt now, in retrospect, if he was assessed today, he would have been diagnosed as, 'Oh, yes, he is a FASD', because he is like so many other clients I have had, so many other witnesses I have cross-examined in my capacity as a criminal lawyer with Legal Aid, and he may not get out after 20 years because he does not have the skills to function very effectively in community. He could spend 40 years in gaol at $100 000 a year, but that is just the direct cost of looking after him.

What about the family of his two victims, one of whom survived but whose life has been blighted? What about all the appalling consequences for the rest of the family and the – you guys know. This is a gigantic problem.

I work for the Northern Territory Legal Aid Commission, where I have been in charge of the Alice Springs office for the last 13 years. The Northern Territory Legal Aid Commission has made a submission to this inquiry which I helped write, but I am not speaking on behalf of Legal Aid, I am speaking as a community member and part of the People's Alcohol Action Coalition. If I can take you to our submission, we made three main points.

The first point is this problem is huge and we do not have a handle on it, we do not know how big it is, but we know it is devastatingly serious and we are bracing ourselves …

Madam CHAIR: Are you talking about FASD or alcohol consumption?

Mr GOLDFLAM: FASD.

Madam CHAIR: Okay.

Mr GOLDFLAM: We are bracing ourselves for when the data comes in. One thing government must do is research so we can figure out the scale, scope and parameters of the FASD problems. When we find out, it will be worse than we think. I am confident in saying that, unfortunately.

The second issue is because this problem is so huge the only real solution is to take a whole-of-community approach and reduce the amount of alcohol available. I am also the president of the Criminal Lawyers Association of the Northern Territory and that is because in 2009, at our biennial conference, I gave a paper in which I said what I say now - we have to reduce the availability of alcohol. I thought I was speaking to people who would say, 'Goldflam, get a life and have a drink'. Instead, they made me president of the association.

This message, which has been so difficult to get politicians from all sides to accept, is one which we have to take on board. If we do not we are sending ourselves down a road which will lead to complete social dysfunction and further misery for all of us, whether we are drinkers or not.

I know you have all heard PAAC say, 'We have to do something about availability, about the supply of alcohol,' over and over again. Our spokesperson, John Boffa, who I think will be addressing this inquiry wearing another hat, says it until he is red in the face. We keep saying it because it is a bedrock proposition which must be responded to. If we do not take a whole-of-community response to reduce availability we will not address this problem effectively; it is too big.

The third issue we focus on in our submission is treatment. Treatment is terribly important, but it has to be treatment which is shown to be effective by the evidence, and it has to be treatment which is not based on some theory of race discrimination. Sometimes those two things can clash to some extent, but we are firmly of the view that in the long-term we need approaches which apply across the community because we live in one community. We cannot afford to adopt policies which will ultimately see a community being divided in the way it has been in the past along racial lines.

One more issue I want to just focus on, and which is contained in our submission, is that FASD is not a condition which is caused by irresponsible women knowing they are pregnant drinking in the late stages of their pregnancy. The committee may already be well aware of this from the work it has already done, so forgive me if I am preaching to the converted. All the scientific evidence – I am not a scientist obviously – I have read says the damage is done either at the moment of conception or in the first three to six weeks after conception before anybody knows there is a pregnancy. A woman finding out she is pregnant, going along to the antenatal clinic, getting the advice 'do not drink' and who does not drink, delivers a FASD baby because of something that happened on the night she had sex. It might not be that she was drinking; it may be it was the man.

There is now evidence - and I have read this study from Korea - that a male who has a lot of alcohol on board may transmit through his sperm a genetic epimutation - I think the expression is - which can itself result in serious mutations to the foetus, even if the woman had no alcohol. This is not a problem about women irresponsibly drinking when they are pregnant. The suggestions that have been floated in the media about punishing women for drinking when they are pregnant are completely misplaced. That would not address this problem. It might address the problem of irresponsible women, I do not know, but I doubt it. It certainly will not do anything to help FASD be prevented.

That is the statement I wanted to make by way of opening. Madam Chair, I do not know if you have any questions for me?

Madam CHAIR: No. I was just going to make a note to see if we can track down this Korean study.

Mr GOLDFLAM: I can give you the reference.

Madam CHAIR: That has been - I do not know what the medical words are - statements that it is solely because the women drink.

Mr GOLDFLAM: Yes.

Madam CHAIR: If you say there is work that …

Mr McCARTHY: Epigenetic is the term.

Madam CHAIR: Epigenetics.

Mr GOLDFLAM: The study we referred to in our submission is published at Volume 17 No 6 in the journal *Animal Cells and Systems* in the year 2013, at page 429. It is called *Transgenerational effects of paternal alcohol exposure in mouse offspring*, and there are about 10 authors. I will not read out their names because I cannot pronounce them. In our submission, there is a footnote which takes you to the webpage where you can access the study.

Madam CHAIR: Thank you. I do not have any questions to start with. Do you have any statements or anything you want to say, Gerry?

Mr McCARTHY: I would like to ask you …

Madam CHAIR: Hang on. Did you want to say anything before …

Mr DURNAN: No, no, I do not.

Mr McCARTHY: In 1981 in Alice Springs, were you aware of FASD?

Mr GOLDFLAM: No. I was not aware of FASD until about – I do not know - five years ago.

Mr McCARTHY: Is FASD now regularly talked about in the legal profession?

Mr McCARTHY: It is talked about in the legal profession, but it is not yet talked about much in court proceedings because we do not have proper tools for …

Madam CHAIR: Diagnosis.

Mr GOLDFLAM: … diagnosing it. Roseanne Fulton - everybody knows about that case because it has been all over the media, and everybody knows she is a FASD person. She has been in court, of course, a lot.

We do not yet see it being regularly referred to in sentencing remarks. There has been some work done by Professor Heather Douglas in Queensland - a law professor who used to work here in Alice Springs in the 1990s - where she has argued that our courts should be recognising that FASD is a specific condition which could be a mitigating circumstance for people who have been convicted of criminal offences, as has been recognised in Canada, for example. We are still in our infancy in jurisprudence in this area.

Mr McCARTHY: The medical profession - and this is the high level end we have been hearing from - identifies foetal alcohol syndrome, and that allows the clinician to diagnose through facial features and other physical attributes. But, generally - and this is the way I have been interpreting it - the medical profession is very reluctant to diagnose FASD as it sits within a very broad spectrum of disorders. In the sentencing - and I am focusing on the judicial system - is intellectual disability talked about and decisions made? Are the magistrates focusing in on those intellectual disabilities now?

Mr GOLDFLAM: Not so much magistrates. The problem is the court cannot mitigate or reduce a sentence on the basis of a person's disability unless the court has proper evidence of that. To get a report about somebody's psychological state - a detailed report is going to cost you about $3000. A quick report will cost you about $1000. The Legal Aid agencies who act for all these people do not have the resources to commission those types of reports except in very serious cases. In magistrate's courts it is very unusual for a psychological report to be tendered. Sometimes we are able to pull together material from their medical files already in existence and there might be mention of a diagnosis somewhere in there. It is pretty unsystematic the extent to which we are able to bring before the courts the proper

evidentiary material which will be needed to enable these matters to be taken into account as they would be in an ideal legal world.

Mr McCARTHY: The research in Canada and elsewhere suggests there could be quite significant levels of people incarcerated who are foetal alcohol-affected and it has never been considered because the system cannot deal with it, medically or judicially.

Mr GOLDFLAM: That is right. As you said FASD, with the 'S' standing for spectrum, is just a broad range of conditions, some of which are not all that obvious. We are just scraping the surface at this early stage. I should have said right at the beginning PAAC is delighted that the Northern Territory parliament has recognised the importance of this issue by establishing this inquiry. This could be a landmark event, in conjunction with the Senate inquiry into the effects of alcohol-related harm on Aboriginal communities, which we have also had significant input into.

Madam CHAIR: We have been told by other people appearing before the committee, and I am not sure if it is quantifiable, that prisoners in gaol, both men and women, a big chunk of them - probably as high as 20% - are probably FASD-affected. If government could do something to confirm that is true, would it be worthwhile for the relevant health authorities to work with those prisoner's such that when they leave gaol there is some better understanding that they do not – I am not making sense, but if they have a health issue and it is definitely diagnosed the government knows they have health problems and when they leave gaol they are better managed such that they do not go back into the system. Would it be worth trying to identify ones in gaol?

Mr GOLDFLAM: It would be. I should have said this earlier - you really have to get these kids right at the beginning. By the time they are grown up there is no treatment. Of course they need special programs to enable them to make best use of the limited potential they have, so perhaps more educational than health, or perhaps educationalists who have special training in how to work with people with brain damage. A form of brain damage is what we are talking about. You will not cure anybody with FASD, but you can make a big difference if you are working with children in the first months and years of their lives. That is a big focus of our solution as well - the early childhood programs, parent/nurse partnerships, programs like some of the ones piloted in Alice Springs.

Ms MANISON: Staying on the topic of prevention in your submission - this is the first time I have seen it raised. You discussed looking at the child protection system and being able to get orders in place if women are reported to be drinking through pregnancy and are not voluntarily ceasing drinking - get more support mechanisms in place to help them with their drinking. Do you think that system should be looked at in the Territory?

Mr GOLDFLAM: It has been highly controversial and before we included that part in our submission we had some very long and intense discussions about this issue. It is pretty heavy handed and we do not think it will stop the child about to born having FASD, but it might help the next child. We can see, where you have one failure by the system to prevent the birth of a FASD child, it is an opportunity to be involved with that family and stop if happening again because most women have more than one child. This is why we put it in the submission. After thinking about it hard and long we decided we should press for the child protection system to extend to antenatal so there is engagement by the child protection system with expectant mothers.

It is already the case that some children are removed at birth. I have had clients who have had their children removed at birth, so it is already happening. It might be worthwhile making that more clear in the legislation - that is the way it can work.

Mr WOOD: You said antenatal. What about prenatal. I know …

Mr GOLDFLAM: That is what I meant – ante. I meant before birth.

Mr WOOD: That is all right because, as Nicole said, you have this down here as a strategy to work with child protection authorities. Further on you say there is very little evidence of success, including criminalising women who drink through pregnancy ...

Mr GOLDFLAM: Yes.

Mr WOOD: Point six in your summary of recommendations says to legislate to allow for a trial of a process with referral type (inaudible) can be made, where there are concerns for an unborn child due to dangerous levels of consumption by the mother.

I have asked this question at all of our hearings: if, for instance, there was a court order, and a woman has been told the dangers of drinking - notwithstanding the information we discussed about Korea, because that is the first time I have heard it. The Senate has already done an inquiry into FASD. There is the Kimberley Valley inquiry into FASD. You hear midwives saying there is no safe level of drinking. I understand that from four to six weeks is the dangerous period. It also does not say that continuing to drink for the rest of pregnancy does not make it any better.

Considering all that, if the court said, 'You have been given all the information', probably more than likely the person has an addiction and cannot stop, do you see a role for the government in a culturally sensitive way? We spoke about the community and that person

is, somehow, placed in a place - could be out in a homelands or wherever - where they are not allowed to drink. But, there needs to be the support of the family and the people they know so the child has some reasonable chance of being born without FASD.

Mr GOLDFLAM: We do support that. We are not saying there should be no circumstances in which mandatory residential treatment is required.

Interestingly, both the current government and the previous Labor government both had plans which involved people being ordered to undergo residential treatment. What we have, however, consistently and previously said to this inquiry and in other forums is there must never be criminal sanctions attached to failing to comply with orders for mandatory treatment because that is counterproductive. And, if you are going to lock somebody up - because that is what it is - for treatment, it is essential there is due process.

This is the lawyer in me coming out. There has to be an opportunity for a person to be legally represented, the same as they are before the Mental Health Review Tribunal, for example.

The Public Health Association has made a strong submission to this inquiry, which I have read, opposing residential ordered treatment. PAAC does not agree with that. PAAC says there is a role in extreme cases for women and men who are completely out of control with their drinking and are a threat to themselves and to the community, and everything else has been tried. Provided there is due process and there is no criminalisation of it, we think there is a case to be made for sending those people into treatment even if they do not want to go.

We are not convinced it will work, but these are desperate times. We think extreme measures - because these are extreme, radical measures. I am not saying we support the current Alcohol Mandatory Treatment Act - we do not because it does not have those safeguards I have been talking about built into it - but we are not and we never have fundamentally opposed the idea of requiring people to undergo treatment if necessary.

Mr WOOD: You mentioned you do not support alcohol mandatory rehabilitation because it does not have the same safeguards as the Mental Health Act?

Mr GOLDFLAM: That is right. It is a bit more complicated than that, but yes.

Mr WOOD: (Inaudible) legislation.

Mr GOLDFLAM: Yes.

Mr WOOD: I do not know what is in that review, but one of the key things you need – you need legislation to say the mother has to have mandatory rehabilitation. You would need a similar section to the Mental Health Act in there.

Mr GOLDFLAM: We have not drafted …

Mr WOOD: No, no, but you …

Mr GOLDFLAM: … legislation (inaudible) …

Mr WOOD: … want that safeguard.

Mr GOLDFLAM: Definitely. We say if you force people into treatment, whether it is residential or ambulatory, there have to be safeguards. A person has to be given the opportunity to get representation and advocacy so that if they do not want to go into the treatment the decision-maker is properly informed about that person's views. Unfortunately, in our view, the current arrangements for mandatory treatment do not provide that safeguard.

Mr WOOD: This probably borders between moral and legal, but a mother who drinks knowing the baby will be damaged cannot be charged with any offence, but if after the baby is born the mother goes whack she can be charged with hurting that child?

Mr GOLDFLAM: Yes.

Mr WOOD: If a mother is drinking - we know that affects the unborn - legally is there an issue?

Mr GOLDFLAM: With respect, that proposition is based on an assumption that is not really supported by the evidence. We do not know that a mother who drinks when she is eight months pregnant is harming the child. What we can say is it seems most likely that the harmful drinking, the FASDcausing drinking, occurs in the first month of pregnancy when the woman does not know.

Mr WOOD: Yes, and it could become complicated because of the issue of unplanned and planned pregnancies.

Mr GOLDFLAM: Yes.

Mr WOOD: If something is planned you have the information and know you should not be drinking around that period. I was asking a relevant question and I understand what you are saying.

Mr GOLDFLAM: We have a culture where drinking is not only legal but is encouraged. We are saturated with advertising. We can hardly criminalise people for responding to these messages they are bombarded with and who have a medical addiction to the substance if they drink. It is not even clear that – you should ask one of the doctors who will be coming along, but I am sure the doctors will say not every mother who drinks ends up damaging their child – some do, some do not.

Madam CHAIR: That is true.

Mr WOOD: Is that not a question we do not know either, because some people do not show the symptoms until fairly late.

Mr GOLDFLAM: Yes.

Mr WOOD: Some show them quite early. That is an area we need to investigate, because that comes down to the question do you tell a pregnant to not drink or drink a little bit? The message from the midwives association is the safe way is not to drink at all.

Mr GOLDFLAM: That is right and that is what the National Health Medical Research Council says too. One of the things we emphasise in our submission is education campaigns aimed at the whole community saying, 'Please everybody, be sensible, do not drink when you're pregnant' are not effective because the risky drinkers will not pay attention to that message. It is common sense, but more than common sense all the research done on community education campaigns about drinking shows it has no effect except it makes people feel good because they – 'We have done something. We put messages on TV' – but they do not work.

There is an important role for education, but it has to be focused on the risk group and it has to be very narrow in the sense that it is people getting messages face to face from a person they are engaging with, a nurse, a social worker or somebody like that.

Mr McCARTHY: Yesterday in Tennant Creek, which was a public forum the day before and a hearing, well attended, and the history of Julalikari Aboriginal Council came out with the

night patrol, the Thirsty Thursday and the other initiatives they put in place. I asked what is the big new one? What do we need for addressing supply? What is the People's Alcohol Action Coalition's response to that?

Mr GOLDFLAM: Price.

Madam CHAIR: That floor price issues?

Mr GOLDFLAM: Floor price; volumetric tax. This inquiry cannot do anything about volumetric tax - only the Commonwealth government can do it, for federal constitutional legal reasons. The Northern Territory could certainly lead the country by introducing a floor price - a simple amendment to the *Liquor Act* which we have explained in our submission. If you could not purchase a standard drink for less than $1.30, we would reduce harms very substantially - just like that.

Madam CHAIR: Is that because it would cost more to buy the drink, therefore, they buy less drinks? Is that the argument?

Mr GOLDFLAM: Yes. It is not so much they would buy less drinks. The people who are most harmful drinkers in our community are people who are on fixed incomes - they are welfare dependants - and they spend every cent they get on grog. Income management we support because it stops them getting hold of some of those cents for grog. The other half of their money they can spend all on grog - and they do. So, if you make wine more expensive - at the moment, wine can be bought in Alice Springs, in some cases, for about 80¢ a standard drink. If you raise the price of each standard drink of wine by 50¢, up to $1.30 which is what it costs to buy beer, people will switch to drinking beer. They will still spend every cent on beer, but they will be absorbing about 30% less ethanol into their bodies, so it will do some less harm.

Mr WOOD: (inaudible) on the core price, it is not the same as making a price just to the amount of alcohol. All alcohol (inaudible) of alcohol, but if 1% of alcohol (inaudible) is price - and that applied through every form of alcohol – is that the same as full price? If beer was 2.7% and, just for argument sake, $2.70 – say that was the price government said we should pay for alcohol. So, it was $2.70 a ml …

Mr GOLDFLAM: It's putting a minimum price per unit of alcohol.

Mr WOOD: That is right. And that does not apply at the moment, does it?

Mr GOLDFLAM: No.

Mr WOOD: Wine is a better value to buy than beer?

Mr GOLDFLAM: Yes.

Mr DURNAN: I imagine in a lot of other places in the Territory that do not have our restrictions, you can still buy the standard drink of wine for 30c or 40c. You used to be able to get a standard drink of wine for about 25c here when the cleanskins and cask wines were at their lowest price. There were some times when you could buy a bottle of wine for $2 discounted. That bought it down to being only about a quarter of what we are currently paying per standard drink of wine. But, if we want the price to go to parity with beer, some people will shift to better quality wines and some shops may sell the existing wines for a higher price and make a bit more profit.

There is a furphy around that this should not be done because it will lead to windfall profits for the manufacturers and, maybe, the retailers. We reckon the evidence actually shows different to that. There is a bit of windfall profits. But, it is not automatic that everybody who is currently buying the cheapest wine will buy that same wine at a higher price. Most people shift to other products - better wines or beers - when they have the full price mechanism in place. There is a number of reasons. I believe that some of them are outlined in our submission.

Mr GOLDFLAM: The most important evidence for this, in a way, was the previous CLP government's Living with Alcohol program in the 1990s - this is before the High Court said you were not allowed to fiddle with the tax arrangements for alcohol. They made a full strength beer a bit more expensive than mid and light strength beer. They made wine more expensive too, by putting an excise on it. It was a beautiful social experiment because the researchers were able to go in and look at what happened over the five years, I think it was, that was in place. It was Marshall Perron's idea. It saved $129m and 129 lives, they estimate. It is referred to all over the world - this research out of what the Northern Territory achieved in the 1990s.

Mr McCARTHY: Except we shifted to drinking port in Tennant Creek.

Mr GOLDFLAM: No, not as a result of that.

Mr McCARTHY: That is when the product shift first started.

Mr GOLDFLAM: In Alice Springs another move was made in about 2004 where the Licensing Commission banned four and five litre casks. There was a huge shift to port which made things worse.

Mr McCARTHY: We went through that as well.

Mr GOLDFLAM: I am sorry, Mr McCarthy, I cannot recall the exact detail of what happened in Tennant Creek but I am convinced the Living With Alcohol Program was a fantastic example of how you can save lives by controlling price. Unfortunately, we cannot do it now in the way it was done by Perron's government for legal reasons, but a floor price would achieve the same result. It would result in a product shift from wine to beer because the hard core drinkers on fixed incomes will always find the cheapest alcohol available. That is what their life depends on and the cheapest alcohol will become beer. Beer is not as harmful as wine if you drink as much as you can. For a start, there is a lot more water in it so your body cannot absorb as much.

Madam CHAIR: I am conscious of the time. Bess, did you have anything you would like to ask?

Mrs PRICE: When we had the BDR - even though we talk about a floor price people will still buy grog from wherever. There are theories of sly grog and you and I both know it is sold around here. I know some of my relatives would pay $100 for a carton of beer. How do we stop it? How do we find ways to make people to understand what damage alcohol is doing to them?

Mr GOLDFLAM: That is a very important issue. We do not suggest for a moment a floor price, or any other simply measure, is the silver bullet which will knock this problem on the head. There will be people who have, somehow or other, access to more money than their dole cheque gives them and they will spend vast amounts of money buying alcohol and will do enormous harm to themselves and their families as a result. The penalties for grog running have been increased, ironically - as an unintended result of the Commonwealth intervention in some cases penalties for grog running were, by mistake, reduced but the courts are pretty strict on grog running. People go to gaol when they are caught and prosecuted successfully for grog running now. They did not in the past but now it is quite common. There will always be people who slip through the nets we cast over the grog problem. Yes, we have to keep patching up those nets as best we can.

The Banned Drinker Register - PACC supports it. We asked, in our submission, that consideration be given to reintroducing it. We do not believe it will solve all the problems overnight. Unfortunately, the Banned Drinker Register was never properly evaluated so we cannot really say whether it was all that effective or not. Of course, people were tricking the

register by getting their cousins to buy grog for them if they were on the register. The operation in Alice Springs, Tennant Creek and Katherine of temporary beat locations is a kind of de facto Banned Drinker Register and it seems to be very effective, even though it is race based. I have had many complaints from Aboriginal people who say they hate having to see a black crow on a sandwich board outside the grog shop every time they go there because it makes them feel like they are rubbish. I even had one client who went to gaol for three months - he was so angry with the sign he ended up assaulting a police officer.

Madam CHAIR: What does the sign say?

Mr GOLDFLAM: The sign has a dot painting by Andrew Spencer Japaljarri, who was a police officer - I am sure the sign has been used with his permission - of a black crow which he used in a painting he did as a public health promotional campaign to represent people who got on the grog. The crow symbolised them going the wrong way in their lives. That image has been appropriated and placed on a sandwich board which police have outside Coles, Woolies, and the other grog shops in town, together with some text saying if you do not provide proof of identity, then we are going to confiscate the grog you buy - and proof of residence. Putting aside the text, which may actually misrepresent the extent to which police have the power to confiscate grog - we do not need to go there - a lot of people have taken great offence at the black crow sign because it is black. They say, 'That is about us black people'.

In Tennant Creek, the police have recognised it was so offensive they stopped using that image because they were asked to, and they did so. In Tennant Creek, in the Barkly, the black crow has a particular cultural significance, so it was an even more loaded picture. So, that is what it is.

Madam CHAIR: Okay, we might try and get a photo.

Mr WOOD: Has it ever stopped them complying? At this stage, are we taking them to a place where they are not allowed to consume it?

Mr GOLDFLAM: The latter but, after having had their carton taken off them a couple of times, people stopped buying, or find another way of getting hold of the alcohol which does not involve challenging police.

(Editor's note: Audio missing between 9:06:35 and 9:13:53)

Mr WOOD: Are more people asked?

Mr GOLDFLAM: I have never been asked. I do not know every single police officer in Alice Springs. I know a lot of them and they know me, so I suppose they know I am not likely to go and drink the alcohol in a place where I am not allowed to. Overwhelmingly, it is Aboriginal people who are challenged. This is not a criticism of the police officers. The laws introduced by the intervention are racially based. They say it is illegal to drink on a town camp. The only people who live on town camps are Indigenous people. So, by definition, the police are going to suspect people who live on town camps of offending, if they say they are going to drink at home. All those people are Indigenous so, it is just the way the law works it means that in practice this is a racially implemented procedure and it upsets people. It is effective and I am sure it saves lives.

Mr DURNAN: There are two situations with this looking at ID and checking on people buying alcohol. Police often have their temporary beat locations outside the drive-through bottle shops. In those situations, most, if not all, non-Aboriginal people would be asked to show their ID as part of the procedure because police are there not just checking on alcohol, but they are taking the opportunity to check on everything else - licences, conditions of cars, rego, all that kind of stuff.

Outside the supermarkets and the other little stores which have grog licences, generally police only check Aboriginal IDs or addresses when people come out with grog. Sometimes, if they have suspicions about people, they will talk to them before they go in. Some police sometimes also check non-Aboriginal people in those situations because they are trying to be more even handed and show they are trying to be more even handed. But, that does not happen a lot. So the well-springs of resentment, especially amongst young Aboriginal people, are growing all the time. The growth in serious complaints and negativity a lot of young Aboriginal people have about this whole situation is very noticeable, where they are perceiving unfair targeting.

Madam CHAIR: We had better wind it up because of time. Thank you, Russell and Bob, it is most appreciated.

Mr DURNAN: Could I just say one thing?

Madam CHAIR: Yes.

Mr DURNAN: The issue about the research that we have is our No 1 recommendation. We are not doing that just to be virtuous or to help the research industry. We think it is, in this case, an absolutely essential component for everybody in the Territory.

Madam CHAIR: No, no, that is fine. Thank you.

Mr GOLDFLAM: Thank you very much.

The committee suspended

CHAMBER OF COMMERCE

Madam CHAIR: Good morning, welcome, Kaye. On behalf of the committee, welcome to this hearing into action to prevent Foetal Alcohol Spectrum Disorder. Thank you for taking the time to come and talk with us today. This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply. 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 what you talk about should not be made public we can have the committee go into a private session. For the record, can you state your name and the capacity in which you appear.

Ms EADE: Kaye Eade, the Executive Officer for the Chamber of Commerce, Central Australian region. It takes in from Elliott down to the border and across.

Madam CHAIR: Do you want to make an opening statement or any comments?

Ms EADE: I was a little surprised about the request to present here because health is not one of our expertise areas. We mainly deal with businesses obviously, but in saying that the Chamber has developed the accord in Tennant Creek and Alice Springs - the alcohol accord - and the AHA is now taking over the alcohol accord in Alice Springs.

We continue to act as secretariat for Tennant Creek so in that capacity I could talk on the issues there, as well as from a business point of view, their views on serving pregnant women. A lot of them, as a moral obligation, do not serve them. A little business background is all I can offer.

I do not understand the health ramifications. I know the causes and I am not quite sure what capacity the Chamber can assist with this one.

Madam CHAIR: I guess the reason for - we have done it at all the centres we have visited - is because the Chamber of Commerce or business people are part of the community. This committee saw it as being part of a community where there are issues - all your members, and I guess that is the reason for asking you. It is not the health issues of people in management, but if people have FASD how does that interact with the community and with your members? Does it have any impact on business - the big picture? That was the reason for asking you.

We have asked the Australian Hotels Association as well because their members supply the product that creates the issue. I am not saying that is good or bad, but that is the reality. That was the reason.

I did not realise Alice Springs had an alcohol accord like Tennant Creek?

Ms EADE: Yes, it first started in Alice Springs. The licensees wanted an accord mainly because there was a lot of violence in licensed premises at that stage, a lot of glassing, underage drinkers and there was no law for minors. There were no penalties for minors to be on premise although the licensees were penalised heavily if an underage was caught on premise. One of the things I wanted to do was common barring so if an underager was caught on premises they were barred for 12 months after their 18th birthday, so they were penalised.

There were some consequences for their actions, whereas legally there is not because they are a minor. It caused them to rethink because they cannot go to dinner with their parents if the dinner was on licensed premises. Once they reached 17 and left school and got a job, if they did training courses in a licensed premise they could not work there, they could not do their training and also they could not work in the premise with a licence. There were penalties and at first they snubbed their nose at them and thought, 'That will not stop us', but when they discovered the penalties and the ramifications, we found underage drinking dropped right off.

Madam CHAIR: How many licensed premises would you have in Alice Springs? I know you have a lot.

Ms EADE: When I last counted there were about 33.

Madam CHAIR: How many takeaway ones?

Ms EADE: That is a hard one. The IGA are a part of it. The two major takeaway licensed hotels were not part of it.

Madam CHAIR: No, I mean generally not a part of the accord.

Ms EADE: Sorry, off the top of my head I could not tell you.

Madam CHAIR: There are 33 licensed premises?

Dr SCHULTZ: A total of 96 comes to mind.

Ms EADE: So, 96 takeaway …

Dr SCHULTZ: No, 96 outlets.

Ms EADE: Is it?

Dr SCHULTZ: Yes, extraordinary.

Madam CHAIR: We can find out from the Liquor Commission.

Ms EADE: The AHA would have an idea.

Madam CHAIR: Are most of the licensed premises involved with the accord?

Ms EADE: Yes, pretty much except the two major hotels are not part of it. I think they are now that AHA is involved because I think they are very heavily aligned with the AHA.

Mr McCARTHY: The Katherine Chamber of Commerce EO spoke about antisocial behaviour, litter and damage to business. The discussion then led into harm minimisation around alcohol. I asked the question specifically whether FASD is on the Chamber's agenda? Has FASD come up? Is it talked about? Are people cognisant of this issue?

Ms EADE: They are, mainly from the employable opportunities for Indigenous because everyone's goal in the NT is trying to get more Indigenous into the workforce. You have the

low literacy and numeracy skills to start with and, if you have the effects of FASD, the employability of certain people, obviously, is lower again.

This type of incident does drain on the community as a whole, mainly because of mental health etcetera, and the organisations that have to deal with this. You find a lot of these children are in foster care, and that also puts on a drain because foster carers are, obviously, volunteers, so there is only a limited number. It is just a whole range of things that affects the community.

Mr McCARTHY: Have you heard the Australian Hotels Association position on FASD?

Ms EADE: No.

Mr McCARTHY: Is that discussed or is that talked about?

Ms EADE: No, I have not heard. I have not been across it.

Mr McCARTHY: Did you mention that the AHA is now going to take over the accord in Alice Springs?

Ms EADE: In Alice Springs, yes.

Mr McCARTHY: So, probably then, it would be important to get that on their agenda.

Ms EADE: I think so. The Tennant Creek accord and Alice Springs accord worked in different ways. In the alcohol accord in Alice Springs, the licensees were concentrating more on violent and antisocial behaviour. Tennant Creek was more on restrictions of the sale of alcohol to try to minimise antisocial behaviour, so they worked together forming restrictions to help the community of Tennant Creek. They work in different ways.

Mr McCARTHY: We heard from Anyinginyi Corporation yesterday in Tennant Creek. They have done a lot of work there - probably led the Territory in a lot of respects in the education and awareness campaigns around FASD. Do you see some important links there for the Chamber to participate in - advertising and businesses promoting the awareness of FASD?

Ms EADE: Yes, it has been around. I have seen it and we did have it in our newsletters and things like that. I saw the one from Anyinginyi they produce, which is really good. However,

we have to be clear where we are. We are a business support organisation, so we are supporting business. The social issues etcetera are really out of our realm although, as a business community, we are conscious of that factor. But, the social and health issues we leave up to the experts because it is not our expertise.

The thing is, with many of our members, a lot of business is caught between a rock and a hard place because their bottom line is the dollar. But, they do have a moral obligation which I see a lot more in Tennant Creek. Since they have taken on these restrictions, their profitability has decreased about 48%. They have done that voluntarily, so it is a moral obligation and they have gone down that path.

Mr McCARTHY: No pressure, but I have three different types of advertising on the electorate office window. I often stop with the electorate officer and we watch people relate to it, react to it, read it. It is really a good feeling to see a young couple stop and actually check it out. It is a great feeling to see young kids pointing and articulating the visuals as well as the text. I see that as a small step we are doing in the campaign. It would be great if business would consider that as well.

Ms EADE: Are you talking about the Anyinginyi awareness program or …

Mr McCARTHY: Oh, there are three different types of material – basically, 2D visual material I have collected. They are in poster format, highly colourful, very …

Ms EADE: I have not seen those.

Mr McCARTHY: Oh, there are lots of material you can get around. CatholicCare has a good production out, Anyinginyi Aboriginal Corporation have some good material out. There are some general materials from the federal government. For any business interested in window space it is a great way to become involved.

Ms EADE: Yes, it affects the whole community. That was one of the reasons the licensees got together in Tennant Creek because there was so much broken glass etcetera causing havoc in the town. People could not play sport because there was so much glass on the ovals and the night time activities were getting out of hand. They had one of the winemakers make plastic bottles and that is in play now. There are plastic bottles, plus the restrictions, plus the TBLs and those three things have really made a difference in Tennant Creek. I do not go up as often as I used to, but about every four weeks I am up there and I can see the difference each time. It is making a big difference and the police were telling me assaults are down. The hospital is saying its intake of assaults and damage caused through alcohol is right down as well, which is good.

Mr McCARTHY: The accord in Tennant also mentioned they use posters in bottle shops and liquor outlets.

Ms EADE: Yes.

Mr McCARTHY: I found that to be very beneficial. It was good to hear.

Mr WOOD: When you said you did not how the Chamber of Commerce would fit into this discussion, what we know is people affected by FASD have some behavioural issues such as knowing right from wrong or a lack of fear. Sometimes those issues relate to criminal offences. Does the Chamber of Commerce see a relationship between people with FASD which might affect commerce simply because those people would break into premises and end up in the court system? Do you see that as something of concern from a Chamber of Commerce point of view?

Ms EADE: Yes, and business has suffered through break-ins. A common occurrence, unfortunately, is breaking into licensed premises. This year it has not been too bad; it has decreased quite a bit and the only time we find it peaks is if there are events on or something happening in Alice Springs that brings people from out of town. Obviously with the TBLs they cannot buy alcohol so they try to get it in other ways. That does affect businesses and the …

Mr WOOD: What is a TBL?

Ms EADE: Temporary beat location. That is the police …

Mr WOOD: What is the Chamber of Commerce view on TBLs?

Ms EADE: As a whole it is beneficial for the community and for business because of antisocial behaviour. It is beneficial for tourism because you do not see alcohol drunk in different pockets of town. I have not seen it like it used to be; it has really dried up. Behind the buildings and in laneways you would see groups all the time. You do not see that anymore. It has had a really good impact on tourism and the business in town.

Mr WOOD: Do you see it as not really different from the BDR because the policeman has an iPad and can check the person, whereas the BDR did the same thing except someone would swipe it and check who you were? Do you see one was better than the other or they could have done the same thing? It is obviously a cost to us as a community having a policeman

stand outside a supermarket instead of finding out who broke into the shop or whatever - doing other duties?

Ms EADE: Yes, the police say it is counteractive. Because assaults, break-ins and everything else is down they do not need as many police going after break-ins, assaults or domestic violence and those people can go on the TBL. It is the same amount of police, I believe. That is what we have been told.

Even though the BDR is not used anymore, in Tennant Creek the devices are still used for the ID because they have the restrictions in place. What it does is allows you to can scan the ID, like your driver's licence, so you know you have bought one bottle of spirits and one bottle of wine. So, they cannot go from one hotel to another because they are all linked up.

Mr McCARTHY: Is that part of their accord?

Ms EADE: That is what the licensees have chosen to do for their voluntary restrictions. That manages it …

Mr WOOD: Is it being considered in Alice Springs?

Ms EADE: I am not sure because, when they started in Tennant Creek, that is when the AHA took over the accord here. I am not sure if they plan to do that or not.

Ms MANISON: Alcohol management is an ongoing topic of this parliamentary committee, trying to reduce consumption and reduce supply for people. Do you feel the current alcohol management tools in place, such as the temporary beat locations and restricted hours and so forth, is something the business community supports? Would they like to see less, would they like to see more?

Ms EADE: The TBLs, although they were not welcomed to start with - people found it an invasion of their privacy or their human rights. A lot of people say it is a racial act. In the scheme of things now, with the town the way it is, there is less violence, less domestic violence, it is a good move, especially with businesses because they are not being targeted for acts of vandalism etcetera. We were going through stages here where there were about six or seven businesses with their windows smashed every night. Now it is just about nil. It is very rare now, so that is a welcome change. It is good for tourism, it is good for everything else. People are accepting it. Some of the licensees still do not like it, but they can see the reasoning behind it.

Mr McCARTHY: It is an interesting story because there was a school of thought that blamed the BDR for crimes relating to alcohol in Alice Springs. It was politically a very hot debate that because the BDR was starting to kick in and become effective, then people where then going to break in. The story around Alice was jumping the back fences and into the beer fridge. There was a very high profile case here from a politician. It is interesting now to hear the TBLs, which are very intense alcohol supply measures, have not incurred the same behaviours; that there is less alcohol getting out there. I am not convinced but it is an interesting debate.

Ms EADE: Yes. it is, but there are not as many people coming into town - the visitors only for certain events. That has helped. It is because most people know they cannot get alcohol when they come here. They cannot go on the splurges like they used to. There are still issues around. Tennant Creek still has the issues when royalties are paid; they still have that problem. A lot of people are working with the CLC to try to change the way they deal with royalties, because that does cause issues in the town.

Mr McCARTHY: Has the Chamber done any analysis around tourist comments with the temporary beat location policy?

Ms EADE: No, we have not. I am not sure whether Tourism Central Australia has. I am not quite sure whether they have. My concern with all these different restrictions in the different towns is it makes it very confusing for tourists. They come here and we have restrictions in Tennant Creek then, if they are driving up the track it makes it very difficult for them. It is very confusing. It would be good to see one …

Madam CHAIR: Consistency.

Ms EADE: Yes, consistency across all towns, especially in the Dry Season when you have the grey nomads going through. It is awfully confusing for them.

Mr McCARTHY: I was very politely asked to purchase wine in the Coles car park - a very convincing argument. I bought into it a bit more to do a bit of research. Yes, it seems to be a fairly active lobby. I have also made mention to our senior police in Tennant of the exploitation of the temporary beat locations that are already word around town. It is going to be interesting policy.

Ms EADE: With secondary sales - I think licensees have come on board with that also. If they find people are buying lots of alcohol the licensee knows they will not drink themselves they alert police. They are negotiating and working together on that issue as well. You will

not fix the whole lot. There will always be somebody there, but at the moment they are working together.

Mr McCARTHY: Is the Chamber aware of any increase in the sale of home brew kits?

Ms EADE: No, I am not.

Mr McCARTHY: It would be interesting to talk to supermarkets about that. I have also articulated that with police because that is definitely one to watch in the future.

Ms EADE: Yes, you get all that online as well so that would be very hard to monitor. I know Alice Springs people buy a lot of wine online. As you can see, we have a got a new storage set at the post office. There is a lot of wine bought online.

It was only erected three weeks ago. It would be interesting to see whether they do - the post office - the big shed they bought for all their online buying. I know a lot of the local wine reps in town are not real happy about it because …

Madam CHAIR: It is a commercial reality.

Ms EADE: It is.

Mr McCARTHY: Are you aware of the Chrisco Hamper issue?

Ms EADE: Yes.

Mr McCARTHY: Did Alice Springs have a problem with the Christmas hamper?

Ms EADE: No, but the communities – there was a lot in the communities.

Mr McCARTHY: Borroloola definitely led the way.

Ms EADE: Did they?

Mr McCARTHY: Yes, I can assure you. That is another example of online, and I took that to government for alcohol policy development because the shift to online sales and the Chrisco Hampers, with considerable high volume alcohol and a packet of 2 minute noodles, was certainly an issue for Christmas then.

Ms EADE: Did they fix that? What did they do to address that?

Mr McCARTHY: The police confiscated the lot in Borroloola - the last big hamper delivery. The police confiscated a lot of the hampers taken into prescribed areas and it became a very sensitive issue because the community were not happy about it. Essentially there were other items in the Christmas hamper - there were toys and people had contributed over a 12-month period. The legislation around the prescribed area allowed police to confiscate them. There was also another issue where police confiscated the container and held it to look at a managed distribution of the hampers. The container was broken into and a lot of the hampers were stolen one night.

Once again for the Chamber's knowledge, the online sale issue is another example of real exploitation of alcohol policy.

Madam CHAIR: We had better wind it up because I am conscious we are over time. I will find out about that. Thank you, Kay.

Mr McCARTHY: You thought the chamber did not have much to say.

Madam CHAIR: Thank you very much, Kay. You will get a copy of the transcript to check everything you said is correct. Thank you very much.

The committee suspended

PUBLIC HEALTH ASSOCIATION

Madam CHAIR: Good morning. I am sorry we are a little behind but we will catch up; we will be right. On behalf of the committee I welcome you to this public hearing into action to prevent foetal alcohol spectrum disorder. Thank you for coming and spending your time before the committee, we appreciate it. This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply.

A transcript will be made for use of the committeeand 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, we can go into a closed session.

For the record can you state your name and the capacity in which you appear here today.

Dr SCHULTZ: Dr Rosalie Schultz. I am here as the Branch President of the Northern Territory Branch of the Public Health Association of Australia.

Madam CHAIR: Okay. Have you some opening comments you would like to start with, or a statement?

Dr SCHULTZ: Our submission really focused on the third term of reference, which is about prevention. We did not put energy into the first two terms of reference about prevalence and nature, but we just focused on actions the government can take to reduce FASD based on evidence and consultation.

You will be aware that just before this inquiry, there was the national inquiry into Harmful use of Alcohol among Aboriginal and Torres Strait Islander Communities. That really upset me because it makes it almost as if harmful use of alcohol is a feature of Aboriginal and Torres Strait Islander communities, and it completely overlooks the huge amount of harm done to the non-Aboriginal community. I can see, even in the previous speaker, we had this little hint that this is an Aboriginal problem ...

Madam CHAIR: No, it is not.

Dr SCHULTZ: I say alcohol is an Australian problem. When we think about how we are going to reduce harm from alcohol in Australia, we need to look at a community-wide response. By stigmatising Aboriginal people we may actually make it more difficult to deal with this because we further stigmatise the most disadvantaged group. By recognising it is an Australia-wide problem, we can work together to get a solution that is going to work for everybody.

Madam CHAIR: No, this committee is looking at across the Northern Territory.

Dr SCHULTZ: I appreciate that. Absolutely.

Madam CHAIR: That is one of the challenges or dilemmas we face, not only as the committee, but also as a community. We do not know how far the problem goes - is it black, is it white, is it both, is it more remote, is it urban, or is it just everywhere? Are there pockets where it is higher? Clearly, there will be and for reasons.

One thing I know we do not have, is we do not have good data collection.

Dr SCHULTZ: Absolutely, yes.

Madam CHAIR: We have lots of anecdotal information. It might be - what is it? - 20% of prisoners could be FASD affected of some kind which is, obviously, 1000, 20%, that is 200 - if my maths is right - or thereabouts. There has been quite a lot of focus on the Aboriginal side of public health because they are the people who have come before the hearings. But, it is a broad spectrum …

Dr SCHULTZ: Yes.

Madam CHAIR: Some people indicate it might just be that problem, but it is not. Probably, more of the hearings in Darwin have been a bit more broader than places down here. Do you want to start with any comments or questions?

Mr McCARTHY: Dr Rosalie, in your medical training, how much time or energy was spent on FASD and foetal alcohol syndrome?

Dr SCHULTZ: I am going to show my age here. I can say absolutely nothing. There was absolutely nothing in our training related to the teratogenic effects of alcohol, nor even the carcinogenic effects of alcohol. I note I am Western Australia trained and many of my trainers - the doctors who taught me – have shares in those vineyards in southwest Western Australia. I suspect they did not want to hear harmful effects of alcohol because that was their side business besides being doctors.

I am a bit older than I look, and it certainly has become more of an issue. It is in the more contemporary medical courses, but I could not be confident of that.

Mr McCARTHY: The medical professionals we have talked to as a committee, tend to put this whole issue in a spectrum of disorders and syndromes, and there is a reluctance to diagnose. Do you share that professional opinion?

Dr SCHULTZ: Part of the reluctance is related to the difficulty of it. It is not a blood test or an examination finding, it is a syndrome of multiple criteria across four different aspects. I am speaking outside my area of expertise, but part of the issue is the difficulty of it. As a primary care provider, our role is to screen and identify people who might be at risk, and refer them on for specialist diagnosis. I guess I am also more comfortable talking about the preventive element and that is what our submission focused on. It is quite obvious to me that you can prevent foetal alcohol spectrum disorder either by preventing pregnancy or by preventing pregnant women being exposed to alcohol. That is where I am more comfortable speaking and, looking at the recommendations we have made, there are elements of both improved sexual education so we do not have unwanted, unexpected pregnancies which might be at risk of alcohol exposure. If we have better sexuality education that is less of a risk in itself. Alcohol aside, that is an area where we can reduce the prevalence of this devastating condition.

Mr McCARTHY: In the essence of this inquiry and the potential to make recommendations to government and government acting in the Northern Territory, you would really put a big emphasis on the education and awareness component and the prevention of …

Dr SCHULTZ: Basically sexuality education. I know there some work was done recently with adolescents and, sadly, our teachers currently have minimal training in sexuality education and assume kids will work it out on their own, with disastrous outcomes. You have an unwanted pregnancy and the risk of alcohol exposure, whereas if pregnancy is planned and wanted people can behave in a safe way during the pregnancy.

Mr McCARTHY: This morning we heard some very strong comments about education and awareness not being an effective tool.

Dr SCHULTZ: We can certainly prevent pregnancy. It is well documented that if kids know about contraception they use contraception completely outside the area of alcohol. I am not talking about preventing alcohol exposure specifically, pregnancy generally - there is very good evidence of the effectiveness of sexuality education. Often it is too late. By the time kids are 15 or 16 is way too late, but in the pre-adolescent phase - nine and 10 year olds - teaching them about sexuality is absolutely effective.

I am not talking about alcohol. I agree, teaching people about FASD may or may not have any usefulness in preventing it, but if you make them aware of contraception and better availability of contraception and no shame to access it, that is one way we can prevent pregnancy as a whole, prevent all unwanted births and thereby also prevent unwanted births that might be alcohol exposed.

Mr McCARTHY: What is your understanding of the cultural sensitivities around pregnancy and the discussion of pregnancy within the Aboriginal community?

Dr SCHULTZ: It is changing dramatically. There is a government program the name of which eludes me at the moment, but going into schools and working with the teachers to build up their confidence in talking about sexuality and working with the children or the young people to find out what they know and build on that. Cultures around sexuality can change amazingly quickly, and we can use cultural sensitivity as a barrier to what we know is good practice. Everywhere in the world they can teach sexuality. To say, 'Aboriginal people, it is racist, you cannot do it,' is regressive.

Mr WOOD: Some Aboriginal groups also have difficulty in – taking up what you were saying - it was not their cultural belief? My wife is Aboriginal and she knows that some girls should not have any dealings with those boys because they are not the correct skin group. It is easy to put that all in with sexuality and sort that out, but there are other sensitivities that are sometimes western ideas and not necessarily the same ideas the Aboriginal people believe in or accept. Their relationship in having a child may be a slightly different approach to what we have.

Dr SCHULTZ: Let me tell you, children are conceived in the same way in all cultures.

Mr WOOD: I realise that. I did not mean in that sense, but they sometimes have a difference focus than we have because of their cultural beliefs. I am not talking about whether they are Christian or anything like that, but from my understanding of my time with living with Aboriginal people, sometimes I feel it is a little different than the way I was brought up, especially in relation to family, which is much broader, and their excitement about children. All sorts of things are different. I do not know how you can (inaudible) one thing fixes all, one approach fixes all.

Dr SCHULTZ: I am certainly not suggesting that one approach fixes all. I am suggesting that appropriate education programs about sexuality can reduce unwanted pregnancy.

Madam CHAIR: When we were talking about it is not exclusively an Aboriginal issue - and it is not - in your work and through your public health association - this is partly from some feedback we have had - is there enough information out there - forget the Aboriginal communities for the time being – in the white communities, for young girls warning of FASD? I only came across FASD a couple of years ago, for whatever reason.

Is that a role of government such as the Department of Health? The example I use is - we all know you should not smoke. We are hit with it every day - quit smoke lines, thingy

cigarettes, cigarettes are bad, plain package wrapping, hidden behind doors now. But, there does not seem to be the same level - and perhaps that is something that might come out of this committee - you have to up the ante considerably to let everyone know you cannot drink ...

Dr SCHULTZ: The message about alcohol is a bit more confusing than the message about tobacco. Tobacco is always bad for everybody, whereas alcohol can be drunk safely by some people some of the time. So, there is a little more nuance to be giving the message about that. It does not justify it, but it is one explanation why it is more difficult to put a clear message. The alleged benefits of alcohol to heart disease are now almost completely discredited. I say almost because there will still be people with good backgrounds saying that. It has been grossly overestimated to suggest that alcohol is healthy for anybody ever, but is not unsafe for everybody all the time.

Madam CHAIR: We probably do need to have better education, as you said, into the school system, apart from sexuality and contraception, also about particularly females, that …

Dr SCHULTZ: Then we are in this area where it is not clear that is useful. Education is one thing. People educated about smoking still smoke. A public health approach which is effective is increasing the price. We know that reduces consumption. It particularly reduces harmful consumption. It particularly reduces consumption among the less well-off. That is a much more effective strategy for reducing all alcohol-related harm, particularly FASD, than trying to teach people how much alcohol is safe. We need to have a clear guideline so people are not deprived of knowledge. Obviously, people have the right to know, and NHMRC has put out a very strong, clear guideline of how much is safe to drink. But, as a means of preventing alcohol-related harm, it is a bit less clear.

Ms MANISON: Rosalie, we were having a discussion this morning with the People's Alcohol Action Coalition group. One of the ideas they put in their submission is talking about when you identify a woman who has a problem with drinking, and they are pregnant, your child protection system to go and intervene with some compulsory measures in education, support, which I would expect would be delivered by health professionals in some cases and in some ways. Do you think there would be benefits to health professionals getting involved when a woman is pregnant and is identified as having some drinking issues, to try to help them work through it?

Dr SCHULTZ: There may be benefits. However, we know the central nervous system is formed by about three weeks post-conception. Nobody knows she is pregnant, not even the woman. That is not going to prevent FASD. It may make it milder, it may reduce other adverse effects.

PAAC is very clear that many of the effects of alcohol are postnatal; that you have these terribly chaotic households with alcohol, poverty and domestic violence. Yes, they do a great deal of harm even beyond the FASD. If we really want to prevent FASD, it has to be community-wide. You have to be protecting women from alcohol before they are pregnant, or stopping them getting pregnant, because the most toxic effects of alcohol are so early in the pregnancy before she can get to the court process - even before she knows she is pregnant. It is coming at it from the wrong end.

Ms MANISON: I know you are talking about the alcohol floor price, but I am curious to know if you think there is value in strong communication activities and advertising with public health messages around FASD. Do you see much effectiveness in those type of campaigns?

Dr SCHULTZ: I guess that is where you need to do good social marketing. I do not know; I am not at risk of FASD so I am not your target audience. I do not know what is effective and I think there would be good evidence from elsewhere of what is effective. I know raising the price of alcohol is effective across the community and that is one useful strategy. We need to look at local information and what would affect local people who are our target audience. I do not know what would be affective for them. I think even that image of a pregnant woman and the beer and a big cross through it misses the point. That baby is already affected by alcohol. Yes, it is good to stop her drinking for many reasons, but it is probably too late to prevent FASD.

Mr WOOD: The issue I am interested in is whether a mother who has been given all the advice not to drink - I will come back to something you said before - and continues to drink - the issue is whether a person should have a court order to say they are required to stop drinking and they might have to be held somewhere. I am not talking about criminalisation because that could be done in a cultural or community sense where they are assisted. It is a bit like alcohol mandatory rehabilitation, whether you believe it or not it is a way of restricting someone access to alcohol. My concern is you are saying the most dangerous time is preconception and after conception up to about six weeks. The idea of holding someone against their will to protect the unborn - are you saying that after six weeks …

Dr SCHULTZ: I would not say that at all, no. No, that is stretching the point.

Mr WOOD: … there would be very little advantage - I am trying to see, if you went down this path, is it a waste of time or would it have some benefit?

Dr SCHULTZ: Yes, it would have some benefit. In general, better access to better quality treatment and rehabilitation services is certainly a good investment.

Mr WOOD: I am putting this up more as a last resort. You have provided the education. That person may have an addiction. It may be so hard for that person to give up. It might require the government to say, 'We now what the effects of FASD are'. If we, as a government, can make some decisions which will prevent that happening or make it worse - we need to intervene even though it might be pretty drastic. Do you think that has some benefit? It has to be done for compassionate reasons, not locking people up and throwing the key away. It has to be done with community support and compassion. Do you see a role for that to occur in the whole process?

Dr SCHULTZ: It is certainly part of the whole process. I guess the other side of that is we need to have the community on board. The community support is the potential accusation of misogyny - men are not locked up for drinking - so we have to be very clear the community understands the benefit.

Mr WOOD: Men do not get pregnant.

Dr SCHULTZ: That is right. Of course, the woman might want that. If she is addicted and cannot stop drinking some legislative support to make what she knows it is the right decision - it is only her addiction that stops her - might mean the person who is having the measure against them may support it. It is only the addiction that stops them from entering alcohol treatment otherwise.

Mr McCARTHY: An interesting anecdotal position is the presentation of children in Australia with complex behaviour and more challenging behaviours is increasing. Does the medical professional have any evidence to support that?

Dr SCHULTZ: There is certainly evidence all over the place that we are getting more pre-term births, more low birth weight and more poor growth in infancy. Despite a generally healthier population, there are many aspects that appear to be getting worse and behaviour problems in childhood and adolescence absolutely. I suspect there are many causes of that and it would not surprise me at all if alcohol is one of many parts of the complex changes happening across society - family breakdown, women in the workforce, all these things happening in society. Certainly, we are seeing alcohol consumption probably not increasing though, is it? We are seeing more and more of this high range binge drinking but, as a whole, I do not think we are drinking all that much more over time.

Mr WOOD: Yesterday or the day before was that announcement the Territory is miles above everybody else. We may not be drinking more, but the Territory is drinking more that the average for the rest of Australia.

Dr SCHULTZ: Sure. It has done that consistently since it was first written there in 1990s. So, that is nothing new. But, we are actually reverting towards the mean, aren't we? We are actually slowly coming down?

Mr WOOD: I live next to the bottle shop - two bottle shops ...

Dr SCHULTZ: Obviously, an anecdote of one person saying that is in a bottle shop does not tell you what is happening across the population.

Mr WOOD: No, I know. Regardless of whether it is going up or down, it is very much a part of our culture.

Dr SCHULTZ: Yes. One of the things we are seeing is more and more young - and very young - people drinking extraordinary amounts, which is …

Mr WOOD: They are non-Indigenous, many of those.

Dr SCHULTZ: Yes, across the population.

Madam CHAIR: All Territorians.

Mr WOOD: Yes, true, but there is a lot of spirits being used.

Madam CHAIR: Alcopops.

Dr SCHULTZ: That is the young people, young women, we cannot stop them drinking but maybe we can stop them getting pregnant.

Madam CHAIR: Correct. We are out of time but, thank you for coming in, Rosalie. That is much appreciated. We will send you a copy of the transcript *Hansard* for you to check make sure everything is accurate. Thank you very much. It is much appreciated.

Dr SCHULTZ: Thank you. Good luck.

Madam CHAIR: It is a big problem.

Dr SCHULTZ: It is a big problem. Thank you.

The committee suspended

CENTRAL AUSTRALIAN HEALTH SERVICES

ALICE SPRINGS HOSPITAL

ALICE SPRINGS COMMUNITY HEALTH CENTRE

Madam CHAIR: Good morning and welcome. On behalf of the committee I welcome you to this public hearing into actions to prevent foetal alcohol spectrum disorder. Thank you for giving us you time today. This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply.

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 may say should not be made public we can go into a closed session and take your evidence in private. For the record, can you state your name and the capacity in which you appear today.

Dr DELIMA: Dr Jennifer Delima and I am here as an addiction medicine physician and clinical forensic physician for Alice Springs Hospital, Central Australian Health Services.

Madam CHAIR: Do you have opening statement or are there any comments you would like to make?

Dr DELIMA: I would. I have prepared a handout for each of you because there is a lot to be said about this. I thank you very much for the opportunity and will try and be as succinct as I can.

I have had the fortune to work in the Northern Territory since 2000 across many areas, including remote and mainstream urban general practice in Central Australia and the Top End.

Additionally, I have worked in custodial medicine in Alice Springs. That was exposure to our juvenile justice kids, and also through sexual assault providing services for adults and children as well. For the last few years it has been primarily in addiction medicine.

My exposure to FASD has been quite huge and has made me quite passionate about it. Importantly, before I start answering questions from the terms of reference, it is important for us to touch on the underlying demographics. If we look at Australia's alcohol consumption rate, we sit 30th in the world.

However, if we look at the Northern Territory as a country on its own we move to second place. A lot of the data we extrapolate to get prevalence, ideas of FASD, of FAS - so the syndrome which is part of FASD, the spectrum disorder - is taken from data from the United States, from South Africa, from Europe where the United States is about 33rd in the world in alcohol consumption. South Africa is 53nd and Europe about seventh and eighth. We are well above that amount so we need to extrapolate a bit more of what we are experiencing.

On that handout there is a map of the world and, essentially, Australia or our end of the world is still in yellow with minimal alcohol impact on the community yet the Northern Territory is red. We really have a huge problem. Importantly, if we look at the stats for our alcohol consumption it is women of childbearing age, both in binge drinking, as well as ongoing regular drinking, that is a problem. Further to that, our problem is our population generally, and our women in particular, are dropping in their beer consumption and are choosing the more concentrated alcohols, the spirits and the wines. So, this problem gets magnified even more.

Importantly, over the last 10 years, our alcohol consumption per capita has been rising. Further to that, 47% of pregnancies are unplanned and occur in the social context. Our Australian cultural social context is alcohol. So, that pregnancy at conception is alcohol exposed. Further to that - and I think Rosalie alluded to it - 58% of women continue drinking alcohol during that first trimester of pregnancy because they are not aware they are pregnant. We know worldwide that this is the leading cause of intellectual disability, and we need to start recognising that.

From an adult perspective, drinking alcohol is a reversible effect. There are impairments to these cognitively, behaviourally, but they are all reversible. Stop drinking the alcohol and you have the ability to reverse, unless you get so far down the track into structural damage. From a foetal point of view, from the moment of first exposure this is permanent and irreversible.

We know we may not pick up every child or every foetus in advance proactively, but if you miss that chance and miss our second chance at managing these kids, then we get to what we call a secondary disability. The impact of the brain injury then being expressed is our secondary disability, and 94% will go onto secondary disability if we do not step in. When they have looked at data from overseas, 60% of young offenders actually meet FASD

criteria. It is something that is highly preventable and we do not need to be still in this position, or looking down the barrel of this gun.

When we are looking at alcohol, it is a poison, a teratogen, and those two things are important to note. For us adults, it is in that poison category only. For our foetuses, it is a teratogen. That means that any exposure to this will cause defects and malformations in the foetus. That is what we are talking about when we are seeing FASD. How do we know all of this? The FAS, or the foetal alcohol exposure effect, has been described for ever and ever, from as far back as 800 BC. There are longitudinal studies, cross-sectional descriptives saying if you drink alcohol your child's brain will be fuddled. We have that evidence and it goes back to biblical times.

Then, we have autopsy results from about 1973. These were by paediatric dysmorphologists. These are paediatricians who look at the odd facial build of a child, the odd structures, and that sort of thing. That was in 1973 when they described FAS, the syndrome – the most acutely affected infants and mothers with a heavy alcohol intake. It was the same thing they were seeing in each of these children, hence we have the FAS described.

Then, further to that, around that time, they were working with a lady called Anne Stryska who is a neuropsychologist, who did a lot of testing on some of those kids who were evidently developmentally and mentally disabled. She demonstrated some characteristic deficits in their behaviour. Then, more recently, we have our neuroimaging - our fancy MRIs, functional MRIs, and MSRs. All of that is adding that information so we can no longer say this is just a moral stand - there is real anatomical stuff happening.

On that page, there is also a picture of the world with some stars dotted around. Those stars depict where we have FASD diagnostic centres. None of them are on our side of the globe. They have done a lot research and it has been going on since the 1980s.

When we come to FASD itself, this is a term - it has only been formally recognised since 2004, so it is only of recent times that we are recognising it.

In the 1980s we started to recognise FAS itself. That was obvious clinical abnormality, the face was different, the heart was abnormal, the kidneys were not normal and these children were – their IQs were on the lower end of normal. That was in the 1970s. From 2004 we were beginning to realise alcohol has other effects and not necessarily as bad as the FAS, which is only a tiny amount of the whole of FASD. The syndrome is only about one-tenth of the whole of FASD spectrum disorder.

The prevalence data quoted in the United States is FAS.2 up to two per one thousand live births. On top of that you have the FASD. They quote their rates at between five and 10 per one thousand live births and probably increasing as we begin to understand more about FASD.

Do not forget the United States rate of alcohol consumption is 33rd in the world. If you take those numbers - prevalence data - and take it to second place in the world in consumption we have a major problem or potentially a major problem on our hands.

Looking at your question on the nature of injuries and the effects of FASD, how does this all work? Essentially, what we are looking at is alcohol on that foetus. Whatever mum drinks rapidly goes across the placenta and is equated in the foetus. The problem with that is mum and bub have the same blood alcohol, but the foetus' liver which breaks down alcohol does not start to function until about the 10th week of gestation and does not have the capacity of mum. That foetus only has 10% of the enzyme to break down alcohol and whatever is left over roams around in the amniotic fluid and becomes a reservoir of continual alcohol exposure. Not only is there alcohol exposure, but the duration of the exposure for that foetus is much longer than mum's drink.

Madam CHAIR: Because it cannot go anywhere.

Dr DELIMA: It cannot go anywhere; it is stuck there. We know alcohol is a toxin, a teratogen, a poison. It works by inhibiting cell growth. It stops cell growth, cell migration and stops neurochemical development, apart from stopping cell growth generally through the body. The FASD kids have cardiac abnormalities and renal abnormalities on top of that.

Madam CHAIR: If the mother was a binge drinker and the alcohol is still going around, why does it not kill the foetus?

Dr DELIMA: Some do. We have a higher rate of spontaneous abortion, a higher rate of still births, a higher rate of intro-uterine growth retardation; these bubs are born small and shrunken - not all, because we are talking about FASD.

Often people will throw up. However, this mother drank, the baby is fine, the kid succeeded, the babe is fine and there is not an issue. We do not know the whole story. It is only since 2004 and only since the 1980s that we are looking at alcohol from that scientific point of view. We do not know what the protective factors are. There are genetic factors, nutritional factors, resilience factors and nurturing factors that might mitigate.

That chart shows little foetal images going along the page and you see the top line is the central nervous system - CNS. That is our central nervous system, our nervous tissue, our brain and our nerves continue to develop right throughout the pregnancy. That is why this is so important that there is no alcohol throughout the pregnancy. It is not like some of the other things we see with toxoplasma - your most sensitive period is in the second or third trimester. This one is right through.

I have on the next page the three trimesters divided - what is actually happening in each of those. In the first trimester we are looking at how the brain cells migrate for the face. So, we get these faces that are typical. And general growth deficiencies is what we see.

In the second trimester, we are looking at the neurotransmitters for the brain and, often times, the rewards transmitters. These are the things that these kids later go on to their substance use behaviours, because their reward triggers have been poorly formed.

In the third trimester, we are looking at white matter. Our brains are made of grey matter/white matter. The white matter is the sheath around the nervous tissue. It is a protective one and it also allows transmission of messages from one part of the brain to the next part of the brain. That is affected in that third trimester so that we lose our ability to go from our reward centres in the middle of our brain, out to the front of our brain where we think and decide and make decisions. That bit is destroyed then.

We have this add-on effect of impact on that brain. We know, with the FAS - there was a lot of talk in the 1980s about FAS and we did not see too much this secondary disability. Why? Because the kid looked the part. The kid looked disabled, so we could identify and know immediately. Very few of those kids go on to secondary disability.

FASD, though, because it is a continuum of impairment, has secondary disabilities. The child, the adolescent, looks normal, they speak normally, but their comprehension and their learning behaviour is where we are stuck. That disability is lifelong and continues on. Within that, there are specific areas of the brain that are more than otherwise affected, so the brain might be shrunken, the corpus callosum which allows connection between different parts of the brain, areas of the brain that deal with memory, emotion, understanding, comprehension, consequencing - all of that gets affected.

What we are looking at is adolescents who then commit a crime because, ‘That is what I was doing’. They get pulled up by police - how many times? I have seen that in the juvenile justice. They are pulled up by the police - ‘You should not be throwing a brick through that window otherwise you will end up in trouble’. ‘Ah yes, I do know that’. Two weeks later, same thing, and they have not learned it. Three weeks later, and we are doing this again and again and again, because they have not understood. Yes, at that point in time they can

say, 'Yes I understand', but this is a different shop, this is a different brick, this is a different environment. They cannot actually match or join the dots. For what many of the neuropsychologists have looked at, they have put together any acronym called ALARM, which describes the behaviours these kids demonstrate. ALARM stands for adaptive behaviours – often, inappropriate sexualised behaviours, which might account for why we see so many young kids who are offenders and we cannot find any good reason why they should be offending. They have not been abused themselves. Why, therefore? Often times, when I was doing my sexual assault role, it was, 'Was this possibly an FASD kid?' In many cases, yes.

There are abnormal eating behaviours and team relationship difficulties. They do not stand in the classroom well. The teacher is having difficulty keeping that child as part of the group. So, these kids get kicked out of school early. Their attention is poor. One of the major mental health disorders as a result of FASD is ADHD. It is an attention disorder, neurotransmitter problem, and that is all that ongoing problem.

Their reasoning, as I said before, is poor and they have memory problems. Hence, that recidivist behaviour.

On there I also have a bar graph demonstrating chronological age at 18 with foetal alcohol exposure. That demonstrates what an 18-year old FASD person is functionally doing. Emotional maturity is only that of a six-year old. Their social skills are only that of a seven-year old. Their living skills are only that of an 11-year old. These are quite dramatic things because if at 18 you are only at a six to 11-year old status you will not be able to achieve independence. It becomes a community burden, however in their physical appearance they are as an 18-year old and in their expressive language as a 20-year old. We mistakenly think they should understand and should know what is going on but they keep returning with more problems. Because of that immaturity, that neurological impact and that learning impact you get on to secondary disability.

We have a higher group of these people needing mental health services who are disruptive at school. As the child gets older the magnitude of the disability becomes greater. A two-year old may only behave like a six-month, a six-year old might only behave as a four-year old, but a 12-year old may only behave as a six-year old and an 18-year old as a seven-year old. The magnitude of discrepancy enlarges. The problem is huge for the families because they are trying to deal with this chaotic child and, if alcohol was one of the precursors to that pregnancy because of chaos and poverty and lack of social supports, then this whole thing is magnified. The feeling of failure for that parent is magnified and we say, "Why can't you look after and discipline your child?' but this is a very hard case.

There are lots of things to look at. Importantly, we need to note the history - this child was exposed to alcohol and there are a lot of screening tools we could use at every stage of that

child's development. Importantly, if we remediate early less than 15% go on to secondary disability. These are the stats and the evidence from Canada, the United States and South Africa.

Mr WOOD: What year are we talking about for remediation?

Dr DELIMA: For remediation?

Mr WOOD: Yes, how old?

Dr DELIMA: Ideally, if we can get these kids before the age of six. Before the age of six the impairment is not as evident, but if we identify a child with possible FASD, and we keep an absolute busy eye on that child and start putting in remediation - appropriate psychotherapy, appropriate behavioural measures - for these kids, then we actually minimise that and bring it down to less than 15%. If we do not do it, it goes towards that 94%. If we can even get these kids up into adolescence, pick them up in adolescence and support them, identify to them this is why they are having difficulties, then you are starting to break the chain. You are starting to identify it, you are starting to break the chain and help those families as well. However, once the person gets to adulthood, then it is support for that person. We cannot do any remediation really, not in a great way. It really is a big ask then.

I have put down a list of possible things to do to mitigate against FASD. Importantly, we need to recognise this early as a lifelong disability and put supports in. We are needing to develop some appropriate tools and resources to assess, diagnose, and remediate every state in that individual's age. We do not have any standardised tools at present. There is …

Madam CHAIR: Why can you not? Or why have they not – the medical …

Dr DELIMA: It is just partly because it is only since 2004 we are starting to know about it, or worldwide know about it. Australia has only picked it up in the last couple of years. I remember going to a child protection conference in America in 2006. We were struggling with the kids here through sexual assault, with the adolescents through addition medicine - what do I do, why am I not getting through for a number of them? There it was - a light bulb moment - this is probably what we are looking at because these kids met the criteria. We do not have services or resources to do that. We actually need to garner some support and work groups to be able to do that. Currently, we are trying to do it on borrowed time at the end of the day and outside of things.

It needs some real backing to make it happen. We need diagnostic centres this side of the world, and multi-disciplinary teams at that. Having said that, we know that alcohol use is taken up more in rural remote regional areas. For us in the Northern Territory, we could call ourselves in that regional remote zone. So, services like MRIs, diagnostic services, neuropsychologists - we do not have. We need to have something that at least is tiered. I do not expect every one of us to have all the services you have in a big city, but we need to have something that is tiered so you can do this amount assessment and provisional diagnosis in the remote community, then you move it up to the next chain and the next chain, and that might help us get somewhere closer to this.

We need to improve access in high-prevalence regions for education and correctional facilities. That is where we are seeing most of these kids. They are not physically unwell, but they have a mental disability. We need improved family and carer supports so we de-stigmatise this. The adults who are looking after these adolescents and children are struggling.

Further, we need to develop more appropriate and safe detoxification residential rehab places that acknowledge women and children, families, adolescents and their family so we actually can do something. We do not have any in Alice Springs. As Rosalie mentioned before, we really need the collaborative teams of Health, Education, and Justice together. We are currently approaching it from each one's angle, and we need to come at it together. It needs appropriately resourced and skilled trained workforce that really know where they are at. Otherwise, we will keep going in this never-ending spiral.

Madam CHAIR: How many children are born at Alice Springs Hospital you would think would be FASD, anecdotally?

Dr DELIMA: I do not know. I can find out. Historically we have never - because alcohol is part of our positive culture we have not taken a great interest in getting that alcohol history and it is taboo land. If you ask about alcohol it is like sex, drugs and religion. You do not do that. We need to break through and start bringing it on board as something that needs dealing with.

Epilepsy used to be the devil's disease; everyone was possessed by the devil. We still treat alcohol in that manner.

Ms MANISON: Can I ask about knowing somebody has FASD before they are six years old so appropriate strategies could be put in place to give them the best chance for a good life? Granted we do not have a diagnostic tool set in the Territory, how easy is it today to get a child that presents itself - you know there is a history of alcohol - to look at that under the age of six and recognise if they have FASD?

Dr DELIMA: It is difficult other than we can get the history. Physically they may not have any signs. Their face might be normal and they look otherwise fine. Behaviourally, from talking to a number of teachers, they describe quite clearly the behaviours and learning deficits in those children. In picking those up and starting remediation on that it is simple things like that child needs to be in a quiet environment and not so stimulated. Their brains, when they do functional MRIs, they are asked to do a simple task. You and I, when we do a simple task, need a couple of areas in our brain to light up. These children are asked to do a simple task and the whole brain goes into overdrive. They expend a lot more energy to do that very tiny thing and it creates havoc for the child. Learning to provide them an environment that allows that quiet ...

Ms MANISON: This committee will be putting a report together and recommendations to the government. Would it be your view a uniform diagnostic tool to diagnose FASD should be introduced in the Northern Territory?

Dr DELIMA: Ideally, yes. However, there are some tools out there and we do not need to reinvent, we need to modify it to our environment. Things like the facial characteristics - at this point we do not have benchmarks for our population. We have benchmarks for the Caucasian population, we do not really have benchmarks for our Indigenous population and we have so many other people here. That is a soft one. It gives you FAS and we all know one, but it is the behavioural disorder we need to get on top of.

Ms MANISON: If a child is to go through the process of being diagnosed with a form of FASD today, are there formal processes that follow for recommendations or support? You talked about the remediation tasks, so we do not

Dr DELIMA: We do not have services. Recently the paediatricians and myself and a group of others that were interested actually tried to put together form a working group outside of our normal (inaudible) of work to see what can we do, how can we start in-roading on this and the (inaudible) response from a lot of people is, but if we identify, what next. What will we tell these families, what will we tell them. Yes you have potentially FASD, but we have got nothing to offer you.

Madam CHAIR: And then you have got the issue of the mother then thinking well you have identified my child as FASD, are you accusing me of being a drunk.

Dr DELIMA: Exactly and that poor mother, the reasons for her to be drinking, we need to support and we need to be more proactive rather than say, oh well you naughty, naughty. There are reasons why people use substances and we need to be supported by that to bring them out into an environment where there are positive outcomes.

Mr McCARTHY: The federal government has just announced $9.2m as an investment and that has very limited resources adding value on the scale of the problem. How would you advise the government on that investment? Where should it go now in 2014?

Dr DILEMA: It is limited. We need to do some work towards the screening and the diagnosis. That is a must. But, we also need to put in a fair amount of that work into just the remediation on the screening that is - query - this might be the diagnosis. Start the remediation for that behaviour and that learning disorder. In one breath, I sometimes say hang the actual diagnosis, I do not care about that. Let us get to where that child needs some help.

In addition to that, maybe put some of that resource into teaching our community how to prevent this. There are programs that have been done in Canada amongst some of their remotes communities of their Inuit population, where they have mustered and garnered the community to work to looking after those families with FASD kids, who have then taken on that role of educating their families that 'We do not go near the alcohol. That is mainstream population's rubbish, we are not going there'. And they have turned things around. Sometimes, we cannot have the money to do everything but, if we can somehow use the whole community to actually try to build that resource ...

Mr WOOD: On more scientific discussion, I have spoken at other meetings about the plasticity of the brain. People have said to me that does not apply here because the alcohol affects all the neurons and the brain is totally damaged. Then, you say if you deal with a child for the first six years some changes can occur. Is that changes to the brain? Can you actually see some repair?

Dr DILEMA: A guy called Ira Chasnoff and a guy called Michael De Belos in America have done a lot of research on this. Although you may not change if there is structural abnormality such as the corpus callosum is shrunken and has not formed completely, what they are looking at and they suggest is that you actually utilise other parts of the brain to get to that same task. So, you create new pathways.

Mr WOOD: The argument against that discussion was the whole brain - where someone gets a bullet in the brain, sometimes that damage can get the other side of the brain to take over that function. But, they were saying it could not happen in a baby's brain because, simply, the whole brain was damaged.

Dr DILEMA: This is where the FASD thing is. We cannot, at this stage, say X,Y & Z behaviours equals this, and these are the only areas of that brain that are affected. We do not know why, in this individual, this, this, and this area are targeted and, in another brain,

another set of areas. So, it is not just a global thing, it is in different patches, though there are some areas that are more sensitive.

Mr WOOD: Just another question in relation to you showed the trimesters. Even though we understand the baby is more likely to be damaged very early in the pregnancy, if you can reduce or stop the alcohol as soon as possible, you still will have some beneficial effects on the unborn?

Dr DILEMA: Absolutely! And also into that neonatal period. Whilst mum is breastfeeding it is also important because that liver still has not matured, that brain is still developing, and that brain continues to develop. What happens at adolescence is we start doing our myelination - our white matter starts kicking in. If there has been impairment, then this adolescence is uncomfortable, does not know what they are doing, goes into substance use from an early age - and a lot of these kids start substance use from 12/13. That is the next stage of development in that brain - vital development to thinking and executive function. You have another whammy on that brain. Again, right through life until about, they say, about 24/25, that brain is still developing.

Mr WOOD: Just one other question. The People's Alcohol Action Coalition, Russell Goldflam, came and gave us a talk. He mentioned about a Korean experiment where – obviously, done with mice - there was a belief if a male was drinking, the sperm could be affected by alcohol and it could play possibly a part in FASD. Have you heard any more about that?

Dr DELIMA: There are studies on that but we have not done a huge amount because we have left it as a women's problem. The reality is that infant or that foetus is made up of two halves and alcohol affects male cells as much as it does female cells and it is a toxin, a general toxin across the body. That is something that they are starting to look at.

Madam CHAIR: Thank you, Dr Jennifer. That was excellent. I have learnt a lot. Thank you very much.

Dr DELIMA: This is my passion.

Madam CHAIR: We will send you a copy of the *Hansard* draft so you can check to make sure things are technically correct. what we have talked about. Thank you very much.

The committee suspended.

CENTRAL AUSTRALIAN ABORIGINAL LEGAL AID SERVICE (CAALAS)

Madam CHAIR: Welcome. On behalf of the committee I welcome you to this public hearing into action to prevent Foetal Alcohol Spectrum Disorder and taking your time to be with us today. We appreciate that. This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply. 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 what you say should not be made public at any time we can go into a closed session. So could you for the benefit of the record say your name and the capacity you are here.

Mr O'REILLY: My name is Mark O'Reilly, I am the Principal Legal Officer at the Aboriginal Legal Service here in town and saying that I oversee the branches of the provision of legal services within the organisation.

Madam CHAIR: Thank you. Would you like to make any opening comments or a statement?

Mr O'REILLY: I can do. We provided a joint submission with NAAJA, our sister service in the Top End, so I commend that report to the inquiry. It is worth giving an overview of the sort of work initially that CAALAS does.

The three main areas of practice within the organisation are the criminal law practice - we have a civil practice which covers a range of areas of legal practice. Most interestingly for this inquiry is the fact that we do a lot of public housing work. We also have a strong care and protection practice as well within the organisation. Those three areas are areas where FASD is likely to have some real potential. Dr Delima is a hard act to follow. She touched on, for example, things she has seen within the youth justice court where the same sort of offending behaviour is repeated over and over again by offenders who are affected by FASD. It is quite clear how FASD can impact on the criminal justice system and how people with FASD can be overrepresented within that system.

In relation to care and protection, we have had situations at CAALAS where we have acted for mothers of children where the mothers are FASD-affected and it has impacted on their ability to care for children. In the housing situation, it is hard to point to any specifics, but it is

not hard to imagine the situation where the symptoms of FASD would make it very difficult for people to comply with obligations of public housing, and the placement situations where they are looking, potentially, at eviction and homelessness.

They are, as I see it, the main areas we deal with that are impacted by FASD. I am happy to expand on any of those, or just take questions from the panel.

Madam CHAIR: You raised an interesting comment about the public housing. It is probably across the Territory and not just in Alice Springs. Do you think there are many cases of where a woman, a family, a couple, or whatever, are FASD hence, their issues with - what we heard from Dr Jennifer – the ability to comprehend the consequences, and then they get evicted? Do you think there are many?

Mr O'REILLY: It is always really difficult in all of these areas to talk about numbers because of the under-diagnosis of FASD, and the fact that there are not appropriate tools or resources to do that. I know of one situation, for example, where a FASD-affected person has had difficulty maintaining housing without pretty strong assistance. Even in the end, that was not enough to keep her in a particular housing situation she was in.

You are talking about one of the things that is affected which is the ability to plan, for example, the ability to pay rent when it is due, and the ability to maintain the house as required. These are things that could all easily be affected by FASD.

Madam CHAIR: Yes. Okay.

Mr O'REILLY: That is one of the areas where we see a lot of non-compliance with the obligations of public housing and potential evictions, where people are falling behind with their rent or they are not maintaining the house to the proper standard.

Mr McCARTHY: How do you deal with a client when you recognise there is a cognitive disability?

Mr O'REILLY: It depends very much on the nature of the work you are doing for that client. I suppose the first difficult step is the actual recognition. That is apparent in their criminal law area, particularly.

As we sit here today, at court there will be a handful of lawyers dealing with, potentially, a very busy list of people in custody, and people walking in off the street. The first contact we will have with a vast proportion of our clients is we will see them in the court cells in the

morning when we are aware for the first time they have been charged with offences and brought before the court.

That first communication with clients is often very swift because of the volume of matters, and it is often very difficult. It is pretty common for us to get situations where there is a noticeable lack of communication. Getting to the bottom of why that is is really difficult. Sometimes it is a language issue, a cultural issue, a hearing issue and, very often, it is a mental health issue. For untrained people to pinpoint and diagnose that, or make their own assessment about what may be going on is very difficult.

There is no access at the courthouse to any quick assessment or diagnosis of that. That is probably a large reason why we know, in this jurisdiction and other jurisdictions, there are a disproportionate number of people with cognitive impairment in prison, and there is probably a big under-diagnosis of those people. It is very difficult to pick it up in the first place. How you go about dealing with that is very problematic in the Territory. Obviously, there is a broad range of scope of cognitive impairments, so some people are able to instruct and are less-affected and, at the other end, are people who are not able to instruct and who are unfit to plead. There is not a very good process in the Territory for dealing with those people. The Court of Summary Jurisdiction, for example, does not have a good mechanism for being able to cater for people with

intellectual impairment in how their matters proceed through the court. They are treated in the court system pretty much like everybody else, even when it is recognised and accepted that they may be suffering.

The Mental Health Act allows, in some circumstances, for some matters to be dealt with in a way that is more health-based than justice-based, but that does not work very well or very often.

Mostly what happens with clients who may have a mental impairment or who may not be fit to plead is they end under another piece of legislation which takes them to the Supreme Court. That is a very long drawn out process that has the potential to have some good outcomes, but most of them fail because of lack of resources to deal with people.

Ultimately, the problem is finding an appropriate place for people who suffer from cognitive impairment and who are offenders - finding an appropriate place for them in the community is the really big problem we have.

Mr McCARTHY: If it was a serious offence they would be kept in custody and …

Mr O'REILLY: That is usually the case; for serious offences they are kept in custody. Sometimes it is a case also for mid-range offences, and often if offences are not particularly serious, because of a lack of options. People tend to spend a fair bit of time in custody while everyone tries to sort out what the response should be.

Custody is not an unusual experience for any of them, but for serious offending custodial options are often the case.

Mr McCARTHY: Would it be easier to advocate for a client you suspected had a cognitive disability outside of custody?

Mr O'REILLY: The aim should be to respond to the offending behaviour in a way which appropriately suits that particular offender. Some offenders, where there are no cognitive impairments, the outcome is clearly this person will go to gaol for a while.

Sometimes the outcome is we should look at community work, sometimes the outcome is fine. Any sentencing response should be directed towards that particular offender and the particular offence they have committed.

The problem we have with people with intellectual impairments who are coming before the court is there are no appropriate options for those people. What should be put in place are appropriate health responses, appropriate care plans, appropriate behavioural management plans which look at making sure this will not be a problem into the future; there is a response which will assist them live in the community in a way that will reduce the likelihood of offending and, consequently, protect the community and protect them.

Mr McCARTHY: A mandatory sentencing regime would significantly disadvantage that cohort, and medically we are hearing this is a big cohort of offenders across the Northern Territory?

Mr O'REILLY: Mandatory sentencing for those people is a real curse. The first response should not be an assumption that this person will serve a term of imprisonment. The first response, when it is recognised there is cognitive impairment, should be how we are going to appropriately place this person in the community in a way to protect the community long-term and protect this person. Mandatory sentencing does not easily allow that to happen.

One thing that exists within the current mandatory sentencing regime is the exceptional circumstances clause where, if you can illustrate to the court that in this particular case there are exceptional circumstances, that form of mandatory sentencing should not apply.

The outcome for that still is an actual term of imprisonment. The mandatory sentencing regime does not let anybody who has been charged with or convicted of a qualifying offence - does not let anybody escape gaol.

Mr McCARTHY: I asked Russell Goldflam this morning, when he spoke extensively about his history with Alice Springs - he said he came here in 1981 and I asked if he was aware of FASD in 1981. He said he was not. As a criminal lawyer, he was not aware of it in 1981. Were you aware of it in 1981?

Mr O'REILLY: In 1981 I was not here. I do not have the same longevity as Russell. In 1981 I probably was not aware of it even as a concept and probably did not become aware of it until probably sometime later in the 1980s or early 1990s as a concept, but while people know about the fact of it, I do not think there is a lot of expertise within the profession about the symptoms of it, how easy it is to diagnose, what the responses may be and what kind of therapeutic responses there may be to it. I think everyone knows it is out there as a concept, but it kind of is, in a way, irrelevant because there are not the tools to recognise it.

I can only point to my whole time – I have been at CAALAS for 16 or 17 years doing criminal work representing people before the courts and I have had, over that time, a particular involvement in dealing with matters where there are psychiatric issues or cognitive delay. I do some work within the mental health system as well, and out of that whole time I could only point to a few cases where there has actually been any kind of formal recognition and diagnosis of FASD. There is lots of recognition of cognitive impairment and cognitive delay, but putting the FASD label on it has been pretty minimal and there is a lot more out there than is diagnosed.

Mr McCARTHY: So with a bucket of resources the feds have come out with a statement. What would the judicial system say to the Northern Territory government? In essence this inquiry is to gather evidence to present a report and hopefully recommendations. What would the judicial system say about their share in how to prevent, support, deal with …

Mr O'REILLY: Sure. I think one of the things that the judicial system would say straight up is that when we see these cases come before the Supreme Court under the Part 2A legislation in the Criminal Code the bottom line in the end is everyone might go to court and say, 'This person has got a mental impairment. They are unfit to plead. They were not aware of the consequences of their actions.' By this stage they have been in custody for sometimes a very long time and the question at the end is, 'What do we do with them now'? I think if there were expanded resources within the community to actually house people appropriately that would be a huge step forward.

There have been some steps towards that over the years and the secure care facility out near the prison is an example of that, but initially when that was created it was going to be 16 beds, eight for adults and eight for juveniles and there was going to be a similar facility in Darwin. It has now been decimated. There are eight beds. I think at the moment three of those beds are being used, because it has been a fairly careful and staged approach for people to be transitioned into that unit and for the people who have done it, it seems to be working very well, the people I am aware of, but the other half has gone, the juvenile half has gone. The Darwin facility has gone. So you have got eight beds across the Territory that I am aware that cater for people who are potentially affected by FASD and other cognitive impairments and it is a situation that allows people a much better quality of life.

So the people out there at the moment are getting regular day release. They will visit the community. They will be under constant care, but they are housed within this secure facility that lets family come in, that lets them visit family, that actually implements behavioural management plans so that people are progressing their ability to function in the community. There is still a big question mark at the end of all that about where to from here, because that is only supposed to be a medium term facility as well, but that is the big problem, about placing people, because with the best will in the world courts might say, 'We need to do something for this person. We need to improve their situation and the consequence of that will be that it improves community safety,' but there is nothing and so people end up in gaol. There are notorious situations where people have been in custody for a very long time and that is happening now, not necessarily with FASD, but there are certainly FASD examples of that around, but there are people in gaol simply because no one can think of where they might go.

Madam CHAIR: Where else to put them? Nicole?

Ms MANISON: I suppose my question was, when a client presents themselves to you, when you are trying to help them, would it be more constructive and helpful for your staff and being able to do their job to the best of their ability if they were aware that they had a FASD diagnosis straight up?

Mr McFARLAND: The easier access to that sort of diagnosis - and it cannot often happen on the spot in a busy courtroom -the knowledge there was an avenue to explore that when it was suspected would make a really big difference from the outset to practitioners, the court and looking towards ultimate dispositions. My understanding was there was some interest recently in coming to an arrangement with a local psychiatric practitioner to be based at the court house once a fortnight or once a month for a day - we did not get to the fine detail - so you say, 'I have some issues with this person. I might adjourn it to a day when we know there will be someone there who can provide us at least a preliminary assessment.' However, there was no funding and that was never secured but something like that would be great. A court ordered assessment of people when there was a reasonable suspicion they were suffering from some cognitive delay and, potentially, FASD.

Mr WOOD: The issue of FASD, from your point of view, seems to be you get the end of the spectrum and have to deal with it. The other issue for me is it is a cost to the society. There is also the moral issue that the unborn child needs protection. We know if we can stop or reduce the drinking we have a reasonable chance of having a healthy child born, or a child who will not be as bad as if there has been no intervention at all.

One of the issues raised - and you raised it - was the criminalisation of putting people into custody, but if we get rid of the criminalisation do you see the role of government - I am talking about this in a compassionate way not a formal criminalised way - government has a responsibility - if a person has been given all the education about not drinking it will hurt the baby, and they continue to drink, do the government have a role to play in some form of intervention to stop that person drinking? That could be from an Aboriginal point of view involving family or their groups taking them to a place where they – it may be like mandatory rehabilitation but with some safeguards – Russell Goldflam mentioned safeguards not in alcohol rehabilitation but in the Mental Health Act - some of those safeguards included - the government should look at that as a means of protecting the baby and the long-term social implications - is if we do not do anything we will have more cases to deal with.

Mr McFARLAND: As an organisation we have raised concerns about the alcohol mandatory treatment regime and there have been three basic reasons. One is we have always had a question mark about whether it works as a therapeutic model - forced rehabilitation - and that is for other experts to really weigh in to, but there are question marks about whether you can put someone in mandatory rehab and have it work. That is one issue.

The other issue we have had is the one you mentioned, the criminalisation of people who may abscond from those places or who do not do the right thing when they are placed in them. We see that as another way of criminalising alcohol dependence and that is something we are opposed to because these people are victims. People with FASD are clearly victims of an alcohol system that is not working.

The other major problem we have with that regime is people are, in reality, going before that tribunal unrepresented and unable to advocate for themselves. There is still no advocate based in Alice Springs to help people through that process. Our view has been where there is a potential criminal sanction at the end and where there is a loss of liberty, people should have the right - not just the right but the real practical ability to access legal representation.

In a situation where some kind of regime was introduced in a way where there was community consultation and it was a genuinely therapeutic and compassionate model and the safeguards were put in there may be a place for it. What model would be could be up for debate. Where there are other resources and resources being put in and genuine attempts to regulate alcohol in other ways, there is, potentially, a place for that to happen if it happens in the right way.

Madam CHAIR: Mark, in your submission you talk about the US and Canada where someone who was FASD-affected gets parole or gets put on bail and they use the picture card system to tell them what it all means. Do you think that would work here? Has it worked there well?

Mr O'REILLY: I do not know the detail of how well it has worked, but I have seen it work reasonably well here for people who have intellectual impairment ...

Madam CHAIR: They use a picture card?

Mr O'REILLY: Yes. The ones I have seen have been, in some cases, specifically tailored for that person. It is a useful form of communication. The benefits of that are best left to those behavioural experts, but it is a tool that is used, and I have seen it used here well.

Madam CHAIR: Okay. Is it possible to get a copy of some of these? How do we get it to see what they look like? Is it just the court system?

Mr O'REILLY: I could make some inquiries of people I know about that. I have an example, but I could probably get a de-identified version that …

Madam CHAIR: Yes, not to identify a person, just the concept.

Mr O'REILLY: Yes, I can make some inquiries about that and get back to the inquiry.

Madam CHAIR: That would be great. Thank you, Mark - much appreciated - for your time here today. We will send you a copy of the *Hansard* so you can go through it and make sure it is all okay.

Mr O'REILLY: Thank you very much.

The committee suspended

TANGENTYERE COUNCIL

Madam CHAIR: Good morning, Blair, thank you for being here. Welcome to this public hearing into the action to prevent foetal alcohol spectrum disorder. Thank you for taking the time, we appreciate it.

This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply. 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, then we can go into a closed session. For the record, can you state your name and the capacity you appear here?

Mr McFARLAND: My name is Blair McFarland. I am a Co-manager of CAAYLUS, Central Australian Aboriginal Youth Link-Up Service, which is a division of Tangentyere Council. I am here as the manager.

CAAYLUS has a board which sets policy of stakeholders from the region in relation to inhalants. I can talk around some of what we have learned rolling out the inhalant strategies over time in relation to what you are looking at, and the work that you are doing in relation to that.

Madam CHAIR: If you want to make some opening comments or opening statement, please do.

Mr McFARLAND: Yes, I have a one-page statement which I will read to you, and then give you a copy for your records.

Madam CHAIR: Yes. That would be great.

Mr McFARLAND: CAAYLUS has 13 years experience in effective substance abuse prevention strategies, having been part of a successful inhalant program that saw a 94% reduction in inhalant abuse in Central Australia. The successful strategy involved supply reduction, demand reduction, and treatment-oriented casework. It is our experience that a strategy must cover all three of these issues.

As such, we recommend the following: that population-based alcohol supply reduction strategy be developed and rolled out including two takeaway-free days per week; reduce morning and late night trading; a floor price for alcohol set at a cost of standard beer with funds derived being directed to the reduction of alcohol-related harms, as happened with the NT Living with Alcohol Initiative in the 1980s, I think it was; and the BDR be reinstated and run long enough for an evaluation.

Our second recommendation is that we are concerned that approaches which apply criminal sanctions as a way of trying to deal with substance misuse will entrench, disadvantage, and harm. The NT Volatile Substance Abuse Act is a model worth investigating in this regard. It is has been mandating people with inhalant misuse issues to rehab without criminalising them since 2006.

If you have any questions, contact the writer. Can I hand that over? I am at your service in relation to any questions you might want to ask.

Madam CHAIR: Any questions? You start at that end, Gerry.

Mr WOOD: In that last section you talked about misusing volatile substances. I am not fully cognisant of what is in that act (inaudible). I do not know everything in that legislation, but what is in there that you think would be appropriate to try and restrict a woman drinking more alcohol when she is pregnant?

Mr O'REILLY: It really crosses the same issues. Prior to this act there was no capacity for the legal system to engage with people who were sniffing. If you were not a child sniffing then there was nothing anyone could really do and people could sniff on the steps of a police station. Police had no powers to intervene. That act addressed that issue and it addressed a number of issues. It gave the police powers to act. It protected witnesses in relation to dobbing in dealers and it created this mandating thing, which is most interesting for you guys. It also had some other effects in creating dry areas where there was an enforcable set of laws that related to the safe storage of inhalants and storage of inhalants. That is what it was about.

The one that particularly seems pertinent for what you are talking about is the issue of rehab. When somebody has been sniffing petrol they are doing themselves, basically, irreparable brain damage and their capacity to make a rational decision at that point is zero. Research done by Menzies School of Health has shown that, basically, you recover from sniffing very quickly. The intoxication goes away very quickly but the actual damage that you have done even from a binge of sniffing will last six weeks. It takes six weeks for the brain to recover operationally, because the damage is irreversible. The wiring around the damaged bit has to be rearranged in the same way as if you have a stroke and you have to do rehab to redevelop brain pathways through the undamaged portions of your brain.

Six weeks after a sniffing episode somebody could maybe start making some rational decisions. Now, that had implications in terms of when you had people in treatment because there is no point talking to people in the first six weeks really. They always forget you have spoken to them an hour later and similarly with counselling when people are high. It really

means you cannot rely on counselling during that timeframe, which is only a very limited value anyway.

What we had was a group of people who could not make rational decisions about their own situation. It became evident to protect the community that those people needed to have a way of being taken out of the situation because one sniffer, becomes two sniffers, becomes ten sniffers.

Before Opal was widely available there was so much petrol around that eight-year old kids could easily get their hands on it. You only needed a bit of hose this long and you could supply your habit endlessly. The situation was bad. People who were sniffing could not be relied on to make a sensible decisions about anything. The Northern Territory government looked into mandating people into treatment. They did this through looking at the Mount Theo project - what had been happening out in the Walpiri zone - to see what worked there. They put a lot of their practices into this legislation.

The legislation means that somebody is identified either by police, a health professional, a family member of that person or somebody who has done authorised person training such as myself. A formal referral then goes to the health department. The health department opens the case. Trained people who are the inhalants nurses - there is a group here, a group in Katherine, one in Tennant Creek and a group in Darwin - are trained to work with inhalant people and understand the legislation. They go and assess that person and if they find that person is sniffing at a dangerous level - it was not just a case of one-off sniffing with some people - once that is part of a pattern they then make a recommendation to the Chief Health Officer, who then, basically, puts in place a chain of events that results in a warrant being issued. That person is picked up by the police if they will not come voluntarily and they are put in front of a magistrate with representation. The magistrate can look at a report prepared by the health department saying, 'This person is a danger to themselves and everybody else' and they can be put away for 16 weeks, up to 16 weeks in a treatment centre, with an option to extend. We have had people in for 32 weeks.

The person is able to brief their lawyer to the ability that they can because they have probably been sniffing until quite recently. It does not criminalise them. If they run away from the rehab a warrant goes out and they just get put back until the warrant for holding them in the rehab terminates. There is no criminalisation that has resulted in this process.

We have seen it be very effective in lots of cases. There have been literally hundreds and hundreds of people who have been through this mandatory process. After the first couple of years, the act was slicked up a bit. On the ground, we ran into issues which were addressed by changes to the legislation. It is now absolutely cutting-edge, it is the best in the world. It seems to go a long way towards what you guys are thinking about, which is a tricky issue in relation to protecting the unborn child.

Mr WOOD: I suppose the issue is for someone who abuses substances is that person has a mental issue. You do not necessarily have that mental issue consuming alcohol. It might affect you and you are drunk, but it is not necessarily permanent. That person is going in, not so much because they drink alcohol, it is because they are drinking alcohol while pregnant. So, you have a slightly different clientele.

The thing that concerns me - and it is the issue I raised with Alcohol Mandatory Rehabilitation – is it needs compassion, community support, and more than just to be A plus B equals C and that is the end of it. It needs a lot more involvement. How do you see that would occur in the case of a pregnant woman being put in a situation where she is held so she cannot drink? Would the community support work with that?

Mr McFARLAND: I was interested in your question before. What happened with the VSA Act was there was a period of community consultation. After the Northern Territory government got it together as an idea, they made up a draft version of what it would look like, then sent it out for community consultation. CAYLUS was involved in a lot of community consultation in this region where there was a lot of sniffing. That process meant the community was consulted, they had a really good idea of what was involved. We found people almost universally supportive of the idea. There was a lot of buy-in to mandatory treatment for sniffing.

If you were going to go down the same path, an important part of it would be that community consultation and letting people know what is going on, putting forward the case for it, hearing peoples objections, and seeing if there is any modifications that could be made to the act to address people's concerns. That is how it went with the Volatile Substance Abuse Prevention Act, and that Act had a lot of support.

Mr WOOD: It was raised earlier - to make sure we do not make this too race-based - the petrol sniffing clientele. Was that across the board?

Mr McFARLAND: Yes absolutely, it is not race-based at all. The vast majority of people have been Aboriginal, but there have been a bunch of non-Aboriginal people as well. The legislation is not, in no way, race-based.

Mr WOOD: The process, obviously, is not leaning one way or the other.

Mr McFARLAND: No, exactly. Last year, there was a young Maori guy who had issues and ended up in rehab, and the process was exactly the same for him. There have been other ones over the years. It is not race-based.

Madam CHAIR: With your whole Tangentyere Council, is there a general awareness of FASD and issues in the housing associations and within the communities of the town camps, do you think?

Mr McFARLAND: I know there is a lot of awareness of the problems relating to alcohol. Specifically FASD, I could not really say. Everybody's lives have been impacted by alcohol to such a degree that anything we do to address it, I am sure we will get lots of support. It is like a war zone.

Madam CHAIR: Because all the town camps are dry, are they not?

Mr McFARLAND: Yes.

Madam CHAIR: Is that under the intervention, or under some other ...

Mr McFARLAND: Under the intervention. A couple were already dry. One was already dry and others were moving that way. Then, they were all made dry. It is not very effective.

Madam CHAIR: No, we have heard.

Mr McCARTHY: An experienced youth service provider in Katherine had a theory that foetal alcohol affected kids went on to abuse volatile substances. Do you share that theory?

Mr McFARLAND: I cannot really say. So many people abuse volatiles when it is around. When I think about it, though, there are a couple of clients out bush who do have mental development issues who continue to get involved with sniffing when it turns up. In one community, there are a couple of guys – and, in fact, there are a couple of communities now I think about it where people who are not sniffing until it is there, but when it is there, they seriously get involved. They all have degrees of retardation, I suppose you would call it. Yes, I can see how it could contribute. It used to be so easy to get your hands on things to sniff, and it still is in some parts of the Territory where there is no Opal, but the availability of it meant it was something anybody would try. Once you are sniffing you are, effectively, brain damaged anyway. Possibly everybody ends up with a very impaired ability to think straight once they have been sniffing.

Mr McCARTHY: The way I interpret it, and from what I have been learning on this committee, is this impulsive behaviour and lack of strong decision-making processes makes you as a vulnerable target for the peer group. If you have those issues and sniffers are

controlling the environment you are an easier target than a kid that is processing properly. I thought it was interesting.

What is it like with family advocacy in the field? When you have a young person involved in volatile substance abuse in Central Australia - give me a couple of stories, I am very interested.

Mr McFARLAND: On the whole you find families are really keen to get any help they can get their hands on in relation to that. Sometimes there are grandmothers or people who will try hard to stop anything happening to their kid and absolutely deny he is sniffing, even if he is sitting there sniffing and reeking, because she is family first no matter what. However, other people around them - the majority of the family is involved when there is that level of damaging substance abuse – it impacts on them in a very serious way and the smaller kids around, so they are extremely supportive of any interventions.

That said, they are often unwilling. There are various ways to make a formal referral and often they are very unwilling to put their name on a piece of paper because that paper is presented to the person when they get to court. They do not necessarily want to be identified as the person who got that ball rolling, although some strong people will. The majority of people - family members - are concerned and want help, but they would rather the police, the clinic or me make a referral rather than puts them in the front line.

An important part of our negotiations about the VSA Act was to give family members that ability. It was not just seen as the professionals doing; there was a level where the community and the family could get involved and help somebody. That is certainly how they see it - helping people with substance abuse. They run from a very compassionate type of life model.

Mr McCARTHY: When you are intervening into that and working with a family, is part of your team's work the education and awareness side of it? Do you do a lot of that with the family and explain exactly what is going on with this young person who is abusing substances?

Mr McFARLAND: Yes, to some degree. I notice some of the submissions you have received talk about targeted education. That is the issue. If you tell Aboriginal people sniffing hurts their brains it is like telling them how to suck eggs. They know. They know way better than the person at the other end of the flipchart how much damage is done by sniffing and what the consequences to the family are. They tend to skip past that part to the part where they say, 'What can we do about it?' That is where the education is good and that is where we hope that – I do not know how many thousands of times I have explained that law I explained to you to Aboriginal people in the same way and emphasised the fact

their kids can get help, they will not end up in gaol and will not end up with a criminal record and the help is really help and comes through the Health department not the police or the correctional system.

Education is important, but saying to a sniffer, 'You are hurting your brain,' he will say, 'Huh.' He does not care ...

Madam CHAIR: Because he cannot feel it.

Mr McFARLAND: He cannot feel it and he is fearless, painless and not in any condition to make a rational decision. You could lay out all the facts but they could walk away a minute later and completely forget what you had told them. We target people around the sniffer with information of what to do. They know it hurts them. It is what to do and how to harm minimise in the setting, how to get help, who to get help from and what the help. Targeted education is useful, but general education - thinking people will change their behaviour because they see a poster is a fantasy I am afraid; it is not the case.

Would there be anybody smoking out there if education worked at all?

Madam CHAIR: Yes. Blair, a couple of years ago there was a select committee into youth suicide and the committee - I think Bess was on it and I was on it and we came to Alice Springs - the committee discovered that there was something upwards of 35 different agencies delivering youth services, NGOs, churches, communities, sport recreation, since that time is it a good network, do you work together you know for common goals and outcomes? Is there a network of youth, or agencies delivering youth services? Has it changed from a couple of years ago.

Mr McFARLAND: I think there is less in Alice Springs. Most of my work is out bush where there is a dearth of agencies like that, although there is a proliferation of fly in, fly out types, people who want to be role models in the 15 minutes they are in the community. There is a proliferation of those and there is a proliferation of people who will go out and make videos about things and think that is really helpful, and then the videos come to the community and they just get chucked in the bin. There is a really uncoordinated mass of programs that come and go from the bush. In terms of actual players the ones that are there all the time - they are the ones we support, we do not support the fly in fly out model at all - in terms of the ones on the ground there are very few and we assist with their coordination.

Part of our function is to try and get on the demand reduction side, getting the youth programs happening and we have been doing that quite successfully, but in the absence of any comprehensive government policy, either federal or Territory, to provide those youth

services it is very much cobbled together there - 'Here comes a funding submission, we could pull some money out of that for a year' and that is the way it is. There is no coordination of youth services in a big picture out bush, yet there is so much money. I think it was in the strategic review of Indigenous expenditure 2011 that they found the department that put that together - I think it was the department of Audit or something like that. There were 5000 different government departments all putting grants out into remote communities and there was no overall plan, there was no overall logic and they did not know what each other was doing. You can see that is probably what is behind the current government pulling everything into Prime Minister and Cabinet to try and cut back on that effect. That effect was things kept getting funded short-term and there was no long-term strategy. Things would work and they would fall over, or things would not work, but they would write really good submissions and on they go, because they were not judging it by the criteria we judge programs, in terms of which ones we support, for example: local, operate in the community, have local capacity for input from community members into how it runs and, ideally a board that runs it, a local board. If you start looking at community development models on what to fund then it becomes a lot clearer where to put your money to get the best buck.

MADAM CHAIR: So we could do with improvements in coordination of services that cover young people because that is partly where this starts, with educating young people about the dangers of unprotected sex, drinking alcohol and sniffing?

Mrs PRICE: What role does Tangentyere have in helping families in the town camps who have children with FASD?

Mr McFARLAND: There is a program that deals with mothers and young children; they would be helping people, I imagine, in that setting. Otherwise the youth program is a sort of wholesome engagement strategy or diversionary activity, but I do not think Tangentyere really delivers any specific services for mental health and I do not think they do much by way of health anyway.

Mrs PRICE: Do they work with Congress? Do they work with Congress in helping families in these town camps?

Mr McFARLAND:: Congress works. I am not really sure - I know they do - there used to be a cross over but a whole lot of Congress things have recently been defunded as well, so I am not really sure of the status of that level of cooperation. Recently we had a referral that came up through those children's services and Congress was involved with that, although there was some sniffing involved. There was another one recently with metho drinking, where both Congress and Tangentyere were involved in coming together to form a case plan around some issues and some particular people identified by night patrol as drinking metho. We spoke to them, Congress spoke to them and they went into a day program which meant they could get some support for getting off the meth.

Mrs PRICE: Does Tangentyere go around house by house and ask exactly how many people live there, if they are related, how they related and how many children live under that roof?

Mr McFARLAND: They do that. They have regular audits and surveys and keep tabs on who is there, the number of visitors, the number of children and that sort of stuff.

Mr McCARTHY: In Katherine the committee heard there was an escalation in the use of methamphetamines among young people. Have you witnessed that in Central Australia?

Mr McFARLAND: No. We have been checking hard and have not seen any evidence of methamphetamines in remote communities. Sometimes it is anecdotally linked to mining and populations of miners who like to party on but do not want to have anything in their bloodstream when tested soon after they go back out. Some people say if mining took off in this region we might see a bit more trade in that type of drug, but people are mostly concerned about cannabis at the moment.

Mr McCARTHY: What about the young people and prescription drugs? Have they discovered how to abuse prescription drugs yet?

Mr McFARLAND: No, I have not seen anything of that either.

Madam CHAIR: That is good. Thank you Blair, that was much appreciated. We will send you a copy of the *Hansard* in draft form so you can check to make we have it correct for you. We appreciate you taking the time to talk with us today.

Mr McFARLAND: My pleasure. You are doing very important work for generations of children to come.

The committee suspended.

NGAANYATJARRA PATJANTJATJARA YANKUNYTJATJARA WOMEN'S COUNCIL

Madam CHAIR: Good morning. Do you have any objections to the ABC taking footage?

Ms BALMER: No, that is fine.

Madam CHAIR: On behalf of the committee welcome to this public hearing into action to prevent foetal alcohol spectrum disorder. We appreciate you taking the time to talk with us and perhaps answer our questions. This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply. 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 are saying or we are talking about should not be made public, we can go into a closed session and take your evidence in private.

Fr the record, could you state your name and the capacity in which you appear today?

Ms BALMER: My name is Liza Balmer. I am the deputy coordinator of the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council.

Madam CHAIR: Do you have any opening comments or an opening statement to make to the committee?

Ms BALMER: Not really, no.

Madam CHAIR: I know a little about the history of NPY and the work it has done, but I noticed in the documentation we received the organisation has developed the No safe amount - the effects of alcohol in pregnancy campaign. Has that been successful and well-received in the communities?

Ms BALMER: It has been really well-received and, in fact, it has gone across Australia. We received constant requests for a copy of it. The problem has been funding and having it continually aired. I am not sure if everyone is familiar with it, but it was a series of three commercials - actually five because they are in Pitjantjatjara and in English. The first one is a young woman talking about drinking during pregnancy and the effect on her baby when it was born. The second one is an animated version of what happens to the baby *in utero* and then what happens when they grow up. The third one is around responsible fathers and supporting your partner in pregnancy. It won a Deadly Award.

Madam CHAIR: Well done.

Mr HIGGINS: Is that a description of the award?

Madam CHAIR: No, the Deadly Awards. Was that this year?

Ms BALMER: It was 2012. We initially aired them for three months on Imparja and then they went onto NITV and ICTV for another 12 months. However, we have not had any funding to continue. ICTV has just agreed to continue to air them free.

Madam CHAIR: That is good. Within the NPY Women's Council is there much talk by the stakeholders about FASD? Is there a heightened awareness apart from the advertisements?

Ms BALMER: There is a lot. We first started talking to members and directors in 1997 – that was when we initiated those discussions. That was after a young five-year-old girl was run over by a truck in her community. She was a client of mine at the time.

I happened to be reading a book called *Broken Cord*. I do not know if any of you have read that It is a story of a boy with foetal alcohol syndrome in Canada. I was reading this book and the whole way along thinking 'This sounds like this young girl'. In fact, they both died the same way; they both were run over.

Then, we started to talk to our directors about it and asked, 'Do you see this as a problem?' It was no revelation for them at all; they just did not have a name for it. They knew that these kids' behaviour was different because their mother had used alcohol in pregnancy.

Madam CHAIR: So they did make the connection?

Ms BALMER: They made the connection straightaway. We have been working very - not intensely but it has been on our agenda at the women's council for a long time. In fact, the high-profile young woman who you all probably know about who is in the Northern Territory and was in gaol in Kalgoorlie …

Madam CHAIR: Yes.

Ms BALMER: We arranged for diagnosis for her and her siblings, and they were the first in Central Australia to be diagnosed. We had a specialist from Melbourne come up to do it.

Madam CHAIR: Oh, okay.

Mr McCARTHY: Geographically, NPY would cover three states?

Ms BALMER: It does.

Mr McCARTHY: Does Western Australian and South Australia have a good input into anything to do with FASD prevention and treatment?

Ms BALMER: The government you mean?

Mr McCARTHY: Yes.

Ms BALMER: No.

Mr McCARTHY: Who funded your advertising?

Ms BALMER: The Commonwealth.

Mr McCARTHY: Are South Australia or Western Australia talking about FASD regarding the agencies on the ground?

Ms BALMER: Western Australia is, as you would know all that work going on in the Kimberley. In South Australia, there is a very strong movement, but it is very urban. It does not reach our remote communities.

Madam CHAIR: Oh, okay.

Mr McCARTHY: Is that model advantageous, or is it a disadvantage being a footprint across three different jurisdictions?

Ms BALMER: It benefits our members, obviously, because they see themselves as one. They do not separate themselves. It is often a disadvantage in negotiating funding and different legislation, three different child protection systems, three different police, three different governments, and the Commonwealth. In that way, it is an administrative nightmare. In other ways, it is a great benefit because we get a better picture and are able to provide holistic services to the entire region. It does not stop at the border.

Mr McCARTHY: Are there still real cultural sensitivities about talking about a woman's pregnancy?

Ms BALMER: Only in mixed company. When females are together, it is okay. The animation of the baby *in utero* is very well received, and that went on TV. But, it is animated.

Mr McCARTHY: That is participation in that program - that educational grants program? How was that conducted?

Ms BALMER: How did the men get involved?

Mr McCARTHY: Yes.

Ms BALMER: Okay. It is different. It is not so much talking about pregnancy; it is talking about 'my baby'. The young man is playing football and he goes off with a bunch of men to go drinking, then he thinks about it and says, 'No, I should not, I should support my partner'. It is more talking about support rather than talking about the pregnancy.

Madam CHAIR: The pregnancy per se. Gerry?

Mr WOOD: I was just going to ask about advertising. We had some people today saying the education programs do not work. You, obviously, have a program out that is advertising. Do you have some way you can assess whether that has been effective or not? I know it has only been going a short time. Some messages require decades to ram home what the message is. Do you have some way of seeing whether it has been getting home and, if it is getting home, does it make any difference?

Ms BALMER: That is a good question, and I do not know that we can answer that. I can give you little snippets. We also use it as a tool. We have a child nutrition program and that program also works with women who are pregnant because of early intervention, and as you would know all the communities are dry, so the majority of alcohol use happens either in Alice Springs, Kalgoorlie, Coober Pedy or Port Augusta. When we have young women who may present at our office in Alice Springs and we know they have been using alcohol, we will sit down and show them the ads and, on most occasions, they cease drinking.

Mr WOOD: Is there any – I know in the Top End, certain issues become shame jobs and that can work in good ways and work bad ways, of course. Is there any feeling amongst the community that you deal with that a mother has felt it to be shameful if she drinks when she is pregnant or is just something - there is not that shameful feel about what is going on?

Ms BALMER: No, there is not. Not yet and I would say that is because there is still not a good understanding of it. I think the older generation understand it very clearly, but I think the young people still do not get that message.

Mr WOOD: I might ask a question we have asked a lot of people. If a woman keeps drinking and even though you have educated her and she knows all the problems of drinking, do you see the role for government - in this case perhaps using your council - the people in your homelands, as a way of restricting that person from drinking by some mandatory court order that involves community, compassion and saying parts of the homelands may be dry? They could be required to stay in those homelands until the baby is born. Do you see this – I am not saying this should be done for everybody, of course, but there may be a group of people here where the government has got to say the unborn child is the priority, either from a moral point of view or from the point of the view of the effects it is going to have on society later on.

Ms BALMER: It is a really tricky question that one, but I have to say personally, maybe not from the council's point of view but my point of view, when you see a woman who is maybe on her seventh child doing the same thing, you put your hands in the air and say, 'Is there not a way to stop this?' but I think there are a lot of steps that could be taken before you got to that point and there are lots of things - we can learn a lot from Canada - early intervention, brief counselling.

I know prenatal or antenatal healthcare is pretty good in this country and there is quite a good opportunity on many occasions for there to be early intervention and that sort of brief counselling. Contraception is always a great one to advocate for and ensuring that if it has happened before that it does not happen again.

Mr WOOD: I think where I was coming from - Dr Delima has a pretty thorough understanding in a very short time of what the issues are, that even if the woman has been drinking early in pregnancy, if you can stop just that drinking continuing it would at least reduce some of the effects. So even though we might have good (inaudible) hopefully we may have some good antenatal programs and that is (inaudible). If we can reduce the need for that by reducing – stopping the person from drinking – and it has to be done in a community setting. I am not talking about criminalising it, but there are – you come to a point where if it is the seventh child and the other six have got FASD, you would say, 'Well, I think it is time we adhered to being here'– and it would be only, I presume, for a minority of people, but still as a possible way the government should look at this whole issue. It is not the only one, there is a whole range.

Ms BALMER: Yes. I think it is the end of a series of things that could be done, but there are occasions where – there are also children with FASD or people with FASD having children

and their capacity to make those decisions is obviously very limited, to stop drinking or to lead a healthier lifestyle.

Mr WOOD: Have you seen that yourself?

Ms BALMER: Yes.

Mr WOOD: Is it very common?

Ms BALMER: Just off the top of my head I can think of five.

Mr WOOD: And they would not have an understanding of good or bad, right or wrong necessarily, or not easily have that cognitive ability to reason?

Ms BALMER: Yes, the consequences, the cause and effect.

Mr WOOD: That is right. I had not thought of that. I was just thinking of the mother, that it is just the mother.

Madam CHAIR: Gary?

Mr HIGGINS: You were talking about that five-year-old child dying in 1997. You were reading a book that was written in Canada. That straightaway tells me they are 17 years ahead of us. If you add some time to the book, there probably would be 20 years. Is that book actually about FASD, or is it …

Ms BALMER: Yes.

Mr HIGGINS: Yes. So they have recognised this at least 17 or 20 years ago. That is why they are so far ahead.

Ms BALMER: Oh yes, they are a long way in front.

Madam CHAIR: Did you call it *Broken Accord* or …

Ms BALMER: *Broken Cord*.

Madam CHAIR: Oh, *Broken Cord*. Thank you. I might try to get a copy of that book. Would it be a book we could get a copy off the Internet.

Ms BALMER: It is pretty old, but I am sure …

Madam CHAIR: We will search for it. Is it a fictitious book, or is it …

Ms BALMER: No, it is a story. It is a man who …

Madam CHAIR: A real story about a person?

Ms BALMER: … fostered a child. Yes, it is a true story.

Madam CHAIR: It sounds interesting. Gary is quite correct. If it came out in 1997 in Canada, we are way behind.

Ms BALMER: I made contact with Anne Stryska. I do not know if you have heard her. She is the leading expert of FASD from Washington. I made contact with her in 1998/1999 and got reams of information from her.

Madam CHAIR: What is her name?

Ms BALMER: Ann Stryska.

Madam CHAIR: Ann Stryska, Washington. Medical?

Ms BALMER: Yes.

Madam CHAIR: Yes, medical. Okay. Thank you, once again, that was great.

The committee suspended.

ALICE SPRINGS CORRECTIONAL CENTRE

Madam CHAIR: Welcome. On behalf of the committee, I welcome you to this public hearing into action to prevent foetal alcohol spectrum disorder. Thank you for taking the time, and we appreciate you coming here to talk 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. 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 will say should not be made public, let us know and we can go into a closed session and take your evidence in private.

For the record, can you state your name and the capacity you are here?

Ms WILKS: My name is Suzanne Wilks. I am the Chief Prison Officer at Alice Springs Correctional Centre.

Ms JARVIS: I am Lynda Jarvis. I am the Manager of Prisoner Services at the Alice Springs Correctional Centre.

Madam CHAIR: Thank you. Do you have an opening statement or comments you would like to make?

Ms JARVIS: What we have done is try to provide you some general information and hope that if you have questions, we can expand further on that. Do you want me to start?

Ms WILKS: Yes, that would be nice.

Ms JARVIS: We looked at the number of the reports that have already been presented to you and tried to tie facts in that we have from the prison that relate to those, just to expand the information that is there. One of the first things we looked at is, generally, what brings people to prison.

There is a number of factors that bring them in that are evidenced to affect all prisoners. The four main ones, of course, are the history of antisocial behaviour, in particular when this behaviour commences at a young age and in a variety of settings - that is home, public, and school; antisocial personality patterns can be things like pleasure and adventure seeking behaviours, poor self-control, restlessness, and aggression; antisocial cognitions or attitudes where the thinking of someone may have values, beliefs, or rationalisations that support crime, emotional states of anger or resentment and defiance and social support for crimes, which is close association with criminal others, and relative isolation from positive role models. For female offenders the inclusion of substance abuse into those factors is highly substantial. Other factors include family support, marital support, school and work if there is low performance or attendance or satisfaction at work, leisure and recreation activities and substance abuse.

We then pose the question: is this the same for individuals with FASD? It has been found in studies by people like Andrews and Vonter that these factors are found consistently in males and females and also mentally disordered offenders. The parallel between the general risk factors and individuals with FASD is quite strong and the individual with FASD, as you have seen from other presentations, is likely to be quite easily distracted or overwhelmed by sounds and movement, to be impulsive and hyperactive. They are likely to have short attention spans and concentration abilities, difficulty incorporating changes in routines, limitations in problem solving, limitations in ability to generalise information, so to form the link to learn from their experience, to understand the consequences and to take instruction. There may be trouble expressing feelings and understanding the feelings of others and general problems adapting to what would we consider the normal stresses of day-to-day living.

For the FASD individual and their relationship with criminal activity the community understands that a child with FASD, in a sense, has been a victim, that is they are not responsible for the assault that has been delivered by alcohol, but as the child ages their behaviours remain consistent and essentially deviant or at least undesirable. However, the community expectations of that individual do change over time and there is an expectation that the FASD individual conforms to the rules and requirements necessary to live in the community. We have got the risk factors for the individual with FASD to commit offences; we can see that form to be quite considerable, so they are at high risk of offending.

Studies that consider FASD and correctional services are only recently emerging. It was identified in 2013 in a Western Australian study into FASD and the criminal justice system that there is actually no reliable data currently within the Australian justice system, but the issues that they found were very similar to what is happening in northern America, and that includes Canada. Information from the University of Washington study – and this was in 1996 – found that 60% of individuals with FASD had histories of arrest, conviction and/or imprisonment. In a study of 287 youths who were remanded to a psychiatric facility in British Columbia, 22.3% were found to have an alcohol-related neurodevelopmental disorder, which

comes under the umbrella of FAS, and 1% had full foetal alcohol syndrome. There were two compounding factors that increased the likelihood of an individual with FASD offending. Firstly, there were co-morbidity factors such as mental health disorders and, secondly, poor socioeconomic factors.

The most frequent offences committed by individuals with FASD include running away, shoplifting and theft - usually of small value items - burglary, drug offences, property damage and vehicular crime, domestic violence and assault, illegal sexual behaviour and probation/parole violations. As individuals with FASD are often unable to retain learning they are unable to readily adapt to new situations. They may display impulsiveness and diminished problem solving. They are highly likely to be recidivist offenders, so they are people that we will see time and time again.

We looked at how we provide services and support to these individuals and we, as a department, play an important role in keeping the community safe and providing opportunities for people within the correctional system to address their offending behaviours through education, training, rehabilitation and life-skill lessons. This includes a through-care approach that focuses on practical assistance such as the development of work skills and employment, literacy and numeracy support, and vocational educational and training. For this to be successful for offenders with FASD, we believe an interagency approach is required that will continue post-release support both for the individual and the family or others who are supporting them.

Consistent with the standard guidelines for corrections 2012, offenders with complex needs are provided with assistance with programs which address their individual need and their offending behaviours wherever possible. However, the needs of offenders who are suspected of having FASD are high and complex. They require a very different approach from mainstream prisoners, and this is particularly evident in the delivery of rehabilitation or treatment programs where the professional expertise of health and related services are essential.

For individuals with FASD, typically a multidisciplinary approach which includes medical, psychiatric, disability psychologists, and allied health is required to achieve sustainable outcomes and, ultimately, reduce recidivism. This can only be achieved through an interagency approach.

We realise, as an agency, the importance of partnership relationships with our community service providers. It is through the services of these providers that the following prevention strategies are implemented and further expanded upon.

When we look at primary prevention - that is, the strategies to reduce the incidence of FASD that focus on not only women of child-bearing age, but also in the general population, and to be embedded in broader alcohol harm reduction strategies, that is consistent with the NAIDOC report that has been offered to this hearing.

At ASCC, the psycho-educational courses and treatment programs are provided to prisoners where alcohol has been a component of their offending, and they are provided by non-government organisations to both male and female offenders. Notwithstanding, the people with FASD still have difficulty working within those groups, or working with those individuals because it is such specialist care.

It would be of further benefit to prisoners if partnerships with agencies that specifically target alcohol use in pregnancy, for both male and female offenders, would be able to be provided.

For secondary prevention, there are strategies addressing the issue of FASD needing to be aimed at reducing the risk of alcohol-related harm to the unborn child. At ASCC, as in every other jurisdiction, the number of women offenders is rising. There is a relatively smaller number within ASCC who are pregnant, and these women are provided with antenatal services through the remote health medical service that works and operates out of ASCC, and also through women's health services in town.

It may be of further benefit to the women to have access to more intensive educational courses that show how alcohol affects their baby, and the benefits of not consuming alcohol or other drugs. This could also include other women who could, perhaps, take on a mentoring role, or themselves are child-bearing age.

At ASCC during 2012 to 2013, there were 145 women aged between 16 and 44. Across the Territory during that time period, there were 451 women of child-bearing years that we worked with. So, you can see the need in the population is there. Ensuring through the integration services that women are aware of community supports to assist with sexual health, family planning, reducing unplanned pregnancy would be consistent with the secondary strategies.

For tertiary prevention, strategies target women who are known to have a child with FASD and/or women with alcohol-related dependency. As we have spoken about in the primary strategy, we offer services related to alcohol use and misuse and offending behaviour. However, it is unlikely, due to the difficult social and economic effects with women offenders and the lack of identification of this spectrum disorder, that the child would have been identified as having FASD.

The child may be known not to attend school, to be in trouble with the police, or in the care of another adult. The mother may disclose she did consume alcohol or other drugs during pregnancy. However, this does not equate to an awareness by the mother or other support people that the child is affected by FASD.

Inherent in the tertiary strategies are the prevention of further alcohol exposure for subsequent pregnancies, and for the parent's health and wellbeing. These we attempt to meet through the alcohol programs, but, again, using a partnership model is where we need to support that further back into the community. Probably the final area would be workforce training and research.

The Menzies submission to the select committee identified that in the Top End, for Indigenous people the rate of FASD was 1.87 per 1000 live births. The researchers noted this is likely to be an underestimation.

The Menzies submission also referred to a Western Australian study completed in 2000 which showed a rate of 2.76 per 1000 live births and suggested at least 50% of individuals with FASD will have contact with the criminal justice system and, likely, incarceration for offending.

It is known FASD individuals have cognitive and behaviour attributes that makes them susceptible to recidivist offending. Therefore, further research into the identification as early childhood community management can assist the individual and their family to have pro-social coping strategies, research that looks at the pathway of individuals with FASD for the entire criminal justice system and also best practice for correctional management who work daily with these individuals. We feel this will be increasingly important for our future resource planning. Thank you

Madam CHAIR: Very comprehensive, thank you.

Ms WILKS: Within the correctional setting, as Lynda identified, a number of offenders present with behavioural or cognitive disorders, those with an acquired brain injury and a few with the early onset of dementia which can be linked to alcohol consumption. A number of prisoners will have chronic and other illnesses diagnosed as part of the reception process.

While we do not have definitive statistics on FASD within the correctional setting, the health clinic in ASCC reports we have four prisoners who have been diagnosed with foetal alcohol.

Madam CHAIR: That is in Alice Springs?

Ms WILKS: Yes. Where the security and good order of the correctional centre permit, the care and custody of supervised persons, and those under a guardianship order, are managed on the basis that restrictions on their personal autonomy are kept at a minimum.

In the Alice Springs Correctional Centre officers who work within a specialist unit are assisted with the daily management of the prisoner population by aged and disability workers.

Additionally, staff who work in this area are encouraged in specialist training supported by management to assist with the safe custody of these people.

Because English is the second, third, fourth or fifth language of Indigenous people, custodian staff work hard to develop and understanding of those people. While we have only the four who the remote health clinic have been able to advise us of, we see, on a daily basis, others who present with some of the same signs as what Flinders identified.

We also recognise Indigenous people suffer from hearing impairments. As part of our core training all officers undertake an Indigenous cultural program. Because underlining the cause of crime is unemployment, poor housing and educational outcomes, the Sentence To A Job program seeks to address this through up-skilling the prison population and assisting them into meaningful work pre- and post-release.

As Lynda has identified, there is such an increase. While there was a 17% decrease in the number of non-Indigenous centres male prisoners within adult custodial centres in the 2012-13 report compared with the previous year, there was an increase of 32% of female prisoners for that year. So it is similar to all global trends; the rise of female prisoners is continuing.

MADAM CHAIR: Similar offences to males or sort of a different set of crimes?

Ms JARVIS: In other jurisdictions a lot of women offenders are involved with drugs and with perhaps theft or burglary.

MADAM CHAIR: To feed the drug habit?

Ms JARVIS: Yes, but there is an increasing trend and we see the trend here not so much with the harder drugs, etcetera but with violence, so that might be in your range of aggravated assaults, to others that cause serious harm and manslaughter.

MADAM CHAIR: Okay, thank you.

Ms WILKS: During 2012-2013 the average daily proportion of females within the Northern Territory was 6%, which was lower than the national average of 8% in the same period. We saw a 31% increase in the number of sentenced Indigenous female receptions and a 30% increase in the number of unsentenced Indigenous female receptions compared with the previous year. The estimated Northern Territory female imprisonment rate for 2012-2013 was 111 per 100 000 adult females, which was an increase of 31% from the previous year and the estimated Australian rate for the same period was 25 per 100 adult females.

MADAM CHAIR: Thank you. Who wants to start? Mr Wood?

Mr WOOD: In relation to handling people with FASD do you separate them from the rest of the cohort or - the reason I am asking that is do they have a negative effect on other prisoners because of their, you might say, irrational behaviour?

Ms WILKS: At times, dependent on their behaviour or incidents we may have to separate them for a short period, but in the main they manage within the general population. As I said there is an area we call the John Bench Unit, where specialist staff are assisted by aged and disability support workers and we have also brought in EDMUND workers who are also assisting with other people with dementia, so there are some that fit into that area, but it only has 16 beds. Three of the people that have been diagnosed are actually managed out in the general population and if they do have an episode or a period where their behaviour is outside the norm for that spectrum, they may go into that area, just to re-establish their behaviour.

Mr WOOD: What age are they around? They are adults, obviously, but are they in their late 20s and 30s? We have heard that sometimes people are not going to be able to be helped once they get past a certain age.

Ms WILKS: Two are in their early 20s and the other - I am unable to say what age group they are only because I would need to have a look at the records and because, as you know, a lot of the population appear to be older. So I would probably put them in their late 40s and possibly their late 30s.

Mr WOOD: I was asking that to see if they are a recidivist risk because what I gather is, once you get to a certain age, it is very difficult to change the behaviours and if those behaviours cause criminal consequences are they coming back as prisoners again and again?

Ms WILKS: Unfortunately most are recidivists, and unfortunately most of the population do not find the stigma attached that perhaps we would find with going to prison because it is considered to be a safe environment. There is that two-way respect between the support staff and the population, so it is a safe environment where they see their family members and there is no humbug.

Mr WOOD: You said Edmund, is that Edmund Rice?

Ms WILKS: Edmund is a contracting company from down south who also supply support workers to the secure care facility. .

Ms JARVIS: There has been some substantial work in Canada on FASD over the lifespan. The mentorship model supported through a number of disciplines - a multidisciplinary approach including the behaviour support plans - can assist an individual over a period of time to modify that behaviour - with the right social supports in time. Even if it is an older individual, there is still potential because the person, depending where they are on the spectrum, is still easy to engage with. These people are very – I do not mean that rudely, the individuals are quite chatty and quite easy to engage. Where they come unstuck is when there is change. It is building on that mentorship model of support that will eventually, through the behaviour support plan, result in a person that can if not learn lots of new things, at least be able to respond from a difference repertoire of choices.

Ms MANISON: In your opening statement you said when people come into the correctional centre with alcohol issues they go through some programs to help with that addiction. Is FASD discussed with them as part of that program so they are aware of the risks?

Ms JARVIS: Not specifically.

Ms MANISON: Do you think it should be?

Ms JARVIS: Yes.

Ms MANISON: You said you have four clients identified with FASD within the system at the moment. Do you have different treatment programs for those four individuals from other individuals?

Ms JARVIS: What we try to do, where possible, is work with that person as an individual. Essentially, all the work done by the partners we work with in the community are group based. A lot of the prisoners we have with FASD will not do well in a group because there is

too much for them to coordinate, think about and plan around all at once. To work with someone with FASD requires a different way of working.

Ms MANISON: It sounded like you thought about the problem with FASD, and not getting the correct diagnosis is creating a few issues because sometimes you do not know what you are dealing with - with the individual. I was interested to hear about your desire to see more interagency support, particularly with Health, to give people the best possible support while they are with you, but also post-prison. Has any of that discussion started or been done or are just seeking guidance and direction from a government policy setting?

Ms JARVIS: We work with the Office of Disability for supervised persons - that is their legal status. It would be of benefit for the individual prisoner if, rather than looking at someone's legal status, we looked at their range of needs and/or diagnosis to build a platform to work from. There is currently in development an MOU with Health. I am not aware of the progress of that MOU, but from our experience we would rather look at the individual and their needs and say, 'Can we have an interagency plan?' than wait for a diagnosis that is not likely to eventuate. FASD diagnoses are rare but the spectrum disorder is very large. It is about working where that prisoner is at so by the time they complete their sentence the community is prepared for their needs and can support them.

Madam CHAIR: Do you manage the juvenile section centre?

Ms WILKS: No.

Ms JARVIS: No. Adult only.

Madam CHAIR: Is that a separate part of the gaol?

Ms WILKS: The juvenile detention centre is on prison property, but it is not managed by adult custodial staff.

Madam CHAIR: It is a separate centre?

Ms WILKS: Yes.

Ms JARVIS: Yes.

Mr McCARTHY: Does a medical diagnosis influence the classification system?

Ms WILKS: No. Each individual is classified on an evidence-based criteria. If a prisoner is identified as having a chronic illness that may impact on his or her placement within the correctional setting but, no, not necessarily on their security rating. So …

Mr McCARTHY: Essentially, this committee is doing an inquiry and will report to government. Government then, hopefully, will have recommendations and there will be some action in this space. If we look at all the different elements, the judicial system is one very important part. Do you think that could be a good move from government - to look at the classification system and a secure-care environment as opposed to the general prison population?

Ms WILKS: The classification system is only - the sentence management manual has only recently been upgraded. As Linda has identified, the whole-of-government approach to supervising the individuals - and sometimes, unfortunately, within the correctional setting we look after individuals so well that they are able to – what is the word for it? - fit in.

Ms JARVIS: It is often the routine nature of the correctional environment.

Ms WILKS: Yes.

Ms JARVIS: It is very predictable. One of the main …

Ms WILKS: They respond well to the routines of the correctional …

Ms JARVIS: Yes. That does make it somewhat easier for someone. The less change someone has to manage and factor into their behaviours, the easier it may be to respond appropriately.

Mr McCARTHY: Sure. This is perfect world stuff. You can image the resourcing of this - you understand that better than us. If there was more capacity for a special needs unit, for instance, and it was located outside of the general prison population, do you think that would be an initiative to deal with FASD-affected prisoners?

Ms JARVIS: It would have some potential …

Ms WILKS: Yes, it would have a lot.

Ms JARVIS: … because that would be the avenue to begin the interagency – what do you call it? - through care or case management for the community placement. Without those supports the individual may be released, may go back to a family that cares very much about them but, because of the nature of that disability, the family cannot always provide that support. Then, fairly rapidly unfortunately, things can escalate back to contact with the police then, potentially, back in with us.

Mr McCARTHY: You have reinforced a very strong theme that has been coming through about that after care. No matter whether it is school education, community living, or public housing, there is always going to be that higher level of support needed. I am thinking of an environment - and I will use some terms I learnt - outside the wire would then be able to easily interface with the family and all those other support networks which, logically, then, would go into supporting that person's return into the community. There could be some real opportunities in time of stay and ...

Ms JARVIS: If someone is at high risk of reoffending, then it is that step-down approach as well. We go from quite a custodial restricted environment, then you have, perhaps, another facility where there is less restriction, then step down back to as much freedom as the individual can work with and be safe for themselves.

Mr McCARTHY: Yes. It is the recidivist nature of an offender with that low level recidivism. You guys really understand them and that is why it is such a nice welcoming and warm environment. Serial offenders are a different kettle of fish, so in terms of what government could take notice of in the department of Corrections - there are some real opportunities with particularly the younger cohort in establishing that and possibly addressing recidivism. Thank you for that.

Madam CHAIR: With the Correctional Services officers, whilst they do training and get qualified - in the course of the operation in doing their job, do you have protocols that …

Ms WILKS: We work within legislation. Our overarching legislation - we work within the law to different criminal codes, the *Sentencing Act*, the *Justices Act.* We have the *Prisoners (Correctional Services) Act,* which informs our commissioner's directive, which informs them as downward operating procedures. So everything we do is procedural and …

Madam CHAIR: Does this fit into it? I suppose it must fit in when you do your assessment when a person first comes to gaol, you assess - okay, I am with you.

Ms WILKS: Yes, the assessment process - within the reception process, when they are brought in on a remand or sentence warrant, part of the reception process is that they are assessed by the medical clinic, so they do a range of assessments. We are quite fortunate in that remote health is our provider; they have a lot of the history of individuals from the communities as well. A lot of people who come into the correctional centre setting here, a lot of their chronic illnesses or diagnoses are done as a point of follow-up on the reception process.

Ms JARVIS: But not for things like FASD.

Ms WILKS: But not for FASD, that is right.

Madam CHAIR: It is more the physical ailments.

Ms JARVIS: Yes, that is right.

Madam CHAIR: Okay, thank you.

Mrs PRICE: I am just thinking - while I have been listening to people describe FASD it has alerted me to a relative of mine who is in prison, and fits into the description. I am just wondering if he has been picked up because I know he is quietly spoken. I saw him as a baby, I have watched him grow and watched his lifestyle, and what I have heard this morning describes exactly how he has lived that life. I know that he does have that now he is in prison and I am wondering whether he has slipped through or if someone has picked that up in there to actually give him the treatment required?.

Ms JARVIS: I think one of the issues that an individual with FASD has is that - it has always been known as a disorder since the late 1960s, but we were not very good at identifying it - we are not very good at separating someone that has a disability from someone that has just been naughty, if you like, whether that is a child or an adult. I think that is why we miss, as a general population, a lot of individuals who actually have difficulties. Their brain, for one reason or another, is not functioning the same as everybody else's, but we just step back and say, 'You are just not obeying the rules and now you are going to do this', rather than taking that holistic approach, so I cannot tell you whether he would have been picked up or not.

Madam CHAIR: The question would be then - Bess said, 'I know of all of the information that I have been receiving through this inquiry, and my nephew fits into that scale', and she came through and said, 'Scoop him up and put him in that category'. Could you do that?

Ms JARVIS: We could take him and have him looked at.

Mrs PRICE: But his parents were alcoholics, they lived in the town camp down here and they (inaudible) their life (inaudible).

Mr WILKS: And just as an officer on the ground, at different times there will be somebody who does present to staff - you have seen the behaviours somewhere before or you know he is not quite fitting within - so you do develop a management plan for that individual and link him into responsible family members and make sure that perhaps friends get involved or the mental section get involved.

Madam CHAIR: That is something we could take up later. Thank you very much for you time here today, Suzanne and Lynda. It is much appreciated. We will send you a transcript so you can go through it and make sure it is all accurate - what we have talked about.

Ms WILKS: Thank you.

Ms JARVIS: Thank you.

Madam CHAIR: Thank you very much.

The committee suspended

CENTRAL AUSTRALIAN ABORIGINAL CONGRESS

Madam CHAIR: Welcome. Thank you for coming. On behalf of the committee, I welcome you to the hearing into action to prevent foetal alcohol spectrum disorder. Thank you for taking the time, and we appreciate you being here so we can hear from you and you can ask us questions, or vice versa.

This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply. 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 might or should say should not be made public, we

can go into a private session and take your evidence in private. For the record, can you state your name and the capacity you are appearing here today?

Ms AH CHEE: Thank you. My name is Donna Ah Chee. I am the Chief Executive Officer for Central Australian Aboriginal Congress.

Dr BOFFA: I am Dr John Boffa. I am the Chief Medical Officer for Public Health for Central Australia Aboriginal Congress.

Madam CHAIR: Thank you. Do you want to make an opening statement or comments?

Ms Ah CHEE: Thank you, Madam Chair. I first begin by thanking the select committee for inviting us to give evidence today, and also acknowledge it is not often that we have the Northern Territory government establish a process of getting community feedback in this type of …

Madam CHAIR: It is more a parliamentary process.

Ms Ah CHEE: …parliamentary process, in this type of way. I have been in Congress for so long and I do not think I have ever given evidence to a select committee for the NT. So, this is great.

In my opening address, I will begin by highlighting the evidence in our submission. For babies that suffer brain damage from alcohol *in utero*, the majority of the harm is caused by heavy drinking by the parents in the months before conception, and heavy drinking by the mother in the first six weeks of pregnancy. There is further evidence that these pregnancies are unplanned and it is, therefore, not possible to make a major impact on FASD with any programs that only start once it is known that a woman is pregnant, or designed to try to promote better planning for pregnancy.

The key to prevention of FASD are population level interventions that reduce heavy alcohol consumption amongst all men and women. These interventions include: an alcohol floor price of the price of beer; restrictions on takeaway trading hours, including a takeaway-free day linked to Centrelink payments; photo licensing at the point of sale with a Banned Drinker Register; and the restriction on late night trading through nightclubs.

It is also worth noting at this point that the impact of the recent TBL strategy in Alice Springs has been very marked, and it is very likely this approach to supply reduction is having a

major impact on reducing FASD. There are, however, concerns with this strategy, but it does have to be acknowledged that it is effective.

The second point I want to highlight in my introduction is around the prevalence of FASD. There has been a lot of publicity and concern about the lack of good data on the prevalence of FASD. While we agree we need better data on this at an individual level, what is being ignored is at a population level we have very good data showing the level of developmental vulnerability amongst Aboriginal children in Central Australia. We know children entering the school system with the level of developmental vulnerability they have are unlikely to get to Year 12 and beyond.

Finally, we know alcohol addiction among parents is a major cause of this developmental vulnerability, whether the damage from alcohol is occurring in pregnancy or in the early years after birth. At the end of the day, at a population level it does not matter so much as to when alcohol is causing the damage as the group of interventions needed at a population level do not rely on the distinction between the congenital damage which is FAS, and FASD or damage after birth.

It is very likely the majority of children affected by alcohol use in utero will improve greatly in the early years after birth with the appropriate early childhood programs. These programs need to be available to all children from disadvantaged backgrounds and the children who do not progress at the normal rate can be referred for further assessment. For many children the loss of brain potential they initially suffered in utero will be offset by the intensive stimulation in early years after birth and they will be able to function normally as a result.

It is also the case most babies born with alcohol-related damage to their brain potential will not be diagnosable as FASD no matter how good a diagnostic tool is developed. We know alcohol causes damage to the unborn child and continues to cause damage in early childhood due to the lack of responsive parenting and understimulation.

Thus, in any population where there is a high prevalence of alcohol misuse, coupled with a high level of developmental concerns in children, you can make a population level diagnosis of FASD without an individualistic diagnostic tool. We can fix the problem without hiding behind the lack of a clear individual diagnosis.

I would like to hand over to John.

Madam CHAIR: Thank you.

Dr BOFFA: I want to add to that in two ways. The two main points, starting with the second one, which is this issue of the population level diagnosis - in our submission we put in two graphs, one was the British cohort study. Professor Sir Michael Marmot undertook a study where he looked at 70 000 British babies all born in the same week in 1970 and he followed them for 30 years. What he has shown is children – there were children born with a very low IQ and children born with a very high IQ. The children born with a very low IQ out of the 70 000 babies - some of those children dramatically developed their potential after birth and they were the ones in the high socioeconomic families. The ones in the low socioeconomic families hardly made much of a change at all.

Of those kids with low IQ, a lot of them would have had their IQ potential knocked off by alcohol in pregnancy to varying degrees. Instead of being 110, some of them would have been 100, some would have been 90 and the severe end of the spectrum might have been 60 - they are the classic FAS children – but at a population level there are variations of that. That is, in some ways, the bad news.

The good news is the second graph we put in was the graph from the Abecedarian educational daycare program which shows – that is the graph which is in our submission – if you take children from disadvantaged families, many of whom would have been exposed to alcohol in pregnancy and many of whom are in families where parents are trying to bring them up in early childhood with alcohol addictions, if you put those children into educational daycare at age six months – this was a randomised controlled trial which you could not ethically do anymore because the impact is too great – some children were put into educational daycare 28 hours a week from age six months until they were three. Other children were left in their disadvantaged home situation without any intervention. The kids in educational daycare were stimulated with Sparling's learning games; there are 200 of them and you do them sequentially. They are age-appropriate learning games. They were stimulated with conversational reading and responsive care, while the kids in the study arm, almost 100% of them were above normal IQ by age three. The kids who were not in the study arm, more than half of them were mentally subnormal by age three and that was what happened after birth. You can make a massive difference with appropriate stimulation. If, at a population level, all disadvantaged children have access to educational daycare and they are all going through these learning games, irrespective of how much potential they have lost in pregnancy, you would find, firstly, the children who had lost 20 IQ points would gain well, would be normal and would never be diagnosable, but those kids who were at the severe end of the spectrum would become clear because they were not passed through the learning games at the normal rate and they would then get referred for special assessment to find out why. Now, some of that would be FAS, FASD, some would be other causes of congenital brain damage. What we are suggesting is the need to take a population level approach to the problem and a population level approach to interventions, which will pick up a lot of children, the kids at the severe end …

(Editor's note: Missing audio between 1:06:37 and 1:13:59)

Dr BOFFA: Not much will make a big difference to them. You can spend a lot of money on intensive programs for those children without much in return compared to spending the same money on interventions at a population level where you will make a big difference for a lot of kids who have been affected by alcohol in pregnancy. That is the first point.

The second point is the data we have just produced. We were looking at the impact that - what we have in Alice Springs now is a very effective supply reduction measure, which is the temporary Beat locations, with police at takeaway outlets. There are concerns about that but it has been in full force since the end of February and we have seen publicly-reported data from police and from the hospital about a 50% reduction in assaults.

When you look at the data from our Safe and Sober program, at any one time it is treating around 200-plus people with an alcohol problem. One of the tools they look to use to measure consumption is a thing called time-line follow-back. For every client they see they ask how many standards drinks they had the week prior. I want to show you what we did. We analysed the data from – I only have six copies, I did not know how many. This is one graph where we analysed the data for the five months, March through to July this year, which is after temporary beat locations started, and looked at the same five months in 2013. What that graphs shows is that in 2013, there were 80 clients who were drinking 50 or more standard drinks a week. In 2014, there are 30 clients drinking 50 or more standard drinks a week, at a population level. That is matched. This one looks at all clients in the previous week. You can see, again, between the two periods there is a massive shift to the left so that, in 2013, there many bits in the blue - there are many more clients have many more standard drinks in the previous week ...

Madam CHAIR: These are your clients?

Ms AH CHEE: Yes. Our alcohol treatment program.

Dr BOFFA: These are clients in our Safe and Sober program. All this is showing the main point of this is, if you look at that, we will be having a huge impact on the prevention of FASD. At a population level, amongst the heaviest drinkers - which include men and woman of child-bearing age – if you can reduce a significant number of people from more than 50 standard drinks a week down, you actually are going to have a big impact. This has to be at the time of conception. This is the time when pregnancies are unplanned, so this has to be for men. It is important their drinking level prior to conception makes a big difference on the baby as well, not just women.

You have to reduce the level of consumption at a population level and that is what is happening in Alice Springs since this strategy started. That demonstrates just how effective

it is. If you get supply reduction right, you can argue about whether this is the right way to do it. That is a different discussion. But this shows that you can actually reduce supply to the heaviest drinkers in a significant way, you will reduce consumption and you will have a big impact in the primary prevention of alcohol-related brain damage, both *in utero* and in assisting parents.

Anecdotally, what is being said in Alice Springs is also children are sleeping at night and they are going to school. We have asked for the data on this. We would like to be able to look at the data. We would like to look at what has happened to alcohol consumption. We know what has happened to assaults. We want to look at what has happened to hospital admissions. Also, we want to look at what has happened to school attendance since this has been happening. When you put all of that together, we could well be sitting on a very important example of the impact we can have in the prevention of FASD and every other type of alcohol-related harm. That is all I wanted to add to what Donna said. The two key points we are making is if we get population measures right, we will have an impact. In addition to that, if we get stimulation - if we get the right early childhood programs - we can also have a very big impact on children, even if they have had 20% of their brain potentially knocked off *in utero*. We will not have such a big impact on the kids who have had 50% of their brain potentially knocked off *in utero*, but that is a very small number of children. There is a much larger number of children, which is what is showing up in the AUI scores, who have lost potential and are losing it after birth at a rapid rate, not just in pregnancy. We can make a big difference for those children with the right interventions.

Ms AH CHEE: We have been looking and have been in this space for a few years now. For me, the tragedy is that kids can be born with full brain capacity. It is what happens thereafter. So, we really have to get in early and prevent those situations that have them where they lose their full potential to go on and be active participants in our community.

Madam CHAIR: Has the Education Department responded to your request to try to get data of attendance during the period of the temporary beat? No?

Dr BOFFA: What we have done is put in a freedom of information request for this data. When I say 'we', we are here today as congress, and Congress is part of the People's Alcohol Action Coalition. So, PAAC has applied for that data under an FOI application. That, so far, has been knocked back. We do not have the data yet. But, it is important. One of the problems is lack of data in this whole space. This is strategy is government policy. It would be really good to demonstrate …

Madam CHAIR: The police are working.

Dr BOFFA: … and there would be - and this strategy is government policy - it would be really good to demonstrate. You can have the debate about whether this is the right way to

reduce supply, but the first thing you have to always prove is if supply reduction is effective it has a big impact across the board. I think we are sitting on, potentially, an opportunity to do that because since the end of February there is no doubt we have had a varied impact on reducing consumption here in Alice Springs. But this, of course, is not happening Territory-wide.

Madam CHAIR: No, it is in Tennant Creek.

Dr BOFFA: Yes, it is in Tennant Creek

Mr McCARTHY: In terms of the temporary beat location there is already various kinds of exploitation going on around that and there is also cross border migration going on around that. We have seen people go to Mount Isa, for instance, to live. What I want to say about the intervention in the early childhood area is - so I make an assumption that from four years up to eight the now normal system is handling those sorts of nutrition, education simulation and the physical programs - governments really need to be looking at the zero to three group, which even then defines investment even further, yes?

Ms AH CHEE: Absolutely, Gerry, that is exactly right and that is where we are not - there is not enough investment in that space. Federally, there has been investment into preschool, and that is a good thing, but at the end of the day if we do not get in any earlier we are actually not preparing our kids on that trajectory of doing really well. So yes, we are advocating that we need to get more investment from nought to 3.

Dr BOFFA: And in our preschool awareness program - we have not presented this data - we take children aged four to get assessed, we assess all the kids through health checks, we find the kids that are behind and they get a (inaudible) developmental assessment, so children at age four who have a receptive language ability of two-year olds get a three-week program based on the Abecedarian learning game and conversation reading. In those three weeks one child went from the receptive language ability of a two-year old to that of a three-year old, so they improved 12 months in three weeks.

The cohort of seven kids that went through it on average improved six months - one child did not improve at all, and so when you have done that, again, we are finding that depending on the level of neglect and abuse the kids have been exposed to, if it is too severe you do not make a big difference, but for many kids you make a very big difference.

Now if those kids when enrolled - because we enrol all the kids in preschool - had a receptive language ability of age two, were enrolled at age four without any extra help, they would not understand what is being said to them from the moment they start preschool. They will not

understand what is being said to them in primary school. It will not be the school's fault that those kids will not do well in school.

They have come up to the school system with a level of a receptive language development problem. They have often come as well - that is the cognitive side of development - they have often also got an emotional impairment in their emotional development, they lack self-control and are impulsive, which is a bigger disability than a cognitive impairment.

The AVI scores assess five domains of development - physical, social, emotional, intellectual and communicative development. The two big ones that kids are failing on are the cognitive and language development and the emotional development, which is self-control, self-regulation and impulsivity. If you put those kids into the classroom or even into a preschool, they will not do well and you can actually have very intensive interventions in early primary that make some difference, but it is the law of diminishing returns. The later you leave it the less chance you have got to get a child back to what their trajectory could have been with appropriate stimulation.

So nought to three is the key period and nowhere that I am aware of - there is the Families First Teachers program, which is an Abecedarian chart program in the home - but the Abecedarian research says there is a threshold of exposure, which is 28 hours a week, every week. In that program you are relying on the parents to do the work and the reality is that in many disadvantaged families, no matter how well you support parents, they do not do that often enough with their kids to get sufficient exposure to make a difference, which is why educational daycare in an institutional setting complements what parents do on their own. We do not have that happening anywhere in an institutional way to make a big difference.

Madam CHAIR: With the police beat at the bottle shops, do they wait for the customer to go in and buy the alcohol and then when they come out with it say, 'Where are you going to drink it'? or do they get the person before they go into the bottle shop?

Ms AH CHEE: Before

Madam CHAIR: So they do not waste their money.

Ms AH CHEE: They ask before.

Madam CHAIR: So it is before they purchase the goods?

Mr McCARTHY: There was a lot of episodes of after. It created a lot of grief and people were getting their – and that caused allegations that the police were taking that alcohol and consuming it themselves. I have dealt with a lot of this stuff.

Madam CHAIR: So, if they do it before, that means they are not wasting their money.

Dr BOFFA: And it was earlier on …

Ms AH CHEE: It was earlier, yes.

Dr BOFFA: That was happening earlier, but now people just do not go. They know they are there, they know …

Mr McCARTHY: That is right.

Madam CHAIR: That was going to be my next question. Clearly, there would be some people who get cranky. Let us say it is Aboriginal people. Is there a general acceptance, 'Oh I just cannot buy alcohol, I will go home, or I will go and visit a mate, or whatever?' Or do they just then try to get it from somewhere else? Or do you think they just accept it and say, 'Well I cannot get any alcohol, so I cannot get any'?

Mrs PRICE: Do you know what they do?

Madam CHAIR: What?

Mrs PRICE: They wait until the cops go and then they will make a mad rush to get the alcohol.

Ms AH CHEE: Oh, the data of reduction in consumption is actually ...

Madam CHAIR: Well, it must be going down. They must go home or something.

Ms AH CHEE: Yes. The response is it is working …

Madam CHAIR: Yes, they cannot get it so …

Ms AH CHEE: One of Boffa's - who used to be a patient of ours Safe and Sober program, who no longer is a patient – is just not drinking anymore. She stopped drinking completely because of it …

Madam CHAIR: Oh, good.

Ms AH CHEE: … because she did not want to …

Dr BOFFA: You could get the police to do the same presentation to you as they did to the Alice Springs Alcohol Reference Panel. Although what Bess has said was happening earlier on, now, since the end of February, they are on all the outlets - all 11 of them - all the time. When they miss a couple of outlets every now and then, it is random, and they are not seeing them rebound. When they were doing it four days at a time and then they were not doing it, they were seeing a massive rebound. Now, they are missing outlets so infrequently and so rarely, people are not getting word around quick enough to see a big change in consumption. As long as they are able to do it all day, every day, almost 100% of the time, you do not see that rebound effect. Although there are secondary supply issues - and there are and they acknowledge that - overall the drop in consumption, assaults, and in hospital presentations is very large.

Ms MANISON: I definitely have the message loud and clear today about supply reduction being a key issue that needs to be tackled if we are going to lower the rates of FASD. I wanted to ask you a couple of questions regarding some of the programs through Congress you currently offer, to look at the issue of FASD. Within your Safe and Sober program, is FASD a discussion you have with your participants as part of that?

Ms AH CHEE: I am not sure I understand the question. We do not actually focus on FASD per se. If a patient is referred into our Safe and Sober program, we provide three streams of care - pharmacotherapy, structured therapy, and social and cultural support. It is not necessarily focused on FASD as such, it is about treating the alcohol condition.

Ms MANISON: Okay. I was just thinking about having that conversation with people so they understand the consequences of drinking and FASD. I have heard in the past, I am sure, that you have run a program with mothers or expectant mothers.

Ms AH CHEE: Yes. We have what is called the home visitation program. It is funded by the Commonwealth. In fact, it is going to be rolled out to another 10 sites. We are one of three sites in the country. It works with mothers from 26 weeks of pregnancy up until the child is two. We see this program, along with the one that John mentioned earlier, the Abecedarian

early learning centre, as being complementary, so you are working with parents and mothers during pregnancy up until the child is two, as well as being able to deal with those children who are in really disadvantaged environments. It is a targeted approach to work with those children directly.

Ms MANISON: Discussion around alcohol consumption is part of that program?

Ms AH CHEE: Yes, absolutely. The home visitation program, yes.

Ms MANISON: How has that program been going for you?

Ms AH CHEE: It has been going extremely well. We are still getting trend data, but generally quite good. John, do you want to give some exact data on that.

Dr BOFFA: There is good and bad here. About 50% of pregnant women stay on the program until the end and 50% do not. For the women who stay on the program their kids are really benefiting a lot and will lift that group of kids up to another level. However, the really heavy drinking women who are subject to a lot of domestic violence are not staying on the program. They are being referred but not staying on it, which is why, in our submission, we talk about a more intensive version of home visitation which is what the evidence says works for women who are drinking in pregnancy.

Our program is visiting once a week or once a fortnight. It is designed in a way that you have to get good participation from parents for it to work well. It is designed to address drinking and other issues, and it raises awareness about FASD for women who do it. Not all women access it. It is a very effective program but it needs to be coupled with a more intensive intervention for women who are drinking heavily in pregnancy.

Ms MANISON: People from the People's Alcohol Action Coalition this morning were discussing potentially getting child protection systems involved with those types of mothers to see if they can do more of that intensive type work with mothers to reduce their drinking. Is that what you are looking at there?

Dr BOFFA: Yes, child protection could do case management but they would also need a more intensive nurse-led program seeing women almost daily trying to help them reduce their consumption as well. It would be both those.

Our Safe and Sober program has employed a clinical neuropsychologist because they are very aware of the need for better cognitive assessments on parents who are drinking. Now

this does not get it. We work with children with FASD, but there are many adults who have significant cognitive impairment. That could be acquired because they have been heavy drinkers or they could have had it since birth. No one would know because we have not been doing that.

In the clinic recently I saw a 19-year old girl who was bought in by a support worker from Western Australia who had been cut off her Centrelink payments. She had been referred to various educational sessions and had been sitting in the corner not listening and no participating so she stopped going and her payments were cut. She is significantly cognitive impaired and could well have been like that since birth. To get that assessment though takes three one-hour sessions with a neuropsychologist. Luckily she had a carer who brought her to those sessions.

There would be a lot of people out there and in the prison system. We have not done this research in Australia, but in countries where they have looked at prison populations half are generally cognitively impaired. A study came out a couple of days ago looking at women, and a significant portion of women in prison because of domestic violence are cognitively impaired.

A lot of people, as adults, would have levels of impairment that may have been there since early childhood and we would not know. We need better at assessing people. In the mandatory treatment program - I am sure if they presented the data they would know - out of the people who have been through mandatory treatment I would not be surprised if half of them have significant cognitive impairment because that program is seeing the very severe end of the spectrum of people with an alcohol problem.

You then have to take different pathways. What you offer someone who has significant cognitive impairment is quite different to what you offer someone who has not. They need disability support and supported accommodation, perhaps even supported employment. Other people with pharmacotherapy, cognitive behaviour therapy and good – you might cure - they might be able to get over their addiction and get back into the community. You have to work out who has and who does not have significant intellectual impairment and those resources really have not been in the system.

We have one woman in town and everyone is trying to refer people to her to have these assessments done.

Mr WOOD: You mentioned concentrating on the point of conception and a few weeks after. I do not know if the person Dr Boffa was referring to is Dr Jennifer Delima, but I asked if we could intervene. Even though the person was drinking during that first period, can we still make a difference? She said, ‘Of course you can, there is quite severe damage done to the

baby, even for the rest of pregnancy if the person keeps drinking'. I got the impression that you were saying it was all important in that first section around conception and for the first six weeks, but it was not as much of a concern afterwards. Is that what you were saying?

Ms Ah CHEE: Afterwards, in terms of …

Mr WOOD: After that six weeks.

Dr BOFFA: After that six-week point. Alcohol is a neurotoxin at any age. It knocks off brain cells at any age, so what we are saying is the majority of harm is done in conception and the first six weeks, but harm will continue to be done throughout pregnancy at any time.

Mr WOOD: I was a bit unsure because I asked Dr Jennifer that same question or a similar question and I get the impression that actually there is quite a lot of harm still done through the trimesters. She showed us a table, and I was just trying to clarify what you said as against what she said.

Dr BOFFA: We reference the NHMRC paper from 2009, which really does say the majority of harm - we are talking 80% of the harm - is going to be prior to six weeks. There is harm happening afterwards, but if Jennifer said the majority of harm is happening after that, that is not true.

Mr WOOD: No, she did not say the majority.

Dr BOFFA: There is ongoing harm, which is why in our submission we do recommend the program for pregnant women who are drinking because that will prevent some of the harm, if it works.

Mr WOOD: I was asking in relation to, and you actually mentioned a little bit in your submission - there was a need for a well-evaluated trial of mandatory treatment for those with alcohol dependency who refuse treatment. We did talk to Russell Goldflam this morning about that, with the issue of whether government has a role to play. I am not talking about criminalisation of the issue, but even though you may not agree with alcohol mandatory rehabilitation the consequences of escaping can be criminalised, and I am not necessarily agreeing with that. But it is not a criminal thing to be held in that particular treatment - if it had something that was community-supported, passionate in what it was intending to do and you have tried everything else to try and get this person to stop drinking, you are saying that perhaps we should at least trial that to see if it is effective?

Ms Ah CHEE: Yes.

Dr BOFFA: Yes.

Mr WOOD: And the other last one, because I know we are short on time - the issue of early intervention between zero and three: how can that be put into practice? I know you can say from three years on you can go to preschool - mum is home with kids, she would have lots of other things to do, she might have a few kids, she might be sending kids to school, but how would you get a program to work at home that you say is really important? How practically can you make this program work - and mothers of all different situations, whether they live out bush or whether they are a non-Indigenous woman in Fannie Bay. How would it actually work on the ground?

Ms Ah CHEE: That is the beauty of the Family Partnerships program, because it is a universal program open to all first-time mothers, but we have adapted it to allow mothers who have had multiple births, so it has universal access and it focuses on the mother. The Abecedarian program - these are practical, evidence-based programs that can support the issue of developmental issues with children, but also preventing it by working with mothers through the home visitation program, complemented with the Abecedarian early learning centres, where you are actually taking the child into a centre and stimulating them through conversational reading and enriched nurturing. There are two practical programs that have an evidence base to them that can work from nought to three.

Mr WOOD: And they apply to someone that has not got a disability and they will end up being brain surgeons at the age of three because we have stimulated their brain? Does it apply to anyone?

Ms Ah CHEE: That is the whole purpose of having those two programs. It is to maximise the potential of children, for all children.

Mr WOOD: But in the process of doing that you will pick up people with a disability at the time when they most need to have the stimulus?

Ms Ah CHEE: Yes. And that is what John mentioned.

Mr WOOD: We cannot recognise what FASD is, and you are saying that it should be population based and the only way you are going to try and tackle it is you are going to encourage everyone to do this program.

Dr BOFFA: Yes, I think with the Abecedarian program, again, the law of diminishing returns applies, so home visitation works universally and will work with everyone a little bit, but the Abecedarian program, when it is analysed by the level of education of the parent - if one or both parents had a university degree there was almost no difference in the outcome for the children that went to an Abecedarian centre compared to the ones who stayed at home. When one or both parents has only some high school you get ab IQ difference of 30, and that is a gradient. If a parent has Year 12 the difference is less.

For the Abecedarian program, you would really would …

Ms AH CHEE: It is targeted.

Dr BOFFA: … target the families of children where parents do not have tertiary qualifications and they will get the most benefit. This is coupled with the research by Ridsley and others that looks at – they did an amazing study where they looked at households where one or both parents had a university degree, households where both parents are working class, and households where both parents are welfare recipients and they found children in households of parents with university degrees, by age four, had been exposed to 32 million more words, words of different complexity and words of different tones, and they had had 560 000 more positive affirmations than negative affirmations. The children in the welfare families had 160 000 more negative affirmations than positive by age four, which is a difference of about 700 000. You have got kids who have been told, 'You are great. You could be whatever you want to be. Well done.' Kids are being told, 'Shut up. You are dumb,' and kids have been – that is why you need the extra stimulation for kids from disadvantaged households.

They will not be exposed to conversations in the household. They might be in front of the television, and if you are in front of a television up to age two you will not even hear conversational language. That is why TV is – it is not because of hearing problems. There is a misconception that because kids have pus ears they are not learning. That is not the major reason kids do not hear conversational language in the household.

Ms AH CHEE: In spite of the social environment we can make a difference.

Dr BOFFA: We can make a big difference.

Mrs PRICE: Are the home visitations just in town camps?

Ms AH CHEE: Yes.

Mrs PRICE: Once you do that is there ongoing support for the families?

Ms AH CHEE: Up until the child is two is the program logic. We are also doing it at Amoonguna and Santa Teresa. It is accessible to all Aboriginal women in Alice Springs.

Mrs PRICE: Are they aware of this program?

Ms AH CHEE: Yes, we have done – yes, it has got around through word of mouth as well as our referrals from our midwifery program. We have also been doing a lot of ads and advertising on TV.

Mrs PRICE: Do you have Alukura …

Ms AH CHEE: Yes.

Mrs PRICE: … do they run programs there as well or awareness programs for young pregnant mums who have their check-ups?

Ms AH CHEE: That is the main program, the home visitation one.

Mrs PRICE: Yes.

Ms AH CHEE: Which is obviously supported by our antenatal care which is what Alukura runs as well.

Mrs PRICE: My sister-in-law looks after all these kids and obviously some of them fit this category. Do people like her, who look after multiple children with all sorts of problem, have – does anybody from Congress visit them to ask them whether they need any help with these children with all these disabilities?

Ms AH CHEE: We have a targeted family support service so it depends on whether that - through our referral pathways onto that program. If issues are brought to our attention through our main clinic or through another program then they would be referred to our targeted family support service.

Mrs PRICE: Yes, and I am just talking about these sisters where there are problems. There is a household full of children - maybe 10 all up – of varying ages. These children were born from FASD parents as well.

Dr BOFFA: Yes, so …

Ms AH CHEE: Yes, it is intergenerational is it not?

Madam CHAIR: That is your second generation.

Mrs PRICE: Yes.

Dr BOFFA: Yes. In our preschool program when they are offering child-centred play therapy - so there are children who are already damaged and you have got to work with them as well with it.

Mrs PRICE: In the Congress preschool.

Dr BOFFA: What is that?

Ms AH CHEE: Preschool readiness program.

Mrs PRICE: Readiness, yes.

Dr BOFFA: They offer, for those kids, child centred play therapy as one of the evidence-based ways you can try to help kids who already lack emotional self-regulation and the development they should have. And we offer that. If there is a need in a family like that because there are kids who are really behaviourally disabled and difficult to control, we have a clinical psychologist who works on that program. There is a room where those kids work ...

Ms AH CHEE: But that is only for three and four- ear-olds.

Dr BOFFA: Yes, that is for three and four-year-olds. After that …

Ms AH CHEE: If the children are outside that age …

Dr BOFFA: Yes, after that it becomes – yes, they are all for kids before they get to school. Then, once they get to school, there needs to be special support. You have to fund some classrooms for quite a lot of extra support workers if classrooms have kids who are really – if kids lack emotional self-regulation and have behavioural issues when they get to the classroom, a normal teacher will not be able to control those kids and teach the class. So, you have to have other support workers in the early primary years.

Mrs PRICE: It is the upbringing as well amongst our people. They do not show that affection to that child at all. There is nothing there whatsoever to comfort this child …

Dr BOFFA: And that is a big problem.

Mrs PRICE: We all have to work with parents as well, including whatever programs we deliver out there to make sure they have a relationship as well.

Dr BOFFA: Yes.

Ms AH CHEE: Yes.

Madam CHAIR: We had better leave it there. Thank you, Donna and John, very much for your time. It is much appreciated indeed.

The committee suspended

CENTRAL AUSTRALIAN ABORIGINAL ALCOHOL PROGRAMMES UNIT

Madam CHAIR: Welcome to this public hearing into action to prevent Foetal Alcohol Spectrum Disorder. Thank you for taking the time to be with us today and I apologise, we are a bit behind schedule This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply. 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 think there are things that you might say that should not be made public we can go into a private session and take it in private. So for the record could you state your name and the capacity you are appearing here.

Ms WEDEMEYER: Sabine Wedemeyer. I am here as the alcohol mandatory treatment manager situated in the Central Australian Aboriginal Alcohol Programmes Unit

Madam CHAIR: Did you want to make an opening statement of any kind or opening comments?

Ms WEDEMEYER: Not really, to be quite honest, because I would prefer if you started asking - as you know we work with adults, so we are not actually working with children. It was actually a beautiful statement that Dr Boffa made before. We have a lot of clients with acquired brain injury, but we do not know when it actually occurred, so I cannot comment on if it really falls under the FAS umbrella or not. The clients that are presented to us are adults (inaudible). We have very little history where you can go back and ascertain what the family situation was when they were children, so we are at a little bit a loss here. If you ask me how many of my clients fall under the foetal alcohol spectrum I would not actually be able to give you a number.

Mr McCARTHY: How many would be under 25, since the program started?

Ms WEDEMEYER: In the mandatory program? I think we had two, so our main clientele seems to be around 30 to 60 years old.

Madam CHAIR: So you are part of CAAAPU?

Ms WEDEMEYER: Yes

Madam CHAIR: And that stands for?

Ms WEDEMEYER: Central Australian Aboriginal Alcohol Programmes Unit

Madam CHAIR: And it is attached to the Northern Territory government or to …

Ms WEDEMEYER: No, it is an NGO.

Madam CHAIR: An NGO.

Ms MANISON: It provides the mandatory alcohol rehab for Alice Springs.

Madam CHAIR: I am with you.

Ms MANISON: You also have voluntary programs as well.

Madam CHAIR: I am with you, thank you.

Ms WEDEMEYER: So CAAAPU has, in total, 56 beds now - we have accommodation that is residential - and 20 of them are mandatory beds.

Madam CHAIR: I am with you, thank you.

Mr McCARTHY: How many women are in the AMP?

Ms WEDEMEYER: It has been 50/50.

Mr McCARTHY: 50/50?

Ms WEDEMEYER: Yes

Mr McCARTHY: Any pregnant women?

Ms WEDEMEYER: No. We had one that we suspected, but she completely refused any tests; we cannot force them. We took her to (inaudible) she refused to have our staff members inside, so it is possible doctors did not give us the information because she did not release it to us, she actually asked the doctors not to tell us. We suspected her to be pregnant, but we do not know.

Mr McCARTHY: And Indigenous or non-Indigenous?

Ms WEDEMEYER: So far all of our clients have been Indigenous, so it is 100% at this stage.

Mr WOOD: When I visited when they first started it was not what I would call secure. Is it secure?

Ms WEDEMEYER: It is more secure than what you saw. We have a fence all around now, like a colorbond fence, however it is still climbable if you really want to, and some clients still do, yes.

Mr WOOD: So how many people have you had escaping there?

Ms WEDEMEYER: How many of what?

Mr WOOD: How many residents have you had there since it started?

Ms WEDEMEYER: In total, we had 68.

Mr WOOD: How many have completed your program?

Ms WEDEMEYER: Forty-eight have graduated.

Mr WOOD: How many have jumped the fence?

Ms WEDEMEYER: I do not have the figure with me. It is about 30, at some stage, but some of them came back by themselves and completed the program. Some have been returned by police and completed the program. Three have jumped the fence and not returned.

Mr WOOD: Do you know if they went to prison, or they just have not been caught?

Ms WEDEMEYER: No. One went to prison on unrelated charges. He actually kidnapped his newborn child in hospital and disappeared with it. That was unrelated to the program. He ended up in hospital. For two we have anecdotal sightings in the community of origin. So, it could be …

Mr WOOD: Do you know, have there been any success stories you can tell us about people who have been through?

Ms WEDEMEYER: Yes, there have been. It depends where you start with success. Total abstinence, I am not entirely sure, because we cannot follow them. I know of two or three

women who have been offered jobs and they are holding them down, so they are actually working, which is a massive success. One of them held a job before, but has not worked for 10 years. She has a job in community. One lady is working part-time in town as a translator. The other lady is commissioned with an art gallery. She left town and I think that is a success because she made a decision to leave town and go to her family in Docker River because of very abusive family relations in town which, in turn, drove her to drink.

We have married couples who actually graduated today. I cannot tell if it will work, but they are involved with an apprenticeship program - both of them in the same program – so, hopefully, they will see it through. We have a fair few successes really. Massive success does not sound like much, but we have clients that come in, they really do not care about their health and, all of sudden, they are starting to question the doctors. We have a doctor there part-time on-site and they are starting to question, 'Why do I take this medication? Why do you give this to me?' I reckon it is massive success because, all of a sudden, they actually start to take interest in their own health. Once it has been explained, they start to come up and ask for medication. We had clients come up who were so down on their health - we are talking chronic diseases which are absolutely rampant.

Mr WOOD: Is this mandatory or voluntary?

Ms WEDEMEYER: Mandatory. No, no, at the moment, I am really talking only of mandatory. They have, all of a sudden, taken an interest in their own health and in the mandatory we have that.

We had clients who have left us many months ago - over six months ago - still ringing up our case workers asking for support, which is a success in itself as well.

Mr WOOD: Are the doctors assessing their health and other things besides alcohol abuse?

Ms WEDEMEYER: Yes.

Mr WOOD: Does that make any difference too?

Ms WEDEMEYER: It does. We have people who seriously are so sick when they come in, they really do not care about anything. We are getting them to a level of adequate health and, all of a sudden, they start thinking again. They start getting interested in something else other than just surviving from one day to the other. When they are at that stage that they start to take an interest in life, that is when we can start with the program.

If you have a person who only survives from one day to the other, you cannot expect them to think about why they should not drink in two weeks. Honestly, the clientele we get are survivors. When we get them to a stage where they start to look after their own health, their own hygiene - very basic living skills - that is when we can start implementing the program, not before.

Mr WOOD: Do you think the court should be six months rather than three months, or even longer?

Ms WEDEMEYER: That is individual. For some people, yes. We had a client just asking last month. He asked to stay another three months and he wanted to be mandated. We said sign up voluntary. A lot of them do actually. We had a fair few people stay on voluntary in the program. He said no, he wanted to be mandated because his family was trying to get him out, they wanted his money. As long as he can wave his piece of paper in front of them saying, 'I cannot because I am mandated', he is safe. He actually used the word 'safe'.

Mr HIGGINS: Do people accumulate their benefits while they are in there?

Ms WEDEMEYER: Yes.

Mr HIGGINS: Do they pay a fee?

Ms WEDEMEYER: Yes, they pay rent, which is $25 a day. That is pretty much the standard between all

the rehabs in the Northern Territory as far as I know, but they get rental assistance from Centrelink. Their Centrelink payments keep accumulating and if the family does not take their cards away, which unfortunately they do and we cannot stop them, but they seem to accumulate some money. By the time they leave us they have money in the kitty.

Centrelink has set up this kitty system where it does not go into an account but like a kitty. They personally have to get money out of it and we encourage that because it is their way of saving money where the family cannot access it.

Mr McCARTHY: Would that be 50/50 BasicsCard and cash?

Ms WEDEMEYER: No, everyone who comes through the tribunal - I do not know if that was the original idea but at the moment it is 70/30; 70% is income-managed and 30% is not.

Mr McCARTHY: So 70% would be accumulated on the BasicsCard?

Ms WEDEMEYER: Yes, or in the kitty. They can choose to put in the so called kitty.

Mr McCARTHY: They could access to it as cash when they get out?

Ms WEDEMEYER: Yes, they can. Even when they are with us they do, but if I have my BasicsCard and give it to you, you can access it. What they do now is they do not put all this money into the BasicsCard; they put a bit in it and the rest into the kitty. It is like a trust account almost and the family cannot access this money but they can.

Mr McCARTHY: Is that a conversation piece in there?

Ms WEDEMEYER: I think so. That is one of the major things - as soon as they start contemplating what they want to do and why are they there, the first thing is money. 'Where is my money going, how much money do I have, has my family enough money?' That is one of the big things for our case workers. The first thing is to make sure their family on the outside has enough money to take over. If there are kids involved - no one who has custody of their kids is in the program but the family relations are massive.

We have heaps of grandmothers who want to make sure their grandchildren have enough money so they have to make sure they get some money either on the BasicsCard, or what we are doing now – it is not the original idea of the program but we are doing now – is take them shopping. They literary do the shopping and hand it over to the grandchildren. We find that sense of responsibility is building up. They do not just hand money over; they hand an item over, see the children respond to it and pride and self-esteem come back. That is something we really encourage now as well.

Mr McCARTHY: Are you allowed to smoke in there?

Ms WEDEMEYER: We are a smoke free environment. There are clients who smoke but I do not hunt them down. No workers smoke; that is an absolute no. We have one area on either side, and women and men are separated in the living areas. We have one area where they can smoke and where I do not hunt them, and they know that of course.

Mr WOOD: Are there plans to expand? Is there room for …

Ms WEDEMEYER: Room we have; we have 20 acres.

Mr WOOD: Facilities?

Ms WEDEMEYER: Facilities there are not, no. Robyn Lambley announced on the radio a couple of months ago we were receiving an extra 16 beds - so-called stage 2 - but I do not know where that is at the moment. No contracts have been signed or anything.

Mr WOOD: When I was there one of the concerns I had is even though they are not in gaol they are in detention. There was a concern about the possibility of suicide – hanging points around buildings - and I noticed the one in Darwin was set up for a different purpose. The next time I visited, when the security fences went up, they had made changes to the rooms to make sure there was less of a chance. Is that an issue at all?

Ms WEDEMEYER: I had exactly the same when I started. I came there after the demountables were installed and I went through and checked everything. In the bathroom everything that supports a weight of more than 15 kg breaks down automatically, even the curtain rods. Everything just falls down if you put a very heavy curtain on it.

On the outside there are hanging points everywhere. There are trees, fences, but it is possible, of course. We have, hopefully, very good camera surveillance of the whole area and have staff 24/7. There are no sleeping staff, they are awake and they check on the hour. If we have a client where we have doubts or where we are a little bit hesitant we have observations down to 15 minutes, so it is annoying for the clients, they are not happy about it but if we are very …

Mr WOOD: This is taken as a serious issue?

Ms WEDEMEYER: It is very much so. About the detention, again - when it started, they were not allowed to leave the premises and they were not allowed to leave the area. But now it is more like resort-style - really, it is open. All CAAAPU clients have contact with each other. We have this lawn area - like a common area - where men and women from all areas mingle. I do not know if you have seen it, it is like a hexagonal gazebo kind of thing - that is what they use in summer to sit under, so that it is not hot. We have visitors, basically, at all times, and that is part of the AMT program in the act. Family members can visit any time. I discourage it during program time. We have programs running until 4pm or 4.30pm sometimes, so I discourage it and ask them to come after or on the weekend, but if it is something urgent, family has access at any time to the client and vice versa.

Mr WOOD: Do they have other things to do like looking after the vegetable garden or things like that?

Ms WEDEMEYER: Oh, yes.

Mr WOOD: You cannot just have programs otherwise …

Ms WEDEMEYER: Actually both sections have vegetable gardens. We have chickens as well.

Mr WOOD: I will have to have a look at it.

Mr McCARTHY: Do you have random drug and alcohol testing?

Ms WEDEMEYER: Ye, we do.

Mr McCARTHY: Who does that?

Ms WEDEMEYER: Western Diagnostics, we send them there.

Mr McCARTHY: Do you have drug detector dogs?

Ms WEDEMEYER: We do not.

Mr McCARTHY: Do they visit?

Ms WEDEMEYER: Yes, occasionally the police come through just randomly, just to have a - they have found something once since I have been there, and not in our area; it was in the voluntary area.

Mr McCARTHY: Are visitors monitored as well?

Ms WEDEMEYER: We have a staff member when visitors come, so there are bag checks and - they are not 100% monitored, it is not possible but as much as we possibly can, we try.

Madam CHAIR: So the clients come to you as the mandated rehabilitation people and then there are people that come to you of their own volition and/or referred through doctors?

Ms WEDEMEYER: Doctors - amazingly little through doctors. Dr Delima occasionally refers someone to us, not to the mandatory, but to the voluntary side. The majority seems to be through the criminal justice system. It is either bail or probation.

Madam CHAIR: Oh I see, so they come out of gaol and they still need a bit of help.

Ms WEDEMEYER: Yes, either that or instead of going to gaol.

Madam CHAIR: Oh, I see, you do the program.

Ms WEDEMEYER: So, I would think it is less than 20% that are really voluntary and who knock on the door. I have seen it as well, they knock on the door and come in. One of our success stories – a husband of a client who was mandated just came in - she worked on him for so long that he has now signed up voluntarily.

Mr WOOD: Another thing I asked, because there is a bit of controversy about alcohol mandatory rehabilitation - are the people that go in there - obviously the families all of a sudden become supportive that someone who has been drunk all the time …

Ms WEDEMEYER: Not necessarily. Some yes, and some are exactly the opposite, like, 'Oh, great we have got you as a sitting duck, we know where you are, we will get your BasicsCard off you and go drinking ourselves', so not necessarily, but some are. It is very individualised really.

Madam CHAIR: Thank you that was very enlightening, especially for me. Much appreciated.

Ms WEDEMEYER: That is good.

Mr WOOD: We will come to visit again.

Ms WEDEMEYER: You are welcome. The other thing which may be of interest is that we have the community visitor program coming. I have worked in rehabs before and I have never had such a resort-style rehab anywhere, which just comes back to the community

visitor program, so they make sure that we are the least restrictive as we can possibly be and still run the program.

Madam CHAIR: Thank you very much.

Ms WEDEMEYER: You are welcome.

The committee suspended.

FOSTER PARENT

Madam CHAIR: Welcome Danny!

Mr CURTIS: Hello.

Madam CHAIR: Thank you for coming to this public hearing into action to prevent foetal alcohol spectrum disorder. We appreciate you taking the time to talk with us today. This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply. 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 will say should not be made public you may ask the committee to go into closed session and take you evidence in private. You can use the person's name but we will not record it. This is what we did in Tennant Creek when a foster parent came to talk to us about their young son [name suppressed].

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

Mr CURTIS: My name is Danny Curtis, a local man from Alice Springs.

Madam CHAIR: And a foster parent?

Mr CURTIS: Yes, a foster parent. I and my ex-partner ended up with a child from Tennant Creek, a baby boy named Travis. Prior to us registering as foster carers in Tennant Creek we had to travel back and forth to Alice Springs Hospital for a meeting with the doctor. The

doctor said we need to look after young Travis. We picked him up at Alice Springs Hospital before he turned one and he has been with us - he is 21 at the moment. He was in the care of the minister and after in care with us as a family. My ex-partner and I had a son Adam, who is 25 at the moment.

When we came to Alice to pick up Travis he cried all the way from here to Tennant Creek. I think it might have been the first time he was in a car and we did not know what to do so we pulled up on the side of the road to comfort him the best way we could. Later we found the reason he was screaming was because he had things up his nose tissue and also in his ears. He had a grommet in, which the health specialist did not find until later. He then started to hear properly, but when we were communicating with him he used baby talk because he was so far behind.

Madam CHAIR: At what age did you get him?

Mr CURTIS: We got him just before he turned one. His birthday is on 6 June, so about a few months before that he came into our care. We took him back to Tennant Creek but the doctor was saying - his doctor was in Alice Springs but has now moved to Adelaide. He said if Travis went back into a town camp environment he would not last long. We caught up with him because we ended up moving down to Adelaide - just taking him down there. I will just go through what we just put up.

For schooling, we found out he was way behind in some of the subjects. Then, you hear when he went to school here, he had an ISA …

Madam CHAIR: Oh, yes.

Mr CURTIS: Give credit to the ISA, but she was not trained around foetal alcohol disorder. She did her best, she tried her best, which was great. At least that way he had a support person in school where, if he did not have one, he would just run total amok. He would disrupt all the other kids in the class. The would either send him to the principal's office thinking, 'Why are they doing this, sending me over here?' Or they would send him out to the caretaker of the property of the school. I was just thinking about that now. I wonder if those guys were trained in that area. It is a lot of pressure to have, especially with Travis because he was full on - on the go, he was just like the Energiser battery. If you wanted an ad for that, he would be the one to do - even today he is 21.

He would take off from home here in Alice Springs. We were concerned about him, so one day at the shelter I said, 'No, you need to go and get a photo ID of him'. We also spoke with police about if he went missing. In town here in Alice Springs, it is not so hard because

everyone knows the family. But, when we moved down to Adelaide, just trying to teach him about stranger danger - you would walk along the beach and see an old man walking with his dog. He would say, 'Oh, there is a dog', and start running up to him, grabbing him and also the dog. We were trying to say to him, 'You have to ask permission so you can play with the dog'. Big dogs, or any dog he would just go up to and play. It was frightening. They could end up turning around and biting him. He had no fear of anything.

The reason why I moved down to Adelaide is because we used to organise his trip down to Adelaide every 12 months to see his specialist. We used to organise that, also around my son going always for baseball around his sporting trips. So, we used to take our holidays every 12 months to go to Adelaide. It got too much for us, and that is why we said, 'No, we will move down to Adelaide because, at least that way, if we ring up for a specialist appointment, it will happen the same day or next day'.

Ms NUSKE: That Dr Saremien commented on the difference, hey?

Mr CURTIS: Yes, his doctor worked at the Women and Children's. Adam had to go there because he hurt his arm at footy training, and the doctor even saw Travis there. My ex-partner sang out 'Gavin' – he was Travis's doctor …

Ms NUSKE: So, then the doctor came up and was surprised at how well Travis had developed. If he stayed - if Danny and Suzie had not taken him on, then he would have probably died in the town camps. So, Danny coming along gives you another insight – you had foster carers talk to you in Tennant Creek, but it gives you an insight into not only is the person with foetal alcohol, it is awful for them, but it is also hard on the community and the families who are looking after these kids.

Madam CHAIR: Particularly if they do not have access to a lot of information. They know what has caused the issues but …

Mr CURTIS: Yes.

Madam CHAIR: … then how to manage the child that best suits that child.

Ms NUSKE: That is right and going to Adelaide - Danny said he had better access to treatment, easier access, whereas yearly visits …

Madam CHAIR: It is just not quite the same.

Ms NUSKE: … from here was not good enough. Also getting down to Adelaide, there was better support too for Suzie because her family was down there, so it was good for her to have support, and these – especially Travis, he became – he is just referred to as a son in the family.

Madam CHAIR: So did the management, the treatment and the medical support in Adelaide – obviously that has contributed to his wellbeing now, so did they explain along the way how it would help him in his development, the doctors?

Mr CURTIS: Yes, it did in some ways, because they were trialling some of the medications with him. Some of the medication would make him droopy and mellowed out, but some medication that he was taking did not affect him because he got so immune. They were looking at other ways of utilising medication, but when he is on medication he is great, especially because he is working at the moment at a place called Barkuma, similar to what they have here with the Bindi Centre.

Madam CHAIR: Yes.

Mr CURTIS: Because he works – they put all the stuff for Ikea in Adelaide - put them all together - and he is good in that sense with his eyes and hands, but you try and give him money - if he gets $5 he thinks he is a millionaire. He has got no concept of money.

Madam CHAIR: Of value.

Mr CURTIS: Yes, value, and it took us a long time for him to – he wanted a baseball glove, so we said, 'Right, here is $5, put it to one side, put it in the jar, so when you get $79, $80, you can go and buy your baseball glove', but when he saw it all in that jar he reckoned, 'I can go and buy a car, a motorbike, a boat,' and everything like that. We are just trying to teach him around the value of money and life.

In Adelaide he would end up – because we were living at Tea Tree Gully, up towards the hills - when we first moved down we lived at Semaphore, down near Semaphore Park; he would walk from where we were staying up at Tea Tree Gully all the way down to Seaton Primary School, because that was the last school he went to before he went to the special school at Tea Tree Gully. He walked one night all the way down - it was great because we worked closely with the police down there, because we were more concerned about stranger danger and back then there was a van going around and picking up young kids. We were trying to – we got him to sit down and watch the news and said, 'If you see a van like that, that person is no good, because he takes young kids' and 'You have got to tell us where you are going,

even just around the corner to the park'. He will go to the park, but will end up somewhere else, and we got more stressed down there looking after him because there are just more people. Here in Alice Springs everyone knows you.

Ms NUSKE: But here in Alice Springs there was maybe more opportunity for him to run amok a bit more because of other people, peer pressure and more people like him being out and about and just in the –as everyone is – community, and not having such caring parents.

Madam CHAIR: Was he into sport? Were there any issues, because we heard from a foster mum in Katherine that her young foster child who was FASD had real – was it motor skills? Walking, batting and all that, are they motor skills? – motor skills.

Ms NUSKE: Had poor motor skills?

Madam CHAIR: Yes.

Mr WOOD: We asked somebody would sport have helped, but they said they were not very good at sport.

Madam CHAIR: Yes, because they could not understand the rules. They did not mean anything.

Mr CURTIS: Yes, well, just like Travis with – he could hit the ball and he can run, but where would he run from first base to second? What we worked out with the parents who were coaching to say, 'Ready Travis?' then when he looks at you - because he looks at the parents saying, 'Yes' and he will be standing up there. The other kid is running up to first base, he is still standing there, 'Oh, am I meant to go there?' That is what I mean - got to go second. If you point him and show him, he will be right. Even out in the outfield, he will sit down there and, if a plane goes over that baseball diamond, the umpires have to pull up the game and say, 'Hang on, Travis is having his moments'. When the plane goes, then they will start the game again.

Madam CHAIR: We have seen that in all our presentations. It is the attention, the distraction, and not connecting cause and effects.

Ms NUSKE: A lot of disabled people – we went to Adelaide not long ago, and I am not used to public transport. So, Travis, he was fine. He could take me on public transport, show me where to put the money - because a bit backward coming from the Territory - and he was really good. So, there are some things he is really good at.

Madam CHAIR: Routine.

Ms NUSKE: Yes. Now he is in support care accommodation, they expect him to help with meals.

Mr CURTIS: Meals, yes. He does cooking, where at home he would not help. Even when I used to take the boys out bush, I would say, 'Time to clean up our equipment. Swags, roll it up and clean them', he would not do it. He would make up an excuse. When he does make up an excuse he is in there watching, playing a game on the play station.

Ms NUSKE: But the supported care accommodation came about because Danny was working bush and then moved up here. He was becoming stronger, just growing into a young fellow, and a bit more violent, so we did not want to leave Suzie with that risk. So, he went into supported care – hey? - and he has just …

Madam CHAIR: Blossomed.

Ms NUSKE: Yes, he has really grown.

Mr McCARTHY: Did you know that Travis was foetal alcohol-affected when you started the foster placement?

Mr CURTIS: Yes, because Gavin spoke to us before. That is why he is saying that if he does go back to town camp in Tennant Creek, he will not be around. A a couple of years later, his mum gave birth to his brother, but he only lasted not even one year. He had all his internal body just closed down. He was in care with a family in Melbourne.

Mr McCARTHY: Did you notice a big difference when you had the Adelaide education support when he went to school in Adelaide?

Mr CURTIS: Yes and no. He would do the same thing down in Adelaide at the school - just take off. But, in saying that, the caretaker there was great with him. He would get a pile of wood and he would say to Travis. 'You need to make something out of that'. Out of that, he made this beautiful big double winged old aeroplane. He has it at home in Adelaide. That was just out of wood.

Mr McCARTHY: Was that a special school placement?

Mr CURTIS: No, he was in a primary school. But, at that time, they had about five or six other kids there. But, they had a special room. Instead of putting him through mainstream, they had a little room where they could all sit down. But, he would run such amok they would all end up down at the principal's office or down with the caretaker, just walking around and picking up rubbish around the school. That kept his mind occupied, doing things with his hand. But, sitting him up in a classroom environment - even at home we used to sing out, 'Travis'. He is that quick, he was locked up and all that in the house, but he was like Houdini, he would find a way out. You think kids like that who have problems with their frontal lobe, it is nothing. It is amazing what other things they can pick up.

Mr McCARTHY: How did the two boys get on growing up?

Mr CURTIS: They used to fight like normal brothers would. But, if anything happened to Travis, Adam would stick up, and vice versa. Even though Travis was small he would stick up for Adam. Adam is six foot four.

Ms NUSKE: They are quite different.

Mr CURTIS: Yes, different.

Ms NUSKE: They are not blood either, but …

Madam CHAIR: Travis is just a short fellow.

Mr CURTIS: A short fellow yes, up to here. He asked, 'Will I grow tall like Adam? 'No bub, you're going to stay small like me' - short.

Mr WOOD: Obviously you love Travis. Has Travis shown affection to you? Have any human feelings been lost because of FASD?

Mr CURTIS: I think so. When we were living in Tennant Creek I would invite family to our place to see him. Not once did his family approach us, and that is the saddest bit. When I went to Tennant Creek to have a family meeting - I also had my father there and I said, 'It's not fair this young fellow is going to grow up knowing only the Curtis family and the McCumskie family' - my ex-partner's family.

He knows his mum and his sisters because recently she got in contact with me so I gave the number to mum to give him a call. He has photos because when Michelle was in Darwin she ended up catching up with mum at Palmerston. She has photos of him. When she first saw the photo she looked at it and said, 'That is not Travis'. When Travis came to us he was only a little baby.

Ms NUSKE: Does Travis show affection towards you, Susie and Adam?

Mr CURTIS: He does, and mainly his pop - Susie's father - because they recently went up to Flinders for a camp. He goes over to Kadina's to sit down with nan and pop. He goes on trips with his pop.

Even when I was working on the APY lands and went home every six weeks I would take the boys out bush. Go to Adelaide - you have to drive for an hour and you are out bush. It was a great feeling to get out bush and feel the country. I find the boys, even though they are living in Adelaide, yearn for the country. For me, living in Adelaide for 10 years was daunting because I am not from that area and I wanted to come back and re-energise my battery, my soul and my spirit. That is what needs to be done for the likes of Travis. If they are living in a carer situation they need to go back to country.

Madam CHAIR: Will he come back to Alice Springs to live with you or your family in the future?

Mr CURTIS: I think he would come back to live.

Madam CHAIR: He would still need supporting care network like Bindi or something?

Mr CURTIS: He still needs supporting care, yes. If we can find supported accommodation - that is what I said to Michelle. I said I would not mind having Travis live here but have his own house somewhere else. If we brought a block of land anywhere it would be his little house over there so he can do whatever he wants to, but let us know what is going on.

Madam CHAIR: Thank you very much.

Ms NUSKE: That is just sharing a story.

Madam CHAIR: It fills the picture. It is a multiple jigsaw picture. There is medical, science, research, correctional, justice and then the people who have to deal with them.

Mr CURTIS: The other thing I would add is he got into trouble in Kadina. He broke into a house and wrecked it inside. I am lucky we have a good police officer at Tea Tree Gully or Holden Hill who checks on him every now and then to see how he is going. He is aware of Travis because he did the school-based stuff and …

Ms NUSKE: Those people who go the extra bit are invaluable.

Madam CHAIR: They keep an eye on them because they know they have the potential, but they have the risks as well.

Mr CURTIS: Even when he went missing, what we used to do was call the unit at Holden Hill and they would put an alert out to other officers.

The hearing concluded.
