LEGISLATIVE ASSEMBLY OF THE NORTHERN TERRITORY

12th Assembly

Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder

Public Forum Transcript

4.30 pm, Tuesday, 29 July 2014

Council Chambers, Katherine Town Council

Members:

The Hon. Kezia Purick, MLA, 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:

Mr Geoff Lohmeyer, Sunrise Health

Ms Surinder Crichton, Department of Business

Ms Denese Woods, Katherine High School Ready

Ms Sally Pannifex, Katherine High Special Needs Unit

Ms Eugenie Collyer, Parent and Interpreter

Ms Elaine Jaesohke, Office of Disability, Department of Health

Ms Kate Bishop, Good Beginnings

Ms Kylie Stothers, Flinders University Northern Territory

Ms Josephine Nicholson, Katherine Women's Crisis Centre

Ms Pascale Dettwilles, Flinders University Northern Territory

Ms Marion Scrymgour, Wurli-Wurlinjang

Mr Warwick Jack

Madam CHAIR: Welcome everyone. Welcome to this forum on foetal alcohol spectrum disorder. The purpose is to allow the community in places we are visiting - which is Katherine, Tennant Creek and Alice Springs - for people to put forward their views or thoughts, or engaging in formal discussion about the issues associated with people with alcohol spectrum disorder, or FASD as it is colloquially called.

Although it is an open discussion, it is still a formal meeting of the public committee which we will record and transcribe it and put on our website associated with the meetings and the presentation here today. We have a sheet that has been passed around. If you wanted to put your name and contact details or if you wanted other documentation associated with that – name, organisation, contact details. We can send a copy of the transcript to check if you what to talk about anything or ask questions or posse scenarios. That is it in a nutshell. I do not know how or who starts.

Mr McCARTHY: Do you want to do an introduction?

Madam CHAIR: Oh, sorry, I should do that. My name is Kezia Purick. I am the chairman of this committee and my electorate is Goyder, which is Humpty Doo, Noonamah, Bees Creek and Virginia area. On my right is …

Ms MANISON: Nicole Manison, the member for Wanguri. I am from Darwin's northern suburbs. In the opposition, I have the shadow ministerial portfolio responsibilitiesfor health and disability services, which is FASD, and is very relevant.

Mr HIGGINS: Gary Higgins, member for Daly. My electorate is from Darwin all the way to Wadeye.

Mr McCARTHY: Gerry McCarthy, member for Barkly. I live in Tennant Creek and am Deputy Leader of the Opposition. I have found this to be a very good opportunity for a select committee of parliament with terms of reference from the government - you have a great support team and Madam Chair to go out and do the research and then report back to the government. It is a really interesting exercise for a parliamentarian.

I find this to be very interesting and important because of my background in education of over 30 years in the Territory. Being nominated to the committee with my colleague, Nicole was great and we have been researching at that high level. Madam Chair has taken the committee on the road and we are holding public forums, which is great. It is wonderful you have turned up, good members of the Katherine community. Thank you.

Mr WOOD: Gerry Wood, and I have nothing to do with this mob; I am an Independent. I am the member for Nelson, which is in a great part of the Territory, south of Darwin out of the suburbs. I have lived a fair bit of my life in Daly River and Bathurst Island, and it is great to see people turn up to this very

important issue. It has some difficult practical issues, we have some difficult moral issues, and it is great that people have turned up today. We have had some interesting speakers today, all from Katherine and it has been excellent.

Mr KEITH: I am Russell Keith, part of the support team for the community helping with logistics and research. You can contact me or anyone else in a white shirt with questions about the committee, or later on, information about the committee.

Ms BUCKLEY: Jennifer Buckley, part of the team. As you can see, I am wearing a white shirt.

Madam CHAIR: Is there a particular reason you came along this evening? Was it to ask us questions, tell us something or perhaps – the people we have had before the committee in Darwin, and of course today, and with the submissions we have received we have a real cross-section. There are medical people - experts, doctors, clinical and paediatricians from down south. We have heard about Fitzroy Valley, have had research people, Aboriginal associations, health associations and the Chamber of Commerce. We have had people tell us about the problem medically, and it is not exclusive to Australia; it is all over the world wherever there is alcohol. How do you manage it, what do you do with it? It is an issue when children present at school. Has it been misdiagnosed in the last 20 years? I do not know. We are trying to find out how big an issue is it in the Northern Territory, where is it, and if we find that out what do we do to see it does not happen again.

We know to stop it women should not drink when they are pregnant, that is the bottom line, but you cannot make them. You cannot force them unless you lock them up somewhere. That is part of what we are trying to find out.

In an American state - I forget which one - they found a woman guilty and have sent her somewhere for harming her child before it was born. I think it was a state starting with 'M'.

It is clearly an issue in the state and it has dealt with it that way. I am not saying that is the right or wrong way, but there are obviously some people who think it is. There are also the rights of the unborn child versus the rights of the mother versus the rights of society. That person is born and creates a problem. As Gerry said today, often they end up down the incarceration route and get into trouble or whatever.

Mr McCARTHY: Would you guys be interested in introducing yourself and letting us know your interest in the forum.

Ms JAESCHKE: I am Elaine Jaeschke, team leader at the Office of Disability in Katherine. We provide the allied health services and early intervention to all these children - disability services to them as they

become old enough, and provide coordination of these. So, yes we see a fair bit of FASD and a fair bit of community kids. It could be that nobody has their history, nobody has made a diagnosis. Certainly, the implications of when if undiagnosed, or (inaudible).

Ms WHITE: I am Caroline White and I am a naturopath. I am new to town and I see that there would, selectively, be a lot of problems in this area. I have only been here for two months so I have not delved into at all. But, I am aware I might have patients in the future who have children in that situation, or I might be dealing with people sometimes I can advise or counsel with that I might have some impact on. That is, women are the majority of the patients I see, so who knows who I can reach. But, I need to know a lot more and so I am here to learn. Thank you for very much.

Ms PANNIFEX: Sally Pannifex. I have recently taken over coordinating the Special Needs Unit at Katherine High School. I have personally been interested in foetal alcohol. Prior to taking over this role I attended some lectures, found out some interesting information about the syndrome and the disorder, but still feel I need to know a lot more. I am interested in knowing what they are doing at Fitzroy Crossing because I have seen a lot in the media around that.

A lot of our students at the school that potentially have foetal alcohol disorder, some of whom have been misdiagnosed or have not been diagnosed at all. That whole idea behind once the kids get to a certain age, it seems their development can be halted in certain areas. Whether it is worthwhile having more of a focus on teaching for life skills and things like, I am also very interested in the preventative side of things (inaudible) main thing we should be doing (inaudible).

Ms WOODS: Hi, I am Denese Woods, and I work at Katherine High in the School Ready program. I have been there for two years now. It is a bit of a unique placing within the Territory and Australia because we have students coming from all areas in the Territory, so we do not just have one mob per se. That becomes interesting in itself. Yes, it is quite evident that from each area there are possibly students that have been affected by alcohol.

I am here to learn who you contact and to learn a little more because it is just something that has probably always been there, but not in the way it is now that we recognise it. So, maybe learn and how to recognise it and a bit more, build up some contacts. Yes, to learn.

Ms CRICHTON: My name is Surinder Crichton and I work for the Department of Business in the area of alcohol management planning. I am here to listen to community views on the issue, and hear a bit about it. Personally it seems it is, obviously, not a new concept but we do not seem to have heard a lot about it. With a lot of alcohol-related stuff, education is an important facet of making improvements.

On a positive note, I was just thinking about you talking about pregnant ladies drinking. I know in a social club in the Northern Territory they already have rules around pregnant ladies. Once they know they

are pregnant, they are allowed to go to the social club but not to consume alcohol, which is a wonderful thing.

Interestingly, I was just recapping on it. I acquired it a few years ago and noticed the rule for a breastfeeding mother - once the child is 10 months old they are not on the banned list anymore. I do not know if they have amended that. I will look into that to see if that is still the case, because that was a few years ago and I really think FASD needs to get out there and promote it as an issue from my perspective. I am here to listen

Mr LOHMEYER: I am Geoff Lohmeyer. I am the manager of the social and emotional wellbeing of Sunrise Health Services. I deal with all of the alcohol and other drugs people who have been sniffing petrol, mental health, and related support areas across all of the communities between Bulman and Ngukurr. Over many years, I have been working the whole of the Katherine region in the area of alcohol and other drugs. I am fairly convinced a lot of our young people who are sniffing petrol have a background. Looking at their family backgrounds, many of them, I believe, have some level of foetal alcohol spectrum disorder and I think that has a big impact on their inability to cope with stresses in life and people (inaudible) on those areas.

I think it is underdiagnosed, and I do not think there is the ability to diagnose accurately the lower levels because in the past the diagnosis has been around facial features. There are many people out there who I believe have a lower form of foetal alcohol spectrum disorder who do not show the physical side, but are in the social, emotional and intellectual development of a young person. I think that also affects the number of the present prison population.

Ms COLLYER I am Eugenie, a Katherine local biological mother of one and step mother of three others. Two of them have been diagnosed with an autism spectrum so far, but I know alcohol was consumed when they were *in utero* so I have been trying to find out as much as I can to see whether that is a better fit.

Madam CHAIR: There is currently a Senate committee inquiry into this same thing.

Mr WOOD: No, it finished.

Mr KEITH: There is a current House of Reps committee looking into alcohol management and FASD is a big feature of that.

Madam CHAIR: What we have heard from people who have spoken to us so far is there is a lack of a diagnostic tool and they cannot test a person to say they have FASD. As someone said today, even if you had a set of diagnostic tools and could say that person has FASD it might help at the very early stage when

they enter the school system, but if they are an adult what does it tell you - they have FASD. I guess it is the management of that person, and if the community or family does not know it …

Mr WOOD: One of the questions I asked the doctors was if you recognised someone has FASD can you do anything, is it beyond repair, can you manage the problems associated with FASD? Perhaps some of you who deal with it at the coalface may know more than me.

A WITNESS: Intervention does make a difference but will not completely resolve the problem. It depends on the severity, but intervention happening earlier is more effective.

Mr WOOD: We have been told they do not know the difference between right and wrong. We are concerned about them ending up in the prison system. Is that the case?

A WITNESS: It is for some people. Some people end up being really resourceful and good at that working out what they can do. In a small community they are better because people are aware of it and the services are aware of it and will better support them. However, they really need that person to assist them all the way through the decision-making processes dealing with stresses and working out what is right and wrong. It is about the support you have to put in place.

Mr WOOD: Like the family or community being the fence they put around to keep themselves from going outside. When they do something there is someone who can pull them back.

A WITNESS: Someone with FASD as an adult in Katherine - we have some – actually cope a lot better because everyone knows them. There is general awareness this person needs a bit more support. They might not know what is going on, but it is a smaller community and it works better once they get to that adult stage. Obviously, if they commit a severe crime they have got through the system.

Mr WOOD: How do they go in high school? Have they support from kids, or do they get seized …

Ms PANNIFEX: Generally speaking, because we do have support systems set up in the schools and the level of support that is provided is improving a bit, but the kids feel quite comfortable in school setting. But, as to whether we are providing the types of education they need - for example, a former colleague who had to (inaudible) children who were diagnosed with foetal alcohol syndrome was saying to me that often when they have foetal alcohol syndrome you have a desire to please people, and you do anything to please someone. That can lead to things like early pregnancy. I am not quite sure if that is true but, as I mentioned before, whether some of these kids there should be a bit more of a focus on their life skills. Because we have not identified - I do not know if we have actually identified any children in the school because, apparently, you have to get an admission from the mother that they were drinking *in utero* to formalise the diagnosis ...

Ms WOODS: That is true. That is where it starts the problem. She can say yes. I have a number of students of mine (inaudible) can see it in the way she did the reading. It might be Year 1 level and she is in Year 7. Until you get that admission you are stuck in a hard place. You cannot (inaudible).

A WITNESS: Often the kids are diagnosed with something else, but, really, when it comes down to it, it is probably the alcohol that has done it in the first place.

Madam CHAIR: It has been pointed out that you have to teach them is a life skill – whatever that means. I would love to know what it means. Taminmin College is in my electorate as Gerry knows, as a lot of those students are from his electorate. In their special education unit – the new one that has been opened – they have three not so bad, medium bad, very bad. In the not so bad, there are couple of Aboriginal girls, as pretty as pretty, about 16, but aged about eight reading age.

One of my questions to the school was when that child goes out of the school system, they have been protected – pretty, young, but really low intellect. Then what happens if they do not have a good family support system? They will just fall into bad company or get lured away. If they get those skills it teaches them something about life, it might help.

Ms PANNIFEX: And when a lot of our students leave the school, certain students are attached to Clontarf. Through this program, you get some level of contact back to the school. But, it is difficult and we do not have the resources to provide any additional support than beyond Year 12 as they get through to the end.

Ms WOODS: Prior to coming here, I worked at Wellington in New South Wales. We just had special education and life skills and stuff, especially when they got through to, say, Year 10. It is something that is lacking in the Northern Territory education in that way. It is not recognised that is a skill in itself. To be able to know where to even layby clothes; that you do not have to spend your money at once to get something, and learning to drive and to learn how to get a licence. Things like that are recognised, I do think are on the curriculum within the school here - without being branded something like special education.

Some of these kids can function in normal classrooms with support. They do not have to be sent down to the back of the school to a special unit, they can be operating in today's society. They just need that support, guidance, and knowledge.

Ms PANNIFEX: That is more of a long-term solution than isolating them. Obviously, out there in the big wide world that is the ratio of people in mainstream society. So, by pulling them out to a specific unit they are doing the bulk of their time there with virtually no contact with the mainstream makes it even more difficult when they get out there.

A WITNESS: I do not know how well this is, but I just wanted to say we have that huge concern with my oldest son, in particular, about what he is going to do out in the big wide world. He is someone who has a lot of family support. He has all of us trying to research this, and he has us talking to him every day, trying to put things in place to support him. We struggle and we struggle. So, even kids who have lots of support in place, are still so vulnerable. So, just to put them in the spotlight too. It is not just people who come from a disadvantaged background. He is in quite a good, stable secure environment now with the support of people and we just struggle.

A WITNESS: It seems to be that some of the triggers - you cannot even pinpoint it. When I talk to people who have had foster kids diagnosed with FAS it is not necessarily they have not had not had much sleep or they had not eaten breakfast, it can be just suddenly snap and have a major meltdown. It is true a lot of the kids in the special needs unit at our school - a lot of their parents are invested in making sure they get the support they need and are happy and healthy.

Mr WOOD: Can they play sport?

A WITNESS: Yes.

Mr WOOD: Can that help with coordination?

A WITNESS: I do not know of any research, but it would have to.

A WITNESS: The area that tends to come in many ways is the area within impulse control. Quite often you find someone will make a suggestion and they go into it straightaway with no thought process behind it. If they are playing sport - some of the young people we work with are usually quite good footballers. It does not help with their impulse control too much because they want to …

Mr WOOD: One of the impulses might be to get the ball, the other impulse might be he gets flattened so it becomes …

A WITNESS: The other impulse is there is not much there to get in and he gets in.

A WITNESS: Also, clumsiness is associated with it as well. My son really struggles to walk down the stairs sometimes, he will practically trip. Another problem he has is being able to hold nonverbal rules in his head. Playing a game, even a board game where there is more than five rules - trying to write is really hard because he knows all the rules - if you ask him one by one where to put a full stop, where do put a capital letter, but he cannot form a sentence and follow the rules because there are too many rules to coordinate them in his head and apply them all at the one time. Playing sport would be difficult as well. He does not really know rules in sports games and physically finds it difficult even to crawl. He has trouble crawling.

Madam CHAIR: Can I ask a question about that disability? If it is listed as a disability on some register that will somehow assist in support or - is that is what it is about?

A WITNESS: That is what a lot of our assessments are about. It is providing people with support, but he is getting appropriate support for him. People with FASD, as is so impulsive - once they get to this stage - 24/7 in being able to be there and being that person who is able to say, 'Hang on, is this a good idea' and help them think through the processes and repercussions. Yes, certainly they can get supports and they could be supports that are structured supports that go in at different times but will never replace the more informal supports of a family who is there for them or someone who is always there for them.

Madam CHAIR: Does anyone in the committee know if it is a Commonwealth thing when it becomes a disability or it Territory or national?

Mr McCARTHY: You could start at school in identifying special needs. The problem for decades and decades is paediatricians have been very reluctant to diagnosis it. We are hearing that from the top level, which is from esteemed paediatricians across the country. I presume this register will provide access to some of the research we have. Is the attendance register …

Mr KEITH: This register is so we can send you out a transcript and give feedback on the committee's outcomes. All the submissions are on the website and past hearings are on the Legislative Assembly website if you want more information.

Mr McCARTHY: So we can share in the learning. We are all in this together in essence, but there will be a report given to government. The government will take the next step, so historically it is quite a big move in the Territory and we all commend government, in a bipartisan sense, for initiating this inquiry and the results that will come from it. But, we are hearing a lot about We are hearing a lot about diagnosis, diagnostic tools, and that pure medicine that has been very reluctant to diagnose FASD, because there is such a broad spectrum of behaviours, disorders, and syndromes.

(Editor's note: Audio missing between 4:55:37 and 5:07:32)

Mr McCARTHY: From my perspective, as an educator and colleague and in that respect, I have seen over the last 35 years this increase in what I define as high support needs behaviour and emotion that relate to behaviours. Having worked a lot of that time in the bush in Aboriginal communities, I assume - my personal opinion - there has to be some links with this new issue that I did not see in such prevalence 30 years ago.

So, in this inquiry, maybe there may be some links drawn but, essentially, it will be a question of government of how we go forward and deal with this. It is quite interesting - and my personal opinion once again - the medical profession seems to be pulling back and more generalising, because it is so much to deal with. We have not heard a lot from the educators or the service providers, so it is good to be able to try to build that perspective into government's information package they will get.

Mr LOHMEYER: One of the problems, of course, is even the experts have differing opinions. You will hear someone like Dr Ryegate from Alcohol and Other Drugs say. 'Yes, have a couple of alcoholic drinks if you are pregnant', whereas others will say nothing. It is not clear cut in so many different ways. I always tell everyone if you are pregnant or trying to get pregnant, do not drink.

A WITNESS: That is the thing – trying. It is not even when you find out you are pregnant, it is way before that.

Mr LOHMEYER: It is. If you are thinking about getting pregnant, stop drinking. Same as I tell them about stop smoking. It is not only that, it is such a wide range. And it is not only just behaviours but intellectual abilities that can be affected in so many different ways. Where has it affected the person and the brain?

Talking to one of our doctors, when I was talking about trying to do some research on FASD, her response was it is only in the facial features, which is definitely not the right information. So there is a lot of misinformation or lack of information that is clear and precise for people. There is an area where we have to do a lot more preventative stuff, and it concerns me in mainstream society - having worked with homeless people in Adelaide - the number of young people binge drinking from mainstream big urban society that will bring about a rise in the occurrence of FASD. I also begin to think about how we can best support those who have FASD who are not diagnosed as having a disability, have not necessarily been given a diagnosis, but when you begin to work with them closely you find the behaviours - the lack of impulse control, the lack of ability at times to retain information, all those things - how can we best work across our society to support people with those problems and minimise some of the antisocial behaviour that comes out as a result and winds up with a lot of people being in prison from that lack of impulse control.

Ms MANISON: This has been quite an interesting process listening to two days of hearings. When this parliamentary committee was put together most colleagues and most professionals would say FASD was a problem in the Territory. What I have found so frustrating so far with this body of work is it is really difficult to quantify on so many levels. Firstly, we have known for a long time alcohol and pregnancy do not mix, but trying to get a clear understanding - the information from most health professionals is do not drink, but people still want some information around how much is too much and is there a small amount people can drink.

It has been really frustrating in the sense that it has been hard to quantify how many people in the Territory are affected by it. You see every day in the workplace - you know there are people affected by FASD but trying to get a real figure on the extent of this problem has been really tough going.

The other issue I have found is we are trying to get a better baseline understanding of the extent of this problem in the Territory so we can put it to government to look at it and ask where we go next with this issue. Is the focus on prevention, diagnosis or treatment? What has come across loud and clear to me through this process is doing nothing is not the answer. It is really important to quantify this issue so we can see where to next, but I have been frustrated by how muddy it is and how hard it is to get a clear picture on the extent of the issue.

It has been a real challenge and that it is why it is good to come to a forum like this and hear the views of people working in education, working in health, on the ground to say yes, it is an issue and we need to stick to it.

Madam CHAIR: One of the gentlemen today, a doctor I think, said it is rare that any of his patients known to have FASD are over 40 – 40 years old and under. Something must have changed in the mid-1970s in regard to consumption of alcohol in the community, community expectation, values or something. I thought it was interesting he said anyone under 40, including children.

Mr WOOD: Another interesting thing that happened too, and Marion would know - I worked on Bathurst Island in the 1980s and we never heard the word suicide. I never heard the word FASD; I just thought it was an aeroplane. It did not exist. Most Tiwi women did not drink, and most women at Daly River – there were a few - did not drink.

There are a few changes that have happened in society, and some of those have had, unfortunately, very negative effects on a lot of people. I do not know whether there is something broader that we have not picked up …

A WITNESS: It was around that time that a lot of the lines were being set up. I remember watching (inaudible) over in Nhulunbuy, talking about (inaudible), but rarely. Over there that was around the time alcohol was available …

Madam CHAIR: That is true. That was the early 1970s.

A WITNESS: … in communities, and then (inaudible) protected it …

Mr WOOD: In places like Bathurst Island, alcohol has been available. I was there in 1970, it was available then. There was no suicide either. There was no mine there, the land has always been theirs. Ask me why when – I do not know, I do not have …

Mr LOHMEYER: It is as question of time when everything changed in the 1970s - what changes occurred around social welfare and all of that sort of stuff; what happened back then.

A WITNESS: Yes, that sense of loss of self.

Mr LOHMEYER: I got married at the end of three …

A WITNESS: We should remember too, it is not just an Aboriginal problem ...

Mr WOOD: No, that is right.

A WITNESS: People see it more and in white society too, because the acceptance of women back in the 1970s - I know my mum did not go out to the pub and have a drink; one wine and she was passed out on the ground. So, the way women – to see alcohol now and the acceptance of the way drinking is …

Madam CHAIR: That is true.

A WITNESS: Statistically, (inaudible) is actually now too. The baby boomer generation drinking patterns are very similar to (inaudible), difference, where the previous generation were quite different, they (inaudible) completely different.

Witnesses interjecting.

A WITNESS: So, it was …

A WITNESS: It is a society thing, it is not just …

A WITNESS: Geoff's point about our kids (inaudible), but the acceptable thing to do on a weekend night was for kids to all go out, get on the alcohol and they would be getting drunk That was a pretty standard thing for many of your friends. The whole expectation around social stuff - in a town like Katherine, that is what they do.

Madam CHAIR: Social structures and social units change. My personal view is a lot of our issues and ails about community are because of the breakdown of the family unit.

How wide a family unit has changed over time, compared to my parents time, is a separate issue, but a lot can be taken home to the breakdown of the family unit - parents splitting, easy to get divorced, and women are more supported, and could go off and have their children and support themselves.

Whereas, in my mother's generation, you did not do it because there was no support. You stayed together whether you wanted to or not. That has to have society stuff attached to it as well.

Mr McCARTHY: If all the anecdotes we are hearing do present, then the reality for government will be providing services into the future. That will impact heavily on the early childhood sector, the learning sector, our school sector, and the disability sector. This is where, if we believe this anecdotal evidence and it seems to be fairly strong, we have a very strong medical sector that is pulling back and saying it has broader ramifications and is related to a much broader spectrum, it is still going to end up in the same place. That is the real challenge. It looks like, from the Northern Territory perspective, we could be dealing with quite an acute level of this here, and this will be within the next couple of generations.

A WITNESS: Can you tell us – you mentioned very briefly more about the concept of self-worth as well. That is a real focus of point of identity and self-worth, because that often leads to drinking to extremes. That is why, from my perspective, I do not really have a lot of kids at school that are very talented, but just have a very low opinion of themselves. The teacher would try to build up that self-esteem, but until they believe in themselves, they probably (inaudible) they are going to be more likely to engage in those risk-taking behaviours and things like that We were talking in terms of identity, so we were not (inaudible). This is very low in a large proportion of kids in our school.

Mr LOHMEYER: That it is connected with no rights and wrongs. No one is teaching how to behave so discipline has fallen down The movement and loss of self as far as country and distance of groups and identity, the brokenness of family and the loss of spirituality in a lot areas is compared to a loss of identity, a loss of purpose and a loss of themselves. What we are trying to do with our programs is to reconnect so there is a stronger self. By building the self with believe we can build the strength of the person to handle life in that way.

Mr WOOD: We have a very materialistic society. Sometimes people get their pleasure out of an iPad for a little while, a new gimmick or it could be having an affair. The vision is not there of why I am here and what worth I have. I do not know what the families of those children would be like. I admit I probably would not be here today if it was not for my mum and dad. They gave me the discipline I needed, but they also – there was far more love than discipline, I can tell you that. Discipline was probably when I needed it, but I do not know the background of those children.

A WITNESS: It is a range. You still get students who want the family to (inaudible) them, then (inaudible) struggling with that concept. I think it is because, as you mentioned, there are all those other (inaudible) as well. Sometimes it is just that in a lot of families many other things are going on; it is not that the love is not there, but probably the kids from extreme cases are the ones who do not have that family support. It is not necessarily the love but the support.

Mr WOOD: Is it too simplistic to say alcohol is the big problem? I am not putting this person in, but the Chamber of Commerce attended today and said alcohol is a major problem in Katherine. I am not saying it is not a major problem elsewhere either, but we are in Katherine at the moment and he was talking about the effect on tourism, the break-ins in the community and all sorts of issues related to alcohol. He was a bit frustrated nothing seems to be – if it is happening it is happening very slowly, or there is a bright idea it does not get going. How much does alcohol play in this issue?

A WITNESS: Alcohol is a symptom. It is not necessarily the cause, it is a symptom of the broken deeper self that leads to – it not just alcohol. If you look at the rates of marijuana used on communities, 60% of 16 to 30 year olds would be using dope.

Ms SCRYMGOUR: Younger in some communities.

A WITNESS: Younger, yes.

Ms SCRYMGOUR: Alcohol is major because it is out there.

A WITNESS: Yes.

Ms SCRYMGOUR: Everyone sees the drunk down the street and the impact that has socially. There is a bigger problem in Katherine which is everywhere else: petrol sniffing. We have huge rates of petrol sniffing in this community and a lot of those numbers came from remote Aboriginal communities. Families moving from remote communities into Katherine are causing all sorts of problems. We have a couple of camps with kids where we call police constantly because we have kids up to nine, 10 years old sniffing and then creating a whole lot of …

Mr WOOD: Can you still buy unleaded here?

Ms SCRYMGOUR: Absolutely.

A WITNESS: Yes.

A WITNESS: We have been trying to, since 2006 …

Ms SCRYMGOUR: There has been a political bun fight here. Politics has to get out of the way and Opal should come in. There has got to be another alternative.

Mr WOOD: We were on that committee together.

Ms SCRYMGOUR: Absolutely. Petrol sniffing – but there is another problem hitting the young teenager and we see it at Wurli every day. Our statistics are probably 100% of the Aboriginal and Torres Strait Islander population of Katherine and surrounding town camps and the communities that come in, but we also service 20% of the non-Indigenous population of the Katherine, which a lot of people probably do not realise. Ice is becoming a major issue as drug of choice with young people in this community with young people. It is that traffic between Darwin and Katherine. The psychosis that comes out of it is actually worse than the ganja and the grog and everything, because the levels of anger and violence that comes out of it is actually quite scary.

We are putting security on for our health staff. Wurli has been in operation 30 years and, for the first time in that 30 years, we are having to put security around our health staff because of the ice use in this community.

Madam CHAIR: Male and female? Both?

Ms SCRYMGOUR: Yes. And young people. It is easy to obtain. If you talk to any young person, it is easy to buy, it is cheap and, because there is so much focus on ganga, there are shifting from the marijuana use to ice.

A WITNESS: And the sniffing.

Ms SCRYMGOUR: Yes. Sniffing is still …

A WITNESS: That is the thing. We are targeting alcohol and …

A WITNESS: But it still comes from low self-esteem …

Ms SCRYMGOUR: Absolutely. And boredom and all those …

A WITNESS: … and no self-worth in the future. It is all a complex mass to me, and they are all in there together.

Mr WOOD: Do we have some – we are going off here a bit - good positives in Katherine with good examples of where people are trying to get (inaudible). Obviously, you work in the high school doing that. I would love to know if there are people who are doing their darndest to turn that around. Obviously, people here …

A WITNESS: Absolutely! (inaudible) There would be a lot …

Ms SCRYMGOUR: This town is full of positive …

Mr WOOD: But it is …

A WITNESS: These people, they do to their (inaudible). You need to, you need to, and you need to.

A WITNESS: We thought this was an exclusive circle.

Mr WOOD: No, no.

Witnesses interjecting.

A WITNESS: That is why I just gatecrashed.

Mr WOOD: It is not a prayer meeting.

A WITNESS: Yes, it looks like that.

A WITNESS: Yes, it looks like that.

A WITNESS: Well, it is better than a big table and us sitting way back here with …

Madam CHAIR: It should just be groups of interested people, or …

Ms BISHOP: I am Kate Bishop. I am the manager of a program in Katherine called Good Beginnings. It is a range of early intervention, early childhood programs, and family support programs. We work around the areas of Katherine and in Beswick where there is a terrible problem with sniffing. Many of our families in the intensive family support program are from Beswick, so we see a lot of small children and their families with these battles every single day. We are all in this. We are all concerned about it. We have some good stories, but we celebrate them really hard because there are lots of other ones that are not working out so well. The wave of …

Ms SCRYMGOUR: It is like a tsunami. That is what it is, it is like a tsunami.

Ms BISHOP: I am not out there with it all, but with Marion and the clinic, they are seeing it every day, and it is just frightening really. Early education, early intervention, services for children is going to get tougher and tougher, and the outcomes for these kids is really poor. So, yes, it is a lot of hard work in early intervention work.

Ms SCRYMGOUR: With Katherine, Gerry, the services, both all the NGOs - and I know from Wurli's perspective we work quite well and collaboratively with the other NGOs. You have to. Katherine is too small a town not to do that. You have to do that to try to get some results.

The intensive family support staff and the DAT early intervention has some good outcomes on it, from Wurli's perspective. We get some really hard core problems, but you do not let those problems drag you down either. We get good outcomes with them. If you could prevent a child from slipping through that gap and something happening ...

Mr WOOD: One thing I have to say - I know we are dealing with FASD, but I was interested in investigating sniffing problems. I have trouble believing that, after all the work that BP did - not that community, BP brought in Opal because they knew there was a problem. I cannot believe why leaded petrol still exists in a place where there is petrol sniffing. I would have thought …

Mr LOHMEYER: We have been fighting to get …

Mr WOOD: Where is the stoppage from?

Mr LOHMEYER: The stoppage primarily started with Shell. Shell said they would not support it. All the other service stations in Katherine in 2006 said they would take it. The Shell company said it would not, it had to be stored in their storage and had to have this and that. Now they are promising, by the end of this year possibly, to have low aromatic but I am not sure if we have finished building that storage facility shed. When I see it I will believe it. It has been an intense frustration for all of us working in that area for the last eight years to get Opal happening across here.

Sunrise and others support it, but the government is yet to sign off in getting a low aromatic storage facility in Beswick so we can say to the community people, 'You fill up on your community instead of coming into town and taking 40 L drums of fuel and jerry cans back'.

It is such a frustration that goes on and on and it is politics within the area.

Ms SCRYMGOUR: I have been here for 15 months and we have been trying to – if government members could take this back - get the volatile substance abuse plan implemented here. Part of that implementation is the region. From that plan will flow low aromatic fuel as part of it. It seems to be caught between a rock and a hard place somewhere, and it would be good if we could get - it will go a long way. A lot of them will come from the regions into Katherine, and if we can get that plan put in place people can be authorised under that plan. We cannot take kids from this region and put them into mandatory treatment under that legislation unless we have that plan in place and we need to be able to be able to. With the armoury there we would be able to do that.

Mr McCARTHY: Get ready for it because butane is the volatile substance of choice in Tennant Creek now. Once again we get back to the underlying cause. The product shifting we have, the glue under the shelves, the paint can locked up, the Listerine and deodorant, and now we have butane lighters. This sort of stuff is not going to go away unless we can continue to go back to your point.

A WITNESS: Unless we go back to the point of saying we have to build the strength and the sense of being of young people, and that is right across.

Mr McCARTHY: The most challenging research I have read recently was if we normalise the male and female with no trauma, good nutrition and all the right supportive patterns, and their first baby has a normal in utero development and all that support network comes together and the first five years' of that child's life goes to plan, we still have up to two generations of affected people who will be working against the outcomes of that child. That is the most disturbing part of the research I have read so far.

Ms SCRYMGOUR: Generational trauma is what is we are talking about.

Mr McCARTHY: That, for me, highlights the real challenges.

Mr HIGGINS: I was chairman of the tourist association here for four years. I have come to Katherine for 16 years with the tourist association and that was very high on their agenda.

Ms SCRYMGOUR: Fuel.

Mr HIGGINS: Yes, and I am going back to 2000.

Mr WOOD: The relationship between petrol sniffing and FASD is probably very similar – damage to the brain.

Ms SCRYMGOUR: They will swap substances.

Mr WOOD: Yes, I know, but you are getting up to a similar problem.

Mr LOHMEYER: I am also saying I believe a lot of the FASD is behind a lot of the the petrol sniffing, with the end price control, the lack of self-worth, the lack of self-esteem comes into that. Of the 60 young people I have worked with at Beswick over the last eight years, probably 75% have some level of FASD, just looking at their backgrounds and their family backgrounds. Of those 60-odd sniffers I have worked with, just give it time. I would think that is a contributing factor to the substance misuse. It becomes that chicken and egg, where their parents who have been traumatised, and even their family who have been traumatised over so many years and in so many areas, and the brokenness that has happened and the disconnect that is happening here, we are reaping the rewards of that. That is why from the 1970s, we are beginning to get the greater numbers. That is just my view.

Ms SCRYMGOUR: Yes. I was listening to what the …

Mr WOOD: Gerry will do.

Ms SCRYMGOUR: … member for Nelson was saying before, and the member for Daly. If you look at those two communities, Daly and the Tiwi Islands, and how those communities were – and your mum was around Kezia, those problems were not there. It was not just suicide …

Mr WOOD: We had also full employment.

Ms SCRYMGOUR: I grew up in those environments. You can look at the generation that grew up in those environments. Then, when the missions and the education and that support stopped, and self-determination - that is a separate and a different argument - when they transferred across and we went away from that model …

Mr WOOD: 1978 is when they put …

Ms SCRYMGOUR: I reckon I watched the demise of my own mob on Tiwi, go backwards …

Mr WOOD: They brought in unemployment benefits in 1978, and the main street of Katherine at that time. They stuck a demountable in there. We employed everyone up until that time. There were some people found that if they did not come up to work, they could go up there and knock on the door and, in three weeks, you got a cheque. We have had three generations of that. I cannot believe that was a good process. It did not help. These people need that belief in themselves and a job, no matter what it was. We tried to get pride into the community, like planting trees and fixing up the airstrip and all sorts of things. They had pride and belief in themselves and their community.

Then, we introduced the easy way and that was one of the bad mistakes. We still have that issue. Governments do not want to change that, they are a bit scared because it might …

Ms SCRYMGOUR: If you talk about alcohol and FASD, there needs to be greater regulation of supply. That is the question. It is politically unpalatable for people get into some hard decisions about the supply of grog and the over-supply.

You count how many liquor licences are in this town, and how many licensed outlets that people – and I heard that and I do not think it should be just a black issue. If you have a look at the consumption rates of this town, people would be horrified at the level of consumption of alcohol. It is not only men, it is women. That is the scary part because that is where we are getting the problems with kids. Without their mums, we have babies that are struggling to be there, to actually get through those deficits. I talked about today the childhood anaemia. How do you work with the family? With those kids, we tried to close the gap - I hate using that analogy. How do you close that gap for that child to try to get rid of the deficits that child is already suffering from? Those are some of the challenges.

Madam CHAIR: The bottle shop in the Woolies complex here – I was down here a couple of weeks ago for a dinner - the daily sales on the average are $75 000.

Ms SCRYMGOUR: Then, you put that up against people's disposable income in this community, and we talk about homelessness and poverty, we talk about - I said to people, 'Let's get real'. I have had this conversation with the Aboriginal organisations; 'Let's get real about the levels of drinking, alcoholism, poverty, homelessness, whatever you want to call it, let us have this debate and argument amongst ourselves'. Our people are drinking too much, their disposable income is not going towards kids and that worries me because little ones are not getting fresh food and not sleeping at night. They need to get a decent night's sleep to go to school.

A WITNESS: In regard to prevention, having recently been pregnant the only education I got was going to the doctor who said, 'You know you shouldn't drink during pregnancy'. I knew that and I stopped drinking when I suspected I was pregnant. I do not drink heavily anyway, but in regard to the amount of information

that was available to me, I had to find it, had to seek it, and most of it was literacy based. I have never seen a poster, never seen a video, and I think that educational message that this not acceptable needs to be as strong as the stop family violence one. You need to be able to say to someone in the pub, 'Put that down. That's ridiculous, what are you doing to your child?'

At the moment there is a huge stigma and people will watch someone who is pregnant drinking and will not say anything. They will walk away and say, 'So and so is drinking, my God', and that will not prevent anything. Perhaps looking at the huge issue of alcoholism which has been dominating the discussion now – perhaps there needs to be targeted programs towards women who are pregnant and are struggling with alcoholism. If they are put in a regular program it may not work. If they do not know what they are doing, particularly with FASD as opposed to FAS where you have no vision symptoms, you have lots of anecdotal evidence of, 'My kid turned out all right'. You do not have any of the presenting problems until the child is about seven. Education is a huge part of this.

Madam CHAIR: It is with any social upheaval. Someone today said early intervention is the key. I am conscious of the time, it is 5.35 pm. Does anyone have any questions.

Ms STOTHERS: I am Kylie Stothers, a local Jawoyn woman born and bred social worker. This is my director of the campus at Flinders Uni. I am a social worker and have worked and been interested in FASD and FAS for the last 15 years. It is interesting this is finally an open discussion forum because it has been an underlying issue for many years. I learnt a lot from Canada. I do not know if people have spoken about that today, and there has been lots of work done in Western Australia by that very same thing – we do not drink by ourselves, women do not drink, it is a society issue and there are lots of campaigns now about that. The Territory could learn heaps from that.

We have been working closely with Fitzroy Valley - Fitzroy Crossing and we promote all the work that has been done there. You spoke before about this prevention treatment diagnosis issue - it is all of the above because the one thing about FASD is it is 100% preventable. We cannot just target one particular area; we cannot just be talking to obstetricians. We know obstetricians – the study done in Western Australia is different to what midwives teach. Midwives are saying they do not know if it is risky or not. A lot of obstetricians are saying maybe one or two late in pregnancy is okay. Women and professionals should be getting some procedures. There are lots of organisations like FARE doing lots of research across the country. We should be tapping into that but we do not.

We talk about anecdotal evidence but we do not have the stats to back it up. We do not know what the data is. We focus on it being an Aboriginal issue and we know it is not because we know of so many women going through IVF now - career women - they are used to drinking a bottle a night - trying to get pregnant. Midwives are saying, 'Have you stopped drinking?' 'No, the obstetrician says it is all okay'. It is not just an Aboriginal issue. That is where we get caught up when we think it is just an Aboriginal issue. It is across the board.

We work training health professionals as part of our job, and we have speech pathology students do placements with us and in schools. I guess when children are being diagnosed with a disability it makes it very difficult for families to access support. Often, these FASD kids end up in the child protection system. Having worked in the child protection system for a number of years in the Territory …

A WITNESS: Or in criminal (inaudible).

Ms PANNIFEX: Yes. Then, they are in the juvenile system, then they are in our gaols system. Geoff was saying in a lot of the petrol sniffing going on we looked at where the mother's drinking misbehaviour …

Mr LOHMEYER: That is right.

Ms PANNIFEX: … we can assume that a lot of those children are FASD kids that do not get diagnosed.

Mr WOOD: Our uniform message was - and Nicole said it before - it has to bring it home. I have heard all those things - people saying 'These doctors said only have one or two', and the midwives association said 'Absolutely none'. I reckon you go for absolutely none and tell the doctors to go down that path.

A WITNESS: The problem is too we blame woman. Society blames the woman, and it is not the woman's fault. As Eugenie was saying, you do not have messages on our alcohol as they do in America and Canada. We do not talk in open forums about no drinking. You have to search for literature for it. We blame woman so that big campaign nationally is No Shame, No Blame' and, if a woman has drunk during pregnancy, we should not be blaming her because everyone around in society drinks as a culture of Australia. We have a problem with that.

Mr WOOD: What campaign is that?

A WITNESS: No Shame No Blame. If you look on fare.org.au - Fare is doing research around alcohol issues.

Mr WOOD: We have been talking about not enough education. What is that? Is it meant to be an education program for everybody?

A WITNESS: Yes, and one of the other campaigns they have done is the problem of if you are having a baby, they are encouraging the fathers to also sign up for not drinking alcohol during the term of the pregnancy and, while their partner is breastfeeding, the father should abstain from drinking alcohol as well. It is a whole family approach to giving up alcohol in support of someone while they are having a baby. I can pass on (inaudible) as well.

There was a massive conference in Brisbane last year - a national conference I got a chance to attend - which was the first conference ever held in Australia where FASD was (inaudible). The idea was (inaudible) so there were lots of things that came out of it. It would be fantastic to have that here in Katherine.

Ms SCRYMGOUR: It would be good to also look at Anyinginyi Congress and what Anyinginyi has developed, because they have developed resources in both Warlpiri and Warumungu. There has been a lot of research and work done from the medical service there.

Madam CHAIR: I think we meet with them in Alice.

Ms SCRYMGOUR: Are you meeting with them? Oh, good. They have worked closely with the WA (inaudible), but also the Canadian/Indian people have come across, and through (inaudible) connection with Red Cross, with a program called RespectED. That has come into Tennant (inaudible)

Mr WOOD: There was a philanthropic group met at the CDU Menzies School of Health recently at the CDU. They combined four universities I think. They had a day on FASD about three months ago. There were moves in that region. I hope we do not end up with lots of silos …

A WITNESS: That is right.

Mr HIGGINS: To finish on a positive note, I have four sons, two of whom were born in the 1970s. The thing I have learnt out of this is why I quite often want to kill them.

Madam CHAIR: On that note, thank you everyone for coming to this forum. We will send these transcripts to you. Please, if you cannot download documents and want specific documents and they are too large to print just let Russell and the secretariat know and we can post these out to you. That is easy enough.

A WITNESS: Can we put in our submissions still, or …

Madam CHAIR: Yes. But, get them in sooner than later. If you want to make an individual submission, please send it in, but sooner than later.

Ms SCRYMGOUR: We will send it through. We will do it.

Madam CHAIR: You will do yours, but if anyone else wants to do anything, your personal thoughts or on any aspect, that would be much appreciated.

A WITNESS: What is the date for that closing for submissions?

Mr KEITH: The formal date was a month or so ago.

Witnesses interjecting.

Ms SCRYMGOUR: The letter I got was October.

Madam CHAIR: No, that is when we present the report to parliament.

Ms SCRYMGOUR: Okay!

Mr WOOD: We are a tripartisan committee. We will make up our own mind.

Madam CHAIR: Just sooner than later if you could.

Ms SCRYMGOUR: You would have told the House. You can make up the schedule.

Madam CHAIR: If you want to put in a submission, let us know so we know to expect it, then we can chase you.

Mr WOOD: Thank you all for coming.

The forum concluded.
