EDUCATION AND HEALTH STANDING COMMITTEE

AN INQUIRY INTO IMPROVING EDUCATIONAL OUTCOMES FOR WESTERN AUSTRALIANS OF ALL AGES

TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
WEDNESDAY, 28 MARCH 2012

SESSION TWO

Members

Dr J.M. Woollard (Chairman)
Mr P.B. Watson (Deputy Chairman)
Dr G.G. Jacobs
Ms L.L. Baker
Mr P. Abetz

Hearing commenced at 11.07 am

O'LEARY, DR COLLEEN
Epidemiologist–Alcohol and Pregnancy Researcher, Curtin Health Innovation Research Institute, examined:

The CHAIR: On behalf of the Education and Health Standing Committee, I would like to thank you for your interest and your appearance before us today. The purpose of this hearing is to assist the committee in gathering evidence for its inquiry into improving educational outcomes for Western Australians of all ages. At this stage I would like to introduce myself, Janet Woollard, and the other members of the committee, Peter Abetz, Peter Watson and Lisa Baker, and our secretariat, Brian Gordon and Lucy Roberts, and today we have Caroline from Hansard with us.

The Education and Health Standing Committee is a committee of the Assembly. This hearing is a formal procedure of Parliament and therefore commands the same respect given to proceedings in the house itself. This is a public hearing, and Hansard will be making a transcript of the proceedings for the public record. If you refer to any document or documents during your evidence, it would assist Hansard if you could provide the full title for the record. Before we proceed to your submission and the questions we have for you, I need to ask you a number of questions. Have you completed the "Details of Witness" form?

Dr O'Leary: Yes.

The CHAIR: Do you understand the notes at the bottom of the form about giving evidence to parliamentary committees?

Dr O'Leary: Yes.

The CHAIR: Did you receive and read the information for witnesses briefing sheet provided with the "Details of Witness" form?

Dr O'Leary: Yes.

The CHAIR: Do you have any questions?

Dr O'Leary: No.

The CHAIR: In what capacity are you appearing before the committee today?

Dr O'Leary: I am appearing as an independent expert witness, or a contributor, as an alcohol and pregnancy researcher.

The CHAIR: We very much accept that you are an expert witness, because we are aware of some of the work that you have done. Some of us, but not all, have heard you present in the past; so for some it is very new. We are hoping that you will now tell us about both the work that you have done, and the work that you believe still needs to be done, if we are going to really address the problems in relation to the prevalence, prevention and treatment of children with foetal alcohol spectrum disorder. So we will hand over to you, and please do not worry about getting too basic at all; we would like it.

[11.10 am]

Dr O'Leary: First of all, thank you very much for giving me the opportunity to address the committee. I would like to address point 5, which is foetal alcohol syndrome, and to address particularly the areas focusing on prevalence, prevention, identification and social and economic outcomes of these children. First of all, I am sure you are already aware that the prevalence of FAS

in Western Australia is considerably lower than that recorded overseas. In Western Australia the prevalence for non-Aboriginal children is 0.02 per 1 000, which is very low. For Aboriginal children, it is about 100 times higher—2.76 per 1 000. The estimates from overseas range from two per 1 000 to seven per 1 000 for the general population, so you can see ours are much, much lower. For minority groups such as First Nations and, I think, the term in South Africa is the Coloured population, they are much higher. The highest are recorded in South Africa at 50 per 1 000, which is actually five per cent. Those studies are in-school studies, where they have looked at the children in school. It is well accepted by researchers and health professionals that the prevalence of FAS in Western Australia and Australia actually underrepresent the true prevalence. But a major gap in our knowledge and a major gap that appears to me on the terms of the inquiry here is the local population best estimates of the prevalence of the broader foetal alcohol spectrum disorders. Foetal alcohol spectrum disorders is an umbrella term. Under these sit a number of diagnostic categories, of which foetal alcohol syndrome, FAS, is one of these. The children with FAS have a characteristic facial feature, which makes diagnosis a little bit easier. It is still hard, but it is easier. For children who have brain damage without the characteristic facial features, the diagnostic term is alcohol related neurodevelopmental disorder, and these are very difficult to identify.

There are a number of issues in WA that contribute to this lack—

Mr P.B. WATSON: Can I just ask why some people have the facial features and some do not?

Dr O'Leary: Sure. There are only about a few days in first trimester, or maybe a week, when the child's face is developing and the alcohol exposure has to occur then and it has to be heavy alcohol exposure. If you do not drink during first trimester but drink heavily in late pregnancy, you can damage the brain but the face is already developed, so you do not get the characteristic facial features. That is why they have another term. Without the facial features, it can be very, very hard—much harder—to identify these children. The issues that contribute to the lack of prevalence are that the diagnosis of foetal alcohol syndrome, FAS, is difficult. There is a lack of recognition of FAS by health professionals in Western Australia. Research here has shown that only 16 per cent of health professionals know the four diagnostic features that are a part of the foetal alcohol syndrome. Only seven per cent have actually diagnosed a child with FAS.

The CHAIR: The four diagnostic features being?

Dr O'Leary: There are facial features. Maternal alcohol consumption that has been documented, there is impaired growth and cognitive or neurodevelopmental delays.

Mr P.B. WATSON: Could you just tell us what the facial thing is, because everyone talks about it?

Dr O'Leary: It is sort of a pixie type thing. They have small eyes. They have a little fold over the eyes, on the eyelids, that is characteristic. I find it very difficult to identify that, but it is there. They have a small head, small chin and a very flat philtrum. This is probably the easiest feature to see. They have a thin upper lip, and this little dip that we have got above our lip and below our nose, that is the philtrum, and that is very flat on these children; that has not actually developed. You can have variations, but those are the classic features of these children.

Mr P.B. WATSON: Can I just ask a question? Is this well recognised? If you are a teacher in a class and you have a child who is misbehaving, can you just look and say—or are teachers trained enough to know—that this is not just a naughty child, this is a child who has got an issue?

Dr O'Leary: No, it is very difficult, and I will come to that.

Mr P.B. WATSON: Sorry.

Dr O'Leary: No; that is fine. It is a good question, and it is very important and it actually comes as part of what I am presenting.

Also, there is limited diagnostic capacity in WA. In fact, we do not have any centralised diagnostic centre. The State Child Development Centre has the capacity, but they do not have the resources.

Importantly, and I think this is the most important part, there is a lack of recognition of maternal alcohol consumption during pregnancy. I think this is a key point. This is what I am actually going to focus my presentation on. Women of childbearing age and pregnant women are not routinely asked about their alcohol consumption by health professionals, including when they are admitted to hospital, whether this be a general hospital, a midwifery hospital or whether it is a psychiatry institute or whether they have come in contact with emergency departments. Importantly, if pregnant women are asked about their alcohol consumption, there is no routine collection of this data onto a database which is then available later on to link with the child's birth data. So when a health professional wants to then diagnose a child or has a child presented at four or five years of age, it is very difficult for them to then say, "Well, this is due to alcohol exposure." So we have a missed opportunity by not routinely asking women of childbearing age about their alcohol consumption. It is a missed opportunity for prevention and reduction of heavy alcohol use per se, just for the community and just for the woman's sake but also during pregnancy. It is a missed opportunity for identifying these children who are at high risk when the mother has been drinking very heavily during pregnancy, because their health and development should actually be followed up more closely.

The CHAIR: Can I just ask, Colleen, bearing that in mind, that lack of data, would you support a plan for pregnancies to be notified, like we have had the notifiable register for STIs? It would be a register so that when any health professional becomes aware, it goes on the register so then someone in that area—a GP if there is no child health nurse, or a child health nurse or someone in that area—can then just go and visit the family and say these are the services available during your pregnancy and maybe ask those simple questions about alcohol and smoking.

Dr O'Leary: Yes. I actually think that the way to do it is to actually notify the midwives notification system.

The CHAIR: That is how it goes. In the UK the notification goes to the National Health Service and then the health visitor, which is the equivalent to our child health nurse, is then notified.

Dr O'Leary: My understanding—and I have not worked in child and community health because I was in the policy unit in the health department for a number of years but I have not worked there since 2004—is at that stage women had a little health book. They would take this health record book to each antenatal visit.

The CHAIR: But that is after birth.

Dr O'Leary: No; antenatally they took this. It would be very easy to have questions about alcohol consumption put into there so that the woman reports that, and then that is notified to the midwives notification system. That is a statutory notification system, so if those questions sit on the midwives system, then it becomes law that they have to have that data reported at the first antenatal visit. For women who are drinking heavily, this will be later on in pregnancy. Some women who drink very, very heavily may not actually access antenatal services; they just rock up for the baby to be delivered.

[11.20 am]

So there are lots of challenges there. So, to me, to collect the data antenatally at that first visit would be wonderful. However, there are issues surrounding asking women about alcohol use during pregnancy, and you have to make sure that people are educated. It might even be better to do it as a survey, you know, so that they are not actually asked in person. But they are given a form with the questions on there with a few other health questions so that they answer those because if they are not asked appropriately, then they may not answer them truthfully. Indeed in Canada, Manitoba has made it a part of the admission for delivery that all women are asked about alcohol consumption during pregnancy. However, the nurses do not ask everyone. They ask people they think might have drunk heavily, so they actually tend to ask Aboriginal or First Nations women or women who just

kind of look like they might have consumed alcohol. So, somebody from the middle class would not necessarily be asked, so they have a very low prevalence of alcohol consumption during pregnancy. But they recognise that that is most likely because most or a lot of the women have not been asked. So there are some issues that would need to go around that, but I think that is something that should be brought in. I do not think it needs a special register. I think we have the register there, which is the Midwives' Notification System, and that would enable research as well because that links with the baby's data and the midwives' links both with the mother's data and that admission data and the baby's.

The CHAIR: Were you a midwife yourself before you did your PhD?

Dr O'Leary: No, I started off with nursing and then I went into science and got a science degree and a master's in public health, and now my PhD a few years ago. So, I have that in the background, and I did obstets.

The CHAIR: Thank you.

Dr O'Leary: Okay, so the ideal thing would be to have that information about alcohol consumption during pregnancy accessible for the health professionals. When the child presents at school, which is what you were asking about earlier, and they have behaviour problems or learning problems or a mild intellectual disability, which they are at increased risk of, or language delay, which is not well recognised but that is actually one of the outcomes that is possible, it is difficult then for the teachers and even the health professionals to say, "Well, that is actually due to prenatal alcohol exposure and FASD." There is anecdotal evidence just from people in conversation who say that there are some kids, particularly in the Aboriginal communities, who are being diagnosed or classified as FAS in the school system, just on the basis that they come from a family that is dysfunctional or the mother has been drinking, and they assume that the child has FAS. Now, that is a concern, because prenatal alcohol exposure is only one of a number of risk factors that can cause child developmental problems and behaviour problems. It is important to recognise that not all children exposed prenatally to alcohol, even to heavy levels of alcohol, will be affected, and those affected will not be affected to the same degree. Even if the child is not harmed from the prenatal alcohol exposure, if their mother has an alcohol use disorder—in other words, they are either dependent upon alcohol or they abuse alcohol regularly—they are at risk of developmental delays happening as they are growing. So they could have been born normal or with no effect from the alcohol, but they are at risk of harm later on.

Mr P.B. WATSON: Is that true for a mother who does not drink during a pregnancy but once she has delivered the baby? Could that be passed on through the milk?

Dr O'Leary: Well, it is a good idea for mothers not to drink when they are breastfeeding, but no, that is not what I am talking about. I am talking about even if the mother was drinking heavily during pregnancy, only a small percentage of children will have FAS or even the broader FASD. However, if a family has a mother who is dependent on alcohol, or in the old terms "alcoholic", or she is misusing alcohol a lot of times, there are a lot of other risk factors that can occur in the family that place the child at risk of having developmental and learning problems later on. These include things like social isolation. If the mother is an alcoholic or dependent on alcohol, it is very difficult to keep contact with families and have that cohesion within society, so they move houses quite often. There is insecure attachment, so the mother does not bond with her baby and that can cause developmental problems. There is parental absence; she may be physically there but mentally not. There is poor parenting, less cognitive stimulation, parental mental illness—and I will go into this more later on—family dysfunction, and even perhaps child abuse is more likely; or there is a higher risk of child abuse in these families. So a lot of these things can cause the child to have delays that are very similar to those of FASD. However, they are not necessarily permanent, because if you remove those risk factors and give the child a supportive environment and extra support at school,

there is not the brain damage that is permanent as it is with the FAS or FASD. So it is important that these children are not mislabelled.

The other issue is when a child presents at six, say at school, and they are sent on for a follow-up with the doctor, if the doctor asks the mother what she has been drinking, she may not report fully because we have to remember that there is a stigma with alcohol-use disorders in particular in Australia, even though we are quite accepting as a community for heavy alcohol consumption and even overt intoxication. We are not so good at dealing with people who actually have that further on and end up with a dependence syndrome. But alcohol is such a big part of our society. And if we want to address FAS or FASD, we need to actually go back to what is happening in society, because when we ask mothers not to drink during pregnancy, we are actually asking them to step outside of society and what is happening and to actually behave in a way that is not part of their social scene.

The National Drug Strategy in 2010, the survey that they do every three years, found that almost 17 per cent of Australians reported that they drink at risk levels; so these are levels that place themselves at risk of harm. But the highest rates for women of risky and binge drinking —

The CHAIR: Is that short term or long-term risk?

Dr O'Leary: Yes, that is both, but for women it is particularly in the child-bearing age that they are drinking at risky levels. So, for long-term harm around 20 per cent of 18 to 29-year-olds will drink at risk levels for long-term harm. For 30 to 49-year-olds it is around 12 per cent. And when we talk about binge drinking, which is drinking at least five or more standard drinks—that is, not as many as serves; a serve of alcohol is usually one and a half to two standard drinks so we are talking less than five drinks—it is really actually quite frightening. For 20 to 29-year-olds, 19 per cent of them say that they binge drink on a monthly basis; and approximately the same percentage reports binge drinking on a weekly basis. For 30 to 39-year-olds, 13 per cent say that they binge drink monthly, and around eight per cent binge drink on a weekly basis. So you can see that this is actually very prevalent in our society.

Mr P.B. WATSON: Where are these stats taken from?

Dr O'Leary: The National Drug Strategy Household Survey, and they send out a questionnaire, or it is my understanding it is a survey. In fact I know that they do because I have actually received one, and I am not in those stats. The percentage of Aboriginal women binge drinking is even higher; it is about twice the rate as non-Aboriginal. So it is actually a really big concern, particularly as about half of pregnancies, 50 per cent of pregnancies, are reported to be unplanned. Even if a mother does not want to drink during pregnancy and she is aware of the risks, she may actually not find out she is pregnant until six, eight, maybe even 10 weeks into her pregnancy, at which time the baby would have been exposed.

The societal tolerance of drinking and binge drinking and to have drinking at risky levels is actually also found in women who are pregnant. Around 50 per cent of Australian women report that they actually drink during pregnancy, and some papers say it is slightly higher and some slightly lower, perhaps 35 per cent. But it is still a very big proportion. Of particular concern is binge drinking, which ranges from four per cent through to 20 per cent of women reporting that they have been binge drinking during pregnancy at some stage, and usually earlier on, and they reduce it later on. Around 22 per cent of Aboriginal women say that they binge drink during pregnancy.

[11.30 am]

Of course, these statistics and the harm related with heavy and binge risky alcohol consumption actually flow-on to increased rates of hospital admissions. My research now that I am conducting is actually having a look at women who have had an alcohol-related diagnosis recorded on health datasets at some stage in their life and who have had a baby in Western Australia whose birth is recorded on the midwifes' notification system. We used data linkage to identify these women and these are women who have had admissions either to the hospital morbidity data system, which

includes any inpatient admission—obstetrics, general hospitals, mental health admissions, mental health outpatients and drug and alcohol services for Perth. These women have had an alcohol-use problem or a disorder that was serious enough to be identified and recorded by the health professionals in these settings. The majority of these women have at least one alcohol diagnosis of intoxication. Some women have multiple diagnoses and over a range of different types of diagnoses. Just over two and a half per cent of non-Aboriginal mothers giving birth in WA have had an alcohol diagnosis recorded at some stage in their life. Almost 24 per cent of Aboriginal mothers have an alcohol-use diagnosis recorded on these datasets at some stage. This means that around two and a half per cent of non-Aboriginal births and around 27 per cent of Aboriginal births have a mother who has an alcohol diagnosis recorded on these datasets at some stage in their lives. There are a lot of children at risk here.

We also have a randomly selected comparison group of mothers without an alcohol diagnosis and their children, which allows us to investigate the risks that these children are exposed to and what their outcomes are. However, only a small percentage of these women have an alcohol diagnosis recorded during pregnancy. Of the women with an alcohol diagnosis—only four per cent of non-Aboriginal women and around just under nine per cent of Aboriginal women had an alcohol diagnosis recorded during pregnancy. When we looked broader at the year before pregnancy or the year after, we found four to six per cent of women had a diagnosis in the year before pregnancy and the same percentage in the year after pregnancy. Of the women with an alcohol diagnosis recorded during pregnancy, one quarter of them had a diagnosis also recorded in the year before pregnancy.

There is an opportunity for health professionals, once they have diagnosed a woman and recorded that there is alcohol use involved in the admission, to then intervene. They need to have brief interventions dealing with the woman's alcohol consumption, but also notifying them or making them aware of the risks of alcohol and pregnancy and also talking about the prevention of unplanned pregnancy. There is evidence from the United States where they looked at providing women with brief intervention—usually only five or 10 minutes—with a health professional, dealing with both alcohol consumption and unplanned pregnancy. This significantly reduced the potential for children to be exposed because if the woman continued her drinking, she was more likely then to have appropriate contraception. That is a really important prevention strategy.

Around 60 per cent of the mothers had an alcohol diagnosis recorded only greater than one year after their pregnancy. We thought, well, we do not know—the timing is not perfect. A lot of these women will be drinking during pregnancy; it just would not have been recognised. They may not have been to hospital or may not have been noticed to have an alcohol-use disorder. So in order to examine this we linked the birth data of the children with the data from the Western Australian Register of Developmental Anomalies, which has all the children who have foetal alcohol syndrome diagnosed by six years of age. They have been notified to the register. We linked there to have a look at how many of these children who have a diagnosis of FAS\ had a mother with a diagnosis recorded during pregnancy. We found that only a third of the children who have a diagnosis of FAS have mothers who have a diagnosis recorded during pregnancy. Over 40 per cent of the children in WA who have been diagnosed as FAS do not have a mother with an alcohol diagnosis recorded on the health datasets used for this study, which raises the question: we have diagnosed the child, but are we offering any services to the mother? They are at risk of health problems and also of having future children who are also—once you have had a child with FASD, unless the mother alters her behaviour future children will be likely to have a FASD as well. Most mothers with children diagnosed with FAS\ are Aboriginal—the majority of them. It raises the question: is there a diagnostic bias here? Are we more likely to recognise this syndrome in Aboriginal children?

We were not able to access the data for Aboriginal-specific services, unfortunately. They do not allow that data to be linked at this stage and we were not able to access data from drug and alcohol services that were not actually run by the government. Any of the NGOs—the Drug and Alcohol Office does have that data, but for some reason it is prevented by law, I understand, from having

those data linked, which is actually a real travesty because it is important to monitor these situations and this condition. Our results show that there was a real under-recognition of alcohol-use disorders during pregnancy.

The characteristics of the mothers themselves really highlight the need to identify these women early. They are more likely to be single. They are more likely to smoke during pregnancy and to have a diagnosis—not just to use illicit drugs, but to have that illicit drug use recognised during a hospital admission. They are more likely to have a mental health disorder other than a substance-use disorder. They are more likely to have four or more children, so there are multiple opportunities for them to have a child who is affected by the alcohol. Contrary to a lot of opinion, it is not just poor people who have an alcohol-use disorder. Although there are slightly fewer women in the upper socioeconomic stratum that have an alcohol-use disorder, it is still a concern. Twelve per cent of non-Aboriginal mothers in the top 25 per cent of the socioeconomic stratum have an alcohol-use disorder. That is compared with 20 per cent of the mothers in the comparison group who do not have an alcohol-use disorder.

The CHAIR: What were those figures?

Dr O'Leary: Twelve per cent in the top 25 per cent of the socioeconomic—that is the top two groups, basically, of the stratum. For the comparison mother it was 20 per cent. You can see that it is weighted towards the poor end of the lower 50 per cent in the socioeconomic stratum, but it goes across socioeconomic groups.

We need to have early identification of these mothers drinking heavily during pregnancy. All pregnant women should be routinely asked about their alcohol consumption at the first antenatal visit, as I mentioned, and have that information put onto the midwives' notification system. When the women are identified as drinking very heavily during pregnancy, it is really important that these children are followed up. This is an opportunity to identify problems early and also to help these children and help the mothers to deal with their children so that we do not have those other risk factors also impacting on the child's development and health. Ideally, it would come through the child and community health services. However, they are stretched and this would require more funding. Mothers with alcohol-use disorders are perhaps difficult to actually follow up longitudinally; they often do not stay in contact with services. So, having a child and community health nurse meeting these women in the antenatal period and developing a relationship—there are some child and community health nurses who will do a brilliant job with this—and then following them longitudinally, even when they move suburbs so as not to lose them, they can then help the children or identify those children who might need a further examination.

[11.40 am]

As I mentioned earlier, these children and their mothers have complex health problems and addressing those is and needs to be a key priority and the services for them need to be implemented. There are very few services across the state for women who are battling alcohol use disorders. They are mostly based in Perth and there are some privacy reasons for some women not wanting to access them in the country areas. But we need to have more services. I am aware of only two services where mothers can bring their children when they are using rehabilitation services—one in Perth and an Aboriginal specific one in Broome.

Mr P.B. WATSON: Rehabilitation services—what does that actually include?

Dr O'Leary: Well, I have never worked in one but they help the mother to try to reduce her alcohol consumption.

Mr P.B. WATSON: Sorry, I was interested in the child.

Dr O'Leary: For the child—no, no. But when the children come in, they come in because who else is going to look after them and because, in a lot of cases, the mothers cannot receive treatment if they cannot look after their children. But it is an ideal time for the children to be screened for

developmental delays and other problems. When I was working in child and community health, in about 2003, I actually had discussions with some of the senior child and community health nurses about the possibility of having the children in the Perth centre screened by a child and community health nurse. But the resources in the suburb where the centre is located were really stretched and the nurses said that they just could not do it. I think that is, again, a missed opportunity for dealing with issues surrounding the mother, her behaviour and how that is impacting on the children.

Mr P.B. WATSON: When we were up north, we heard that a young girl would be more susceptible to drinking if she had FASD. Is this just an opportunity for it to continue through the generations?

Dr O'Leary: Yes; yes, it is.

Mr P.B. WATSON: It's scary, isn't it!

Dr O'Leary: Look, it is scary and nobody is really sure if there are not some epigenetic changes that are occurring in the child as it is developing in utero that then make it more likely that they will pass on some damage. It is still a very under—there is a lot we do not know. However, I think that in just focusing on the children with FAS, a lot of the children who are at risk because of the mother's alcohol use disorder will miss out. I think that we need to look more broadly than at just the children with FAS. And of course we do not diagnose them well. I would hope that one of the recommendations that you could make is that we need to identify the women earlier and the children who are at risk, and follow them through child and community health services. That would be very important, I think, for the community.

The CHAIR: I might come back, Colleen, to something that you said very early on, which I am still not quite sure how it works. We have copies of the book given to mothers when their babies are born. It talks about immunisation, child development and each of the universal visits.

I apologise, some members have to leave because we —

The Witnesses: Sorry, have I gone over?

The CHAIR: No, you have not; it is just that the house sits at 12.

You mentioned early notification and I am trying to figure out how we do it because that information is not in that book. I have had a look at that book —

Dr O'Leary: Yes.

The CHAIR: So what records were you talking about?

Dr O'Leary: No; I was saying that it would be an opportunity to have those questions in that book.

The CHAIR: Oh, to have them added —

Dr O'Leary: To have them —

The CHAIR: And to have them given prior to birth—so as soon as you find —

Dr O'Leary: Well, that —

The CHAIR: That is normally given when a child is born.

Dr O'Leary: No; there is one that the mother has. Well, certainly in 2003–04 they were developing what is, I think from memory, called The Purple Book. The mother would take it to her antenatal visits and they would record her weight and other information for her. And I think they ask questions about —

The CHAIR: I have The Purple Book; I will have a another look —

Dr O'Leary: Okay, but I do not think that they have alcohol in there. I am just saying that is a perfect opportunity.

The CHAIR: Yes.

Dr O'Leary: However, the health professionals can also ask or just give the woman a survey, or there could be an online survey before she comes in or while she is in the waiting room. There are multiple ways, but it would have to be worked out. But, certainly at that first antenatal visit —

The CHAIR: Oh, I think that we agree with you that it has to be during—that is, after conception but before birth that we target the mothers.

Mr P.B. WATSON: My main concern for the Indigenous population up north is about the cultural issues when they come in—the shame and everything like that.

Dr O'Leary: If you do it online, they are not actually saying to one person, "Yes, I have been drinking heavily." However, having said that, in some of these communities everybody knows who has been drinking heavily and that is the difference between Aboriginal communities and some of the communities and heavy drinking or alcohol use disorders in the general population. A lot of women are very covert about their drinking and their drinking problems. In fact, I do not know whether you have read the book by Elizabeth Anne Russell who is the birth mother of a child with FASD. She wrote a quite heart-wrenching book, but I cannot remember what it is called. She states that her husband did not know that she had an alcohol use disorder. She had kept from him that she had a problem with alcohol, and she would drink when no one was around. I have heard this repeated by the nurse who runs the chemical dependency unit for pregnant mothers at King Edward Memorial Hospital. She has said exactly the same thing; that is, one of her mothers had said, "My husband does not know that I am addicted to alcohol." It does happen. It is very closed in the general community. And there is a lot of stigma in the general community too, which means this is something that needs to be looked at: what is the best way of asking the women and what is the best way of getting the most reliable response? But having said that, Australian women are quite open about how much they drink. I am involved in a longitudinal study being run out of the Murdoch Children's Research Institute in Melbourne. We are collecting information on women's drinking during pregnancy, and women are reporting huge quantities to the midwives, but the midwives are all very well trained and, you know, non-judgemental, which is really important. Unfortunately, that is not the case for a lot of health professionals with regards to alcohol consumption.

The CHAIR: That gets back to the fact that we really need more evidence, don't we? Many people accept the moral issues and will say, "Don't drink during pregnancy", but I have spoken with a lady from Canada—I cannot remember her name—where they have been doing so much work, and even in Canada, because the evidence is not there, the health professionals' message is not "Do not drink."

Dr O'Leary: It is interesting. Canada has a lot more money spent on FASD. They have a lot of policy, but they have not done a lot of research. We have actually done a lot of research in Australia. In fact, my whole PhD was looking at the dose pattern and timing of prenatal alcohol exposure and foetal effects. My results showed that three to four standard drinks per social occasion once or twice a week can increase the risk of some child behaviour problems. But the real focus and the real harm comes from binge drinking and very heavy drinking even if the woman does not binge drink but is drinking three or four per occasion, four of five times a week. That is very heavy consumption. But the work that I am doing now is population based and we can look at population-based outcomes; that is, we can look at the prevalence in the population of some of these outcomes. I am looking at the outcomes for the children. I am currently looking at the health outcomes; however, I have also had the data for the children linked with education data, with justice data, and with child protection data. I am hoping to start on the education data soon. I am still looking for funding. Because it is just me, I focused on the health because I wanted to get a handle on some of the key areas where damage may have occurred—things like, cerebral palsy, intellectual disability and mortality—stillbirth and infant mortality, including SIDS. So I have papers—one has been published, one has been accepted and the others are in train.

The CHAIR: Perhaps now might be a good time to remind you that we hope to table this inquiry report in November. That means that between now and November any papers that you publish or any relevant literature that you come across that you believe would help us as a committee, we would very much appreciate you forwarding to us because obviously if we are going to make recommendations, you know, we need the evidence.

Dr O'Leary: Exactly. I know that there is a school of thought that we do not need the evidence, that we do not need the data and that we should just be putting in services et cetera. I am not of that ilk. I firmly believe that we need the evidence. In one of my previous jobs, I worked as a project officer for the National Expert Advisory Committee on Alcohol, chaired by Professor Charles Watson, the then dean of health sciences at Curtin University. As soon as I started working for the committee in 1999, Charles asked me to start gathering evidence about alcohol and pregnancy and FAS—the focus then was on FAS—which I did, but it took quite a while to convince the committee that this was a serious enough problem for the committee to turn its attention to. At that stage, it was thought that around one in 100 000 children will have FAS, and of course we now know that number is much, much higher. The turning point was when Professor Carol Bower from TICHR published a paper in which she linked the data from the birth defects registry with data from the rural paediatric service, and then she published the figures that I reported earlier for FAS in WA. When people started to look at the numbers and they were much higher than we had thought, all of a sudden everyone on the committee was saying, "Well, yes; we should perhaps put some focus onto this." It was that committee's work that put FAS and alcohol and pregnancy on the national agenda for the first time in Australia. The importance of data cannot be underestimated.

The CHAIR: Yes. Because of the time, we would like to have you here longer with us but —

Mr P.B. WATSON: Can I just say on behalf of Lisa who has left that what you have let us know today has been sensational.

Dr O'Leary: Thank you; I am delighted. I am very passionate about the area and I am very passionate about the mothers because I think that they are being overlooked in our focus on FAS and the child.

The CHAIR: Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 days of the date of the letter attached to it. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added by these corrections and the sense of your evidence cannot be altered. If you wish to provide additional information or elaborate on particular points, please include a supplementary submission for the committee's consideration when you return your corrected transcript of evidence.

Also, as I said previously, please keep us in the loop over the next few months—it may be papers or conferences or seminars that you think would be useful for us to go to. Brian and I are going to the Canadian conference and maybe there are some questions that you think would be appropriate for us to ask people at that conference. I will finish now, because Peter is being very good and waiting for me to close because we cannot have a hearing unless he is here with me.

Thank you for your time this morning; we can chat after we close the hearing.

Hearing concluded at 11.53 am