

**EDUCATION AND HEALTH
STANDING COMMITTEE**

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

**TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
WEDNESDAY, 16 MAY 2012**

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 9.55 am**BOWER, DR CAROL****Epidemiologist, Telethon Institute of Child Health Research, examined:****WATKINS, DR ROCHELLE****Research Fellow, Telethon Institute of Child Health Research, examined:**

The CHAIR: Thank you both so much for coming along this morning. On behalf of the Education and Health Standing Committee, I thank you for your interest and 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. The Education and Health Standing Committee is a committee of the Assembly. This hearing is a formal procedure of Parliament. 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, I need to ask: have you completed the "Details of Witness" form?

The Witnesses: Yes.

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

The Witnesses: Yes.

The CHAIR: Did you receive and read the information for witnesses briefing sheet provided with the details of witness form today?

The Witnesses: Yes.

The CHAIR: Do you have any questions in relation to being a witness at today's hearing?

The Witnesses: No.

The CHAIR: We sent you the committee's terms of reference. One of our terms of reference is FASD. You would be aware that a federal committee is also looking at FASD. As a committee we became aware of some of the problems with FASD when we did our trip to the Kimberley 18 months ago. We were told about what some teachers believe to be the high prevalence of FASD in some areas. Before we move to some particular questions we would like to ask you, could you encapsulate all the work that you are doing in FASD? We will sit quietly and listen and then ask you some questions. Brian and I went to the Canadian conference on FASD. We were told that they are doing such and such in WA and such and such over there. We were not aware of all the work that is being done here. Can you give us an overall picture and then we will come back to the questions we have for you.

Dr Bower: We have been engaged in research on alcohol in pregnancy for the last 10 years, really. We did a study through the Australian Paediatric Surveillance Unit that asked paediatricians about their diagnosis of foetal alcohol syndrome—just the syndrome—which was a nationwide assessment of the incidence of foetal alcohol syndrome. Very briefly the findings from that were that it is quite low, but over the course of the study—it ran for three years—there was an increase in incidence, which we think was an increase in familiarity and an increase in diagnosis rather than an increase in the incidence. We also did studies surveying health professionals in Western Australia asking them, amongst other things, whether they knew what the features of foetal alcohol syndrome

were. On average only about 12 per cent of various health professional groups actually knew the four cardinal features of foetal alcohol syndrome, so it is not surprising that it is not very well diagnosed. There was not a lot of routinely advising women about the risks of alcohol in pregnancy or advising them not to drink alcohol in pregnancy. But there was a call from all those health professions—paediatricians, general practitioners, obstetricians, allied health professionals in the public sector, community and child health nurses and Aboriginal health workers—for more information for educational resources and so on. The next round of studies was to develop some resources for health professionals, which maybe I brought last time. I can let you have a copy. There was a booklet with lots of information about alcohol in pregnancy and FASD, a one-page laminated sheet for easy reference and a little wallet card about saying no to alcohol in pregnancy that could be given to women. They were distributed and then we did the surveys again and evaluated whether they had been effective. We felt that they had. It was only a short follow-up period; it was about six months after distribution that lots of them had seen and recalled receiving the information and had found the materials useful and there was a change because most of them by that time were advising women—they said they were advising women—not to drink alcohol in pregnancy. There was not much improvement in the recognition of the cardinal features of FAS. You have probably heard about all the research that Colleen O’Leary has done.

The CHAIR: Colleen told us about FASD rather than about the projects.

Dr Bower: She has looked at quite a few outcomes of pregnancy—using linked data—by exposure to alcohol during pregnancy and found some behavioural problems with women exposed to alcohol in pregnancy. Now she is looking at—again using linked data—data from hospital morbidity, the Drug and Alcohol Office and the mental health information systems on women who have an alcohol use disorder, have reported in the hospital data largely with some alcohol use disorder—alcohol dependency and those sorts of things. These women are drinking at heavy levels and they are linking that to their pregnancy outcomes. Firstly, there is a quite a high rate—a depressingly high rate—of heavy alcohol use, but we all know that. In some of the work she has done, the babies of some of those mothers have an increased risk of stillbirth, an intellectual disability and cerebral palsy. She is continuing to do those analyses. Those are the studies that have already been published.

The other big project that we have been involved in—I am sure there are others—is that we responded to a tender from the commonwealth to develop a diagnostic instrument for FASD for the nation. We did that in 2010-11 and submitted our report in September last year. We had feedback from that. There were a few things they wanted us to do in addition. We have done that. The final report is about to go back in. Rochelle has been the research fellow on that project. We are not at liberty to tell you what we found and what we have concluded, but we can tell you how we did it.

Dr Watkins: The main aim of the project was to develop an instrument that could be used to improve the identification or diagnosis of FASD in Australia. Effectively it was run with a national collaboration of researchers from around the country. We were looking at multiple methods to capture as much evidence as is available. Clearly there is a lot out there in the literature. A systematic literature review was one of the main components, looking at what has happened in Canada and the US in particular. We also looked at community and consumer input to get a more complete view of the issues. What provided the main backbone for our results was a national consultation and consensus development process where we tried to recruit health professionals, medical professionals and allied health professionals who have had some experience or expertise in FASD diagnoses or screening. We used several methods to identify that population as much possible. In summary, we ended up with 139 health professionals agreeing to take part. About 75 per cent of those responded. Most of those had reported experience in screening and diagnosis. But the number who had reported completing any training was a lot lower. Our main findings are still with the department. As a result of the work we have produced a draft diagnostic instrument and resources that we hope to move forward with in future research.

The CHAIR: With that diagnostic instrument, when we were at the conference there was discussion of FASD being included in the DRG in 2013, but I am wondering now whether it is within DSM. It was Dr Sterling Clarren. I had to go back through my notes to check the name. It sounded very much like it was a fait accompli—in 2013 it is going to go there.

Dr Bower: Thank you, that is good to know.

The CHAIR: It is interesting that really you have been doing all this work on the diagnoses so that we can get a foot in the door. They were presenting tools on the Australian Early Development Index. They have added questions for a teacher to be able to refer. They are looking at diagnoses in juvenile settings and in prison settings. We have no funding for FASD. The work that you are doing will hopefully open the door for those other things down the track.

Dr Bower: I think so. That has just reminded me of two other projects that we are doing. One of them is a survey in the justice system—it is rather similar to the ones of the health professionals—so corrective services, police and the justice system. That is happening as we speak.

The CHAIR: So is that 18-plus? When you say the justice system, is that for adults?

Dr Bower: I think it is all. It is about finding out what they know. There have been surveys in North America. The questions are loosely based on that.

The CHAIR: When are the results of that survey likely to be released?

Dr Bower: It is happening now. We hope it will be completed very soon. A similar project—they were both funded by the Foundation for Alcohol Research and Education—has been completed in Queensland with the justice system. I think that is Heather Douglas. The other project that is funded by FARE is a study with foster carers. It is about their knowledge of and needs and wants in relation to FASD. Of course, they often have children with disabilities and there is a high suspicion at least that alcohol might be involved.

The CHAIR: That was something that came out of the conference. A number of foster carers or people who have adopted were not told that the child was possibly FAS or FASD when they adopted and the problem is caused later.

Dr Bower: That is probably not a problem here, because it is not so commonly diagnosed. No-one would know. The Department of Health and Ageing has funded several projects in relation to alcohol in pregnancy. The various researchers involved in that are meeting in the middle of June to talk about the findings and where to next. We are hopeful that—

The CHAIR: We are hoping to table our report in August. Some of the results from the projects that you are working on may not be finished by then. Perhaps you could send us the reports you have published to date. We are very much novices in this area. You are the experts, so it would be useful for us to know what your findings are in relation to each piece of research you have done so that we can look at that as a committee and say, yes, we agree with that, maybe we should put that as a recommendation in our report. We would very much appreciate it if you could send us copies of whatever is out there in the public domain. We appreciate that you are not able to provide us with information about the papers that you are working on.

Dr G.G. JACOBS: I know you cannot say too much about the diagnostic tool for FASD. Will it be something that we can hang our hat on? Is it going to be a working man's tool? Because it is a complex area, will it be a complex tool? Will we be able to use it in practical terms to make a difference in identifying FASD? Our experience in the Fitzroy and such places is that, as you were saying, only 12 per cent of professionals knew the four cardinal signs. Most of us would not recognise them if they were put in front of us, although we are becoming more conscious of them now. My issue is with the diagnostic tool and how practical it will be.

Dr Bower: We hope that it will be extremely practical. It is a complex diagnosis. FAS is not so complicated. The tool should make that a whole lot easier to diagnose. It is really the other aspects

of the spectrum that are a bit harder because those children do not have those characteristic facial features. As you know there is no test that you can do that says yes or no.

Mr P.B. WATSON: Are a lot of these kids diagnosed with ADHD and things like that?

Dr Bower: Yes, we think that is probably the case. Parents are saying that they are considered to be naughty kids. That is really difficult, because then they do not get the right sort of management. I am not sure that the instrument can just be pulled off the shelf and used. I think there will need to be some workforce development. There will need to be training. Most people around the world who are heavily into diagnoses of FASD make the point that there needs to be training of the workforce and that it needs to be done by a multidisciplinary team. One person cannot get the information that is needed for all aspects—in particular, with the neurodevelopmental assessment of children you need people whose particular field is to make those assessments.

[10.15 am]

The CHAIR: Because of the work that you are doing, we were fortunate to have one of your associates, Dr James Fitzpatrick, talk to us last week. He talked about having a mobile FASD team in an area. Could you expand on that? Would there be a mobile FASD team for the Pilbara, for the Kimberley and for the Great Southern? Would you try to have a team for each of the regions that would use a pickup van to go from one place to another? How do you see that working? In Canada there are 40 FASD clinics. They are trying to develop some commonality in the data that they are gathering so that it can be grouped together. We may be a bit luckier in that although we are behind them in terms of getting it diagnosed, hopefully as we get these teams they will start off on the right footing. Could you discuss how that FASD team approach might work and where it would be? Would it be the Telethon institute, a centre in Fitzroy or Broome, at Westmead or the George Institute?

Dr Bower: That is part of the University of Sydney.

The CHAIR: Who would gather everyone from everywhere so that we are all working together?

Dr Bower: I think there is a general acceptance, will and enthusiasm for having a collaborative approach to diagnoses, an Australian diagnostic instrument and the national collection of data. The National Perinatal Statistics and Epidemiology Unit, part of the Australian Institute of Health and Welfare, had a meeting last year—I think it was last year—to discuss having a national data collection for foetal alcohol spectrum disorder. I think that is a really important thing. In terms of providing a diagnostic service, that probably needs to be state based. That is not my special subject, so I am not sure, but because it falls within the local health system it would need to be more state based—but the method could still be a national method.

Mr P. ABETZ: Hopefully the diagnostic tool will make it a lot simpler to diagnose and we will get a more accurate picture of what is out there. Presumably, there will be a massive increase in the number of people identified with FASD. What research is being done in terms of what can be done to help these kids? Obviously the ideal is to prevent it happening in the first place, but we are going to end up with a bunch of people who will be stuck with this condition for the rest of their lives. Is much work being done in that area at all?

Dr Bower: They are already stuck with it for the rest of their lives; they might not have the right diagnosis. Presumably, they are getting some services now, but they might not be the most appropriate services. There is not a lot of randomised control trial evidence about what works best with children with FASD. There are some and some are currently in progress. But there is a lot of observational information about what works and what does not work and what helps these kids. Again, this is not my area, but there is enough out there to know that things can be made better for these children knowing that they have FASD rather than just saying that they have ADHD or some other label. The earlier that management is instituted, the better the outcomes for those kids and their families. Many families say how useful it is to actually know what the problem is, although I

have heard it asked: what is the point in making the diagnosis when we do not have anything to offer? Will it just stigmatise the child and family? That is a concern. The other point about making the diagnosis early is that there could be other pregnancies after that one. If we know that that is an issue, we could intervene and make it better and ensure that the next pregnancy is not affected.

Mr P. ABETZ: Hopefully it will lead to a growth of awareness of the problem in the community, which would then encourage women not to drink. There would be more social pressure not to drink, which would reduce the problem.

Mr P.B. WATSON: Rochelle, how much of your report refers to prevention? We talk about all these things at the end. It is like most medical things in Australia, we are looking at a cure of a so-called disease. How much of your report is about preventing it in the first place? It will be preventable if we can get the right message out.

Dr Watkins: That is it. I suppose there has been wide awareness for a long time that it should be 100 per cent preventable, but for some of the reasons that Carol mentioned and because of society's perceptions it is not necessarily seen as a genetic or passive acquisition. It is possibly seen as self-determined, so there are a lot of issues that will influence how prevention works. It is a complicated genesis of the problem. Often there are other co-morbidities, there are poor services and a lot of other things. In the report we have stayed fairly tight to the diagnosis because the real aim is to make a tool that is usable and that will make a difference and improve capacity. We have certainly considered feedback about trying to make it user friendly and a lot easier for people to follow than potentially some of the other systems that are seen more as a research diagnostic tool than a practical tool. I have a strong belief in the importance of knowing about the problem because that will enable not only research on how we address it in our local context—when you do not have a good handle on what is going on, how big it is and what works and what doesn't, it is very difficult to argue for services and intervention. I see diagnoses as the first stage in enabling prevention and in particular, as Carol said, in targeting prevention to very high-risk individuals.

Mr P.B. WATSON: When we were in Roebourne the health nurse said that they explain to young mothers that their child will be damaged. Women are told that they should not drink because it is no good for them, but when people say that their child could have brain damage and other problems, it turned a lot of them around. The natural instincts of a mother said that they did not want their child to have brain damage. A lot of the time the message is that you should not drink, because it is bad for you and it could affect your child. It should be if you drink you will affect the chances of your child. It might be good to twist it around.

Dr Watkins: I think that is really, really powerful. From my reading of the evidence in other places—because I have not been involved in that research here and I am not aware that it has happened—that really assumes that alcohol provides no other function for that person and that they can voluntarily choose to change their behaviours. There is evidence in the US that even mothers who are aware of that and clearly have an innate investment in protecting the health of their children were, for other reasons, not able to or did not have the support to change their behaviours. I feel that that is an important point. It is good to see the broad nature of your scope in that it is not just a problem that can be fixed with any one sector.

The CHAIR: One of our trips was to South Australia. We were made aware of the fact that when a family was identified as a high-risk family, they would be seen by the child health nurse 32 times in two years. Manitoba in Canada is funding mentors. We know throughout WA that it is not only an Indigenous problem; rather, it is an Indigenous and a non-Indigenous problem. In Manitoba they are funding mentors, many of whom may have been affected themselves, to work with young mums to help them with their alcohol problems and to see the value in not drinking. Obviously, we do not have anything like that here. Apart from the diagnosing, I believe your institute has done some work with child health nurses. I am not sure if you are able to tell us what role they may have made or what you have assessed as part of their role.

We currently have refuges for women who have been subject to domestic violence. Since returning from Canada, I have been wondering whether we should be encouraging the government to fund refuges if we know that FAS and FASD are a problem. A woman can be asked whether she wants help in a mentor role or, if it is going to be impossible to say no because of where she is living, she could live in another area for the duration of her pregnancy and go back to her family after she has had her baby. Can I have your opinion on the mentor and the refuge?

Dr Bower: It sounds like it might be a good idea. I do not have any evidence that it would be, but that does not mean to say it is not. Do you have any knowledge of this?

Dr Watkins: No. From my reading, things like mental health services and support services and other things certainly have been associated with a likelihood of abstaining from drinking

Dr Bower: NOFASARD is the lay support group for FASD.

The CHAIR: That is Sue.

Dr Bower: Sue Miers.

The CHAIR: We remember Sue in Adelaide. She is a very dynamic person.

Dr Bower: There are members of NOFASARD in WA as well. They do provide a very good support service for women who seek it. They have to self-identify that that is what they want to do in that instance. They provide a lot of support as well.

The CHAIR: I want to ask about costs. In America the economic health institute has produced papers and written chapters on the fact one child born with FASD throughout their lifetime is the equivalent of 10 knee replacements or three hip replacements. In order for us, and any committee, to get funding from the government to introduce new services and resources, the government has to see that it is going to get value for its money. So are you aware of anyone in Australia who has looked at the costs of FASD—the short-term and long-term costs?

[10.30 am]

Dr Bower: I am fairly sure that no-one has. Part of the problem is that it is a vicious circle, because until you are diagnosing the cases of FASD it is very hard to put a cost on it. It is something that we have certainly thought about and think would be a useful thing to do, but it is very hard to do when you have not got the diagnosis across the board. There are a few cases that are diagnosed, but they may be the extreme, and they may be particularly costly or they may not be. You need to get the spectrum. Most of the diagnoses are in fact foetal alcohol syndrome, not FASD, which is said to be, in terms of magnitude, more common. So it would be good to have that information. As Rochelle said, we think that we have to start at the hard point, which is making the diagnosis. But that does not mean that we are not, in a research sense, focusing and asking about alcohol in pregnancy and doing what we can to support all those other aspects that are all part of the whole picture. Being able to get an assessment of a child, even when you think that it might be foetal alcohol spectrum disorder, is not easy, as you know, because there are long waiting lists for developmental assessments. So that is a problem, too. Everything is not particularly easy in this area. The other thing perhaps we should mention is that the WA Department of Health has a model of care for foetal alcohol spectrum disorder and it is moving on several aspects of that model of care. We have been involved in that, and there are now implementation working groups, I think they are called, on secondary prevention and primary prevention; and diagnosis is another group, but I do not think they are acting on that just yet.

The CHAIR: Graham, after your question, or before your question, you might like to look at question 18, which Brian would particularly like addressed as part of this meeting.

Dr G.G. JACOBS: Before I ask a bit more about the model of care, I have been wanting the opportunity to ask a research epidemiologist this really hard question. I do not know how you do it, but I am going to ask it anyway. Have there been any studies on the amount of alcohol and the

resulting severity of FASD? Is there a cut-off point? Where are the safe drinking levels? Is there a relationship between the drinking levels in pregnancy and the severity of the disease? I cannot get my head around that, and no-one has been able to do that for me. I do not know whether that is important, but can you give us a bit of a handle on that? We say that drinking in pregnancy produces this condition. But how much drinking, and does more drinking produce a higher severity of the disease; or are there too many variables in this picture?

Dr Bower: Yes, yes, and yes, probably! It is hard to get a handle on whether there is a threshold, really. Certainly the more alcohol that is consumed, the more likely it is that the child will be affected. There have also been some studies that have shown that if women drink a very small amount of alcohol in pregnancy, the outcomes look better. We have some concerns with that. But I think it is the precautionary principle, really. When you do not know whether there is a threshold—I will come back to that point in a minute—and you know that the heavier the drinking, the more likely it is that there will be an adverse outcome, then it seems a precautionary idea to recommend not drinking alcohol in pregnancy. It is like taking a little bit of thalidomide. It might not be harmful, but why would you condone the use of a known teratogen in pregnancy unless there was a benefit to be received? So that is sort of at the theoretical level. Of course the NHMRC guidelines say that no alcohol in pregnancy is the safest option.

The other problem is actually measuring this to find out what the answer is. You cannot do a randomised control trial and tell some women to drink and some not to drink. That itself tells you that this is not something that should be encouraged. The other thing is that all the studies look at standard drinks. I am sure you are aware that most people cannot pour a standard drink, and what people consider to be a standard glass of wine is probably closer to two standard drinks, or at least one and a half. Some of the work that Colleen O'Leary has done has seen an effect with a relatively small amount of alcohol and has shown how easy it would be to get that much alcohol when you think you are only having a low amount—you think you are having only one standard drink, but in fact you may well be having two standard drinks. There is certainly evidence that the more alcohol that is consumed at a particular sitting, the more likely it is to have an effect. A lot of the studies have looked at an average intake over a week, but all of that intake might have been on one day, which is an entirely different proposition. Alcohol crosses the placenta freely, so whatever the mother drinks, that is the level that the baby is getting—and with the baby, we are talking about something that is really tiny. So it is not an easy area to research, and it is not helped by articles like the one in a recent *Marie Claire* that was drawn to my attention that, hey, mother, why would you give up a glass of Moët when it probably does not do any harm? Well, why would you risk your child's development? Having said that rather flippantly, I do acknowledge that, as Rochelle said, for some people it is not easy to stop drinking. I think that is a really important thing that we must take into account, too—that women really need a lot of support. In the community, I think that anything that goes on that raises awareness about the role of alcohol and its effect on the developing foetus should be helpful—we would hope that it would be helpful—so that it is easy for a woman to say, “No, I do not want a drink.” But I suspect there is quite a lot of societal—implied, anyway—pressure not to be seen to not be drinking.

Dr G.G. JACOBS: I want to ask you about the FASD model of care that you have touched on. Given the lack of new money that is being attached to this model, what do you believe it can achieve? What do you consider to be the model of care's strengths? It would appear that it has a preventative focus rather than a support and intervention focus. Is that a fair comment?

Dr Bower: What was the second one?

Dr G.G. JACOBS: What do you consider to be the model of care's strengths?

Dr Bower: I will deal with the first two together. While there might not be any money attached to it, there is an awful lot of enthusiasm and a lot of goodwill and a lot of people putting time and effort into it, for no financial gain, because they think this is really important. We have not had the

first meeting of the working group yet—that may be next week—but I think there is a lot of energy and effort going into the model of care. No other state has anything like this generation of effort going on. So I think we are fortunate that that is happening here in Western Australia, and we feel at the institute that it is important that we put our support behind the model of care in whatever way we can. It would be nice if its prevention focus also had a diagnostic focus and a management focus. But given that there is no financial support for it, then I think it has to start somewhere, and it is great that it is starting somewhere. With regard to its strengths, I think a lot of effort and commitment is going into it, to pursue it and to develop a model of care in the first place, and then to try and implement aspects of it at least. There were a large number of recommendations in the original model of care, and those have been partitioned into various aspects of prevention, diagnosis and management. I think they are making an effort to get on with it. It might not be ideal, but think it is better than nothing.

Dr G.G. JACOBS: There might come a point when eventually we will need some money for it.

The CHAIR: A point, yes—last year!

Dr Bower: I think we have passed that point.

Dr G.G. JACOBS: How long can you go on with enthusiasm? In the end, you have to have money to implement it, surely.

Dr Bower: Yes, and how do we do that?

Dr G.G. JACOBS: That is a message for us.

The CHAIR: I have two questions. One is that James mentioned last week that it would be useful for us as a committee, if we are going to be possibly making a recommendation that there be mobile FASD assessment units in the different regions, to have more of an understanding of the FASD assessment process. I know that someone from Telethon went to Washington to do the three or four-day course that they run there. James did mention to us, and I have not had an opportunity to check with Brian, that there were some videos on the assessment process. It would be very useful if we could chase up with Brian, or maybe chase up with you, Rochelle, whether we could look at those videos—we can get them back to you—so that we can get a better understanding of what goes into that kind of assessment process.

The next question is we have a register for developmental anomalies. Where does currently FAS, and where will—when the funding is finally ticked off on by the federal government—FASD, come into that register? Is that register currently being used for FAS, and will it be used for FASD?

Dr Bower: I do not think we have any videos within our resources.

Dr Watkins: I know there are some online, and I can certainly try to locate those and provide them to you.

The CHAIR: Thank you. It is obviously big funding if we are saying that there should be clinics in different areas. It would obviously make it easier for us if we had some understanding of that concept so that we can write a bit more about what goes into those assessments, and why those mobile clinics need to have in them a paediatrician, a social worker, an occupational therapist and a child health nurse.

[10.45 am]

Dr Watkins: Definitely.

Dr Bower: With another hat on, I am actually the head of the WA Register of Developmental Anomalies.

The CHAIR: So we hit the nail on the head then!

Dr Bower: You did. I thought you might ask, so I brought the annual report from last year. The register is now a statutory register. We receive notifications of all birth defects and cerebral palsy in children diagnosed up to the age of six years. It is a bit of a problem for FASD because sometimes that diagnosis is later than that. The register largely accepts what is sent to us by the notifier. They are usually paediatricians who notify us of FASD. We do not check that they have covered all the features and that sort of thing. Since we have had an interest in foetal alcohol syndrome, we have sent out reminders and notification cards to the paediatricians and encouraged notification in general but with a particular focus on foetal alcohol syndrome. We have seen an increase in notification over that period. So that is another reason why we think there has been under-recognition and/or under-diagnosis and/or under-notification rather than an increase in the actual condition. We will register FASD if it is notified to us. We would include other anomalies within the spectrum but I do not think—I cannot say for sure—we have been notified of an alcohol-related neurodevelopmental disorder. I do not recall that coming in.

The CHAIR: But is that on a form for them? When we were there, we were trying to get used to the different terms that were being used to possibly describe FASD, and that is obviously a term that has been used.

Dr Bower: It is a term that has been used. It may not be what we would be suggesting with the instrument that we are developing. If the instrument is accepted and there is training and it is put into practice, the register would be more than happy to be accepting notifications of anything within the spectrum that is related to alcohol.

The CHAIR: I think under DSM-4 it was something like alcohol-related neurodevelopmental disorder that is maybe going to go in in 2013.

Dr Bower: In DSM-5, yes.

Dr Watkins: It will be a wonderful improvement to have that formal recognition in a very important guide.

The CHAIR: One of the other things that came up in terms of funding in Canada, because we were looking at educational support in the schools, was the so-called cut off for an IQ of 70. They were discussing at their conference the fact that, to start with, that needs to be moved maybe to 75, but even some children at 75 may need more help than some children who are at 105. What do you think about the lower adaptive function score? I could see it as the IQ score. Could you discuss both the IQ score and the lower adaptive function score?

Dr Watkins: I should preface it by saying that I am not a psychologist and I do not have any clinical or real experience in that area.

The CHAIR: You have a lot more than us!

Dr Watkins: Examining it from the diagnostic point of view, the IQ is really just one assessment of cognitive function. Pretty well the literature to date will identify three main areas of impairment that are associated with the damage due to alcohol. It is often not just in the IQ; you can actually have a high IQ—even into the 120s or higher—but in fact show deficits in adaptive functioning, in attention and in other areas of cognitive functioning like spatial awareness or motor function. That is one of the difficulties in diagnosis and one of the difficulties in creating a cut-off. My impression of what I have read is that you would not really capture it in just IQ, and that is why a lot of the diagnostic guides look at quite a comprehensive assessment based on what the patient or the parents or carers or educational professionals might identify as the issues, because in fact there can be some profound difficulties in adaptive functioning, everyday functioning and attention and behaviour that are not going to be reflected in IQ. It is about capturing the broad nature of damage that can have occurred.

Dr Bower: It would be good if the diagnosis of a foetal alcohol spectrum disorder was considered adequate to obtain particular funding for educational support that was not dependent on the level of IQ.

The CHAIR: So that it includes a lower adaptive functioning measurement as well as IQ.

Dr Bower: Yes.

Dr G.G. JACOBS: Carol was talking about the criteria for Schools Plus to get assistance in education and teachers' assistants and whatever. We heard in Fitzroy anecdotal evidence that 25 per cent of the kids had some form of FASD, and the teachers were throwing their hands up but they did not qualify under Schools Plus. A lot of the diagnostic issues were before the age of six, so if you miss the boat there, that was it and you were stuck with this kid who was seven years ago and obviously FASD, but there was no ability under Schools Plus because there was no recognition of the condition.

Dr Bower: Recognising the diagnosis as a reason for having support would be absolutely excellent.

Dr G.G. JACOBS: That is why I was very encouraged by the diagnostic tool. I came in on this committee because of my interest in the fact that the experience there was that there was this potentially significant cohort of kids who were not getting any extra educational assistance that they needed because no-one knew what they were dealing with.

Dr Bower: They were being naughty.

The CHAIR: On our last trip to the Pilbara and the Kimberley, FASD came up again very much in some communities as a larger problem than in other communities. The other thing that really shocked some of us—I do not think I was the only person—was the extent of hearing problems. When you combine the two, you think, "What hope is there?" Could I ask you, through the work of the institute, to talk to us a little bit about hearing problems in general and then hearing problems with FASD?

Dr Bower: I cannot say very much because I do not know very much. There is a group in the institute, though, that has done a whole lot of work on hearing problems in a big project in Kalgoorlie of Aboriginal and non-Aboriginal children. There is a very high rate of ear infections and subsequent hearing loss. So that might be a good source of information.

The CHAIR: They came and presented at Parliament last week. Graham was there. I think you missed it, Peter.

Dr Bower: Because the conference was on the week before.

The CHAIR: It was an excellent presentation.

Dr G.G. JACOBS: Yes, it was.

Dr Bower: Yes; it is great work.

The CHAIR: What about FASD and hearing problems combined?

Dr Bower: It is said, is it not, that hearing loss at least can be associated with FASD? I am not sure of the basis of that—if it is a neurological thing or if it is just because they are more likely to have infections. Do you know?

Dr Watkins: I do not.

Dr Bower: We do not know. Particularly in Aboriginal communities, ear disease is very common, but in any population the combination of hearing loss from any sort of ear disease plus having foetal alcohol spectrum disorder is not going to be better for you; that is for sure. And it may make how the child is able to function a whole lot worse.

The CHAIR: The model of care—we have seen the document and I think most of us have a copy of that document—was put together with support from the health department. What about the

Mental Health Commission? Is it involved now in FASD forums? Because of the relationship with alcohol, how involved is it now?

Dr Bower: I do not know. They may be.

The CHAIR: We might need to bring in the commissioner at some point and find out just what they are doing in relation to mental health.

Following on from Graham's points earlier, I remember as a child my mother was encouraged to drink either Guinness or stout. If they are a bit low on iron, they are encouraged to have one a day. I think when I was a student nurse we used to —

Mr P.B. WATSON: Drink stout!

The CHAIR: I think we used to put women on alcohol infusions if they went into premature labour. If I had a drink—I did have a drink—during pregnancy, I would always think, “I won't go into labour tonight if I have a glass.” That is just how it has changed. Although the evidence now for FAS has been there for 40 years, people are really only now becoming aware of FAS and FASD. We know that alcohol is the problem, but what are the other risk factors? Rochelle, you were saying that you have to look at people in their situation. We obviously think of malnutrition and housing. What are the other kinds of risk factors that you would see being associated with alcohol possibly then leading to women drinking and a child being born with FASD?

Dr Watkins: My only knowledge really comes from research in other countries; I am not really aware of it happening here. My interest in it is mainly due to our involvement in proposals to look at media campaigns to promote safer use or no use of alcohol in pregnancy. For me, it is awareness of vulnerable populations and abuse and particularly mental health problems. There is documentation of mental health issues basically coming before the alcohol use that is then associated with a FASD-affected child. There is definitely literature that looks at a lack of social support as a protective function and particularly economic and other occupational indicators as protective functions that clearly I think those people have. I wonder whether that is more indirect in that they are more able to secure services or have some hope of actually changing their situation or some of those predisposing factors. That is probably my main knowledge of it from US research.

[11.00 am]

In fact, maybe I could follow up. Just in response to your previous query about economic viability here, I find some of the evidence coming out of the US fairly compelling in terms of economic viability. They are looking in the order of about 30 times cheaper to prevent a single case than actually treat one. The costs of prevention include diagnoses for about 18 cases in order to prevent one case. It also includes the support services for that identified user that is at risk of having another alcohol-affected child.

The CHAIR: That would be useful if you could forward on that information. As you saw from our terms of reference, this is one of our terms of reference. Any assistance you are able to give us would be very much appreciated.

Dr Watkins: Okay, I will forward that on. I find that really useful even though it is not local. We do not have the ability; we do not have the resources. I suppose that is the other side of that issue for me; the impetus to set up those specialist clinics to not only diagnose, but also have the resources to investigate, develop interventions, find out what works and what is feasible in the health system.

The CHAIR: Then do an annual check to make sure that people are tracking.

Dr Watkins: That is right; exactly. Also, from the social perceptions issue and influencing what are the standards here—how are we going to influence the wider community—it is pretty valuable.

The CHAIR: I might give you now both a couple of minutes to summarise. If there are questions that we have not asked that you have thought about while we have had discussions, either please

bring them to our attention now, or when I do the summing up I will say, “We will accept supplementary information” in which case can you go away and if there are other things you think of then, please send that information to us.

Dr Bower: I am not sure that there is very much more that I want to add. I think it is great that there is an inquiry into this. There is not an easy fix. It affects a lot of different aspects of health and well beyond health and even well beyond education. But I think we still very strongly feel that it is very important to be able to diagnose this condition, because then we will know how big the problem is; we will actually be able to hang our hat on offering management that is appropriate to the child and the family that, we hope, will improve a lot of affected children and families, and raise awareness so that we can encourage women not to drink alcohol in pregnancy and reduce the risk. That all requires a lot of not just goodwill, as you say, but it does require funding and it needs to fit within services that are already available. We know that there is a limitation on all sorts of developmental assessments in childhood and this is just one of those. It is quite complex and it does require a multidisciplinary approach to the diagnoses, and that really requires funding. You can have the best diagnostic instrument in the world, but unless you are able to put it into practice and be able to offer something to the children who are diagnosed, there is not much point, actually, I suppose. But you do need to start somewhere and that is where we can start.

Dr Watkins: The only thing I would like to add to that is, clearly, you have had a fairly good exposure to the Canadian system and that is pretty impressive from my knowledge of it from afar. I noticed you referred to earlier that they were trying to harmonise their approaches at their different centres. From what I see, that is where, hopefully, our approach might be a little different, because rather than producing a guideline, we are hopefully going to produce the tools to get it running on the ground and facilitate that common standard and common data for improving research.

Dr Bower: Common notification. We would like to have a little app on the phone that you could use. Perhaps, ultimately, electronically the diagnosis could be notified to a central depository.

Mr P.B. WATSON: Would you use social networking and things like that to get the message out to young people?

Dr Bower: I think anything is worth a try.

The CHAIR: Thank you both 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 your corrections and the sense of your evidence cannot be altered. However, should you wish to provide additional information or elaborate on particular points, we would appreciate you including a supplementary submission for the committee’s consideration when you return your corrected transcript of evidence.

Again, if I can remind you that we are hoping to table this report in August, so please keep us in the loop. If we could receive those previous reports with your findings so we can look at those when we are making our recommendations, that would be very useful.

Hearing concluded at 11.06 am
