

**EDUCATION AND HEALTH  
STANDING COMMITTEE**

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

**TRANSCRIPT OF EVIDENCE  
TAKEN AT PERTH  
WEDNESDAY, 9 MAY 2012**

**SESSION FOUR**

**Members**

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

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**Hearing commenced at 3.23 pm****FITZPATRICK, DR JAMES****Paediatric Doctor, The George Institute for Global Health, 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; next to me, Peter Watson; and then Lisa Baker next to him; and our secretariat, Brian Gordon and Lucy Roberts; and from Hansard we have Caroline. The Education and Health Standing Committee is a committee of the Legislative Assembly of Parliament. This hearing is a formal procedure of Parliament and therefore commands the same respect given to proceedings in the house. 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 the questions we have for you today, I need to check whether you have completed the “Details of Witness” form.

**Dr Fitzpatrick:** Yes.

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

**Dr Fitzpatrick:** Yes, I do.

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

**Dr Fitzpatrick:** Yes, I did.

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

**Dr Fitzpatrick:** No.

**The CHAIR:** In that case, would you please state the capacity in which you appear before the committee?

**Dr Fitzpatrick:** I am appearing before the committee today in my capacity as a clinician and researcher with interest and expertise in foetal alcohol spectrum disorders.

**The CHAIR:** Thank you. Before we start, sadly Peter will have to leave us at four o’clock—he will just slip out quietly—and Brian may also have to leave just before the end of the hearing, so our apologies for that now. We have a lot of questions for you, but, before we start asking questions, you have been involved with the Fitzroy Valley project. Can you tell us how you came to be involved with that project and maybe just give us some background first?

**Dr Fitzpatrick:** Yes. First of all, thank you for this opportunity. I appreciate it, and the people that I work with and represent really appreciate us having this voice also. I will respond to your request for background about the work in the Fitzroy Valley, and then, if I am able to, just provide a brief overview of the activities that I am involved with that touch on a number of the terms of reference other than FASD.

Firstly, my involvement in foetal alcohol spectrum disorders began in 2008. I was working as a paediatric senior registrar in Fitzroy Crossing, in the Kimberley and I saw a young boy who was 16 months old, could not yet walk, only had one word, and had abnormal facial features. I spoke with his mother about the pregnancy and alcohol use in pregnancy and understood that he had been heavily exposed. He was the first child that I had seen with foetal alcohol syndrome. So I made that

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diagnosis and telephoned around Fitzroy Crossing to find out what we could do for these kids and what support was available, and it turned out that there was very little knowledge and certainly no support. I spoke with a woman named June Oscar, who is the CEO of the Women's Resource Centre up there, and June organised for me to meet with some elders in the community to discuss FASD and what the community might do about it. The community had introduced alcohol restrictions the previous year, in 2007, so they had some breathing space from this chronic over-use of alcohol, and the women had noticed that the children looked different and many of them had trouble with their learning and development and behaviour. So I became involved with that group of senior women in preparing a strategy, which we call the Marulu strategy. Marulu is a Bunubu word meaning "precious" or "worth nurturing". The aims of that strategy were to overcome foetal alcohol spectrum disorders in the Fitzroy Valley. We knew that it was a very complex problem, but that in that context we needed multiple, simple solutions. So we attacked the problem from a number of angles.

The first thing that the community had done was environmental, when they brought in the alcohol restrictions so that it was less likely that women would drink at high risk levels in pregnancy. The second thing we did was organise an awareness raising and prevention campaign through Nindilingarri Cultural Health Services—the spelling of that service I will have in a document that I will leave at the end of the day. Third, we wanted to diagnose and figure out the size of this problem, so we engaged the University of Sydney and The George Institute for Global Health, where there is a pre-existing relationship with the valley, to arrange a high-quality prevalence study, which we have called the Lililwan project. Fourth, we were concerned to support the children who were affected in their school and home environment and also to support their carers and families. So we have developed management strategies for kids who are affected in school and at home, and we are now in the process of developing a FASD unit, called the Marulu unit, in the Fitzroy Valley. So that is a summary of my involvement.

**The CHAIR:** Will that be a diagnostic unit?

**Dr Fitzpatrick:** It will not be specifically. We are developing a diagnostic capacity, and I will speak to that and read a document relating to that. We have developed a clinical model that we believe is gold standard. It is an interdisciplinary assessment model largely based in schools. We have recently—"we" being the Kimberley paediatric service, Notre Dame University and the University of Western Australia—received a grant to pilot this diagnostic service in the Fitzroy Valley. It will have a broader ring to it than just FASD diagnosis, but it will be the first diagnostic service up there.

**The CHAIR:** When is that likely to commence?

**Dr Fitzpatrick:** It is a private donation, so it is likely to happen quickly. We hope that the agreement to fund comes through in June, and we probably will have somebody on the ground coordinating clinics towards the end of this year. I will just make a statement that that work is part of service delivery in the Kimberley, owned and run by Western Australian organisations. I have been working with Sydney-based organisations for some time, with good effect, but we feel the need to have what happens from now on based and run in WA.

**The CHAIR:** I was asking that because we are hoping to table a report on FASD possibly in August, and I am wondering whether there would be an opportunity for us to see that. I certainly would be interested in seeing the different health professionals working together to come up with that diagnostic team, because it sounds as though a diagnostic team is the way to go. That is from what we have been hearing, and we are going to present that as part of our report. But it is obviously easier to present something that we have seen first-hand than something that we have just heard about.

**Dr Fitzpatrick:** Absolutely. If we are up and running, you would be very welcome to come and observe; if we not, I can talk you through what it would look like. I have some video footage from

the Lililwan project where we videoed the speech therapist, the paediatrician and all of the other health teams, so we can give you that experience. That is very much the way to go, not just for FASD diagnosis but for all child health assessments.

**Mr P.B. WATSON:** What is the likely IQ of a FASD child? In WA and federally, what is the IQ cut-off point for disability benefits—is it, say, an IQ of 85? Could FASD children qualify for benefits on the basis of low adaptive scores, regardless of IQ?

**Dr Fitzpatrick:** Thank you for those questions. A study in the United States looking at a large cohort of children and adults with foetal alcohol spectrum disorders found the range of IQ to be between 60, which is profound intellectual impairment, and 106, which is just above average, 100 being an average IQ. So there is a wide range. I actually cannot remember what the average IQ in that population was, but I believe it was above 70. I know, moving on to your second question, that the Schools Plus funding, for instance, can only be accessed if the child is shown to have an IQ of less than 70. So there is this line in the sand of 70 that enables or precludes kids from receiving assistance in school. We do not think that is a subtle or a finessed enough assessment, because you can have a child with very low adaptive function, as you have asked in your third question, whose IQ is in the 70s or 80s or 90s. The Independent Schools Association I believe will be making a move soon—actually, it might be across the board, but certainly in the independent schools—for a lower adaptive function score, such as on a Vinelands adaptive behaviour scale, to be enough to make a child eligible for in-school assistance. One of the things I strongly recommend is that we are able to move away from this magic number of 70 as being the IQ that —

[3.30 pm]

**The CHAIR:** At the conference we went to, rather than moving away, they are saying that 70 was too low, but in some sessions I went to they are now thinking about 75, which still does not solve the problem, because there are some children who are going to be 95, who will need just as much attention as someone who has an IQ of 70 or 75. Lililwann

**Dr Fitzpatrick:** Certainly back to Peter's question about the range of IQs, in the Lililwan prevalence study in the Fitzroy Valley, which was among 98 per cent Aboriginal kids, we had only two children, from memory, whose IQ was less than 70 on our assessment. We would expect Indigenous kids to do poorly on the types of assessment we used because they are not made for Indigenous kids. That was a real bind for us because we felt there were far more kids than that who needed assistance but only two out of 108 we saw had an IQ of less than 70.

**The CHAIR:** Of the 108 you saw, if IQ went out the window, we were told that DSM IV next year is likely to have an umbrella term for FASD—cognitive behavioural developmental delays. If that comes in, it will not be based on IQ, it will be based on that general assessment of the child. Was your prevalence study based on IQ below 70?

**Dr Fitzpatrick:** No.

**The CHAIR:** Good.

**Dr Fitzpatrick:** The IQ is just one part of the suite of indicators we need to make a diagnosis. A child can still have a diagnosis of foetal alcohol syndrome or one of the other foetal alcohol syndrome spectrum disorders and have a normal IQ. I might quickly outline the diagnostic features for, first of all, the umbrella of foetal alcohol spectrum disorders. Within that there are diagnoses: foetal alcohol syndrome, which is the more severe end of the spectrum; partial foetal alcohol syndrome; and what we call neuro-developmental disorder alcohol exposed. At the foetal alcohol syndrome end the child needs to have been exposed to alcohol, be small so have either been born small or not grown well as a child.

**Mr P.B. WATSON:** Pixie face?

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**Dr Fitzpatrick:** That is the next thing; exactly—the facial features. There are three specific facial features: small eye openings, smooth philtrum and a thin upper lip.

**Mr P.B. WATSON:** We were told when we were in the Kimberley that if the mother did not drink in the first trimester, those features would not show. Is that right?

**Dr Fitzpatrick:** It is not completely right; it is partly right. They are more likely to show in the first trimester of exposure because that is when a lot of these facial features are forming. However, lots of studies are done showing that kids exposed in the second or third trimesters can have the facial features. We also know that our accuracy of determining when the mother drinks is very low. Even if somebody says, “Look, I drank only in the third or second”, we cannot guarantee that they did not drink in the first.

**Mr P.B. WATSON:** Some of those children get put into other categories because they do not have the facial features and they go into ADHD and all the other spectrums that they could be put in. Is it a concern to try to pick it?

**Dr Fitzpatrick:** Yes, it is. I will quickly finish the diagnostic features and bring up things like ADHD. For foetal alcohol syndrome you need alcohol, growth, the face—all three features—and three learning or behavioural areas that are deficient. That might be bad memory, bad at speech and language and bad at executive functioning or planning. Get three of those and you get a diagnosis. If you have only two of those—two domains of impairment—you do not get a diagnosis in the FASD spectrum, because you are not considered to have neuro-developmental disorder. Foetal alcohol syndrome is the most severe; partial foetal alcohol syndrome is just the same as foetal alcohol syndrome, but you need only two facial features; and the third diagnosis, which is neuro-developmental disorder alcohol exposed, is where it is really tricky because you do not need any facial features; you do not need growth impairment; all you need is alcohol exposure and three or more domains of learning or behavioural impairment. ADHD comes into play then because it is counted as one of the domains. We have children with a FASD who also have ADHD and autism. It is not an either/or type picture. Those latter kids who do not have the facial features are very hard to pick up. In our study, for every one child with two or more facial features, there is another child with no facial features—from our data. Other data shows that for every child with facial features, you have another nine or 10 without facial features.

**Mr P.B. WATSON:** It is very hard to pick.

**Dr Fitzpatrick:** It is, yes.

**The CHAIR:** There are no figures for the percentage of children who have been diagnosed as ADHD who might be FASD?

**Dr Fitzpatrick:** I cannot quote the numbers because I cannot remember them, but studies have been done that have looked at all the kids who have been definitely diagnosed with FASD, who also have ADHD. I think it is in the vicinity of 30 per cent—about a third of kids with FASD also have ADHD, because the alcohol targets part of the brain that is responsible for staying still, listening, focusing and paying attention. If that is damaged, these kids will have all sorts of attention problems that we then call ADHD.

**The CHAIR:** Did you mention autism?

**Dr Fitzpatrick:** Yes; autism is another sort of co-diagnosis sometimes. For some kids who have autism and who are heavily alcohol exposed, you cannot guarantee that it is likely that the alcohol exposure has contributed to the autism symptoms.

**Mr P.B. WATSON:** Can you get the symptoms of FASD without alcohol being involved?

**Dr Fitzpatrick:** That is a good question. You can definitely get all the learning and behavioural problems. There are all sorts of causes for those. With specific facial features there are a few rare conditions. One is called Williams syndrome, another one is called fragile X and another one is

exposure to anti-epileptic medicines in pregnancy; they can cause similar facial features. We always make sure that we tease out those in the diagnostic process, but alcohol is very specifically linked to small eyes, smooth philtrum and thin upper lip.

**The CHAIR:** We might ask you to carry on a bit, because we know you want to present, then we will come back to a few more questions?

**Dr Fitzpatrick:** Thank you. I will take probably less than five minutes to address the terms of reference. Firstly, looking at current and future resourcing of new methods and activities to improve educational outcomes, the first I alluded to previously is an initiative we are beginning in the Kimberley that we have called the Kimberley paediatric and child health school outreach service. I will leave a document relating to that with you. It involves bringing health professionals in an allied health and paediatric team as an interdisciplinary team to schools in remote communities in this instance, where children are assessed based on the priorities of the teachers and parents. Kids doing poorly in school would come first to the clinic. The child would be seen ideally on the same day or consecutive days by the allied health team, and that team meeting to discuss the child, taking into account input from the teachers, who often know how these kids do in challenging environments or situations, and then develop a management plan that makes sense to the teachers and that they can do in the school and that makes sense to the family. We bring the family into this model as well and it will be something that the family can go on with at home. It might be simple things such as helping the child with an activity planning chart or a visual diary or something like that. Therefore, we are seeing the kids that the parents and teachers are most worried about and we are developing plans that can be used for the child in the school environment and seamlessly transition into the home environment. It is a new way of doing things. We have some private funding to start that off and will, hopefully, prove it is a model that is efficient and effective and that the schools and communities want.

[3.45 pm]

**The CHAIR:** Is there state or federal funding going into that or is it all private funding?

**Dr Fitzpatrick:** The state will contribute through paediatricians who are based in the Kimberley who are partaking, with Allied Health being involved in the clinic. We are not building a new clinical team; we are providing a clinical researcher to coordinate this clinical model. We have not approached the states or the federal government for funding in regard to this as yet.

**Mr P.B. WATSON:** How early can you pick it up in kids?

**Dr Fitzpatrick:** Very early. With some kids you can see the facial features at birth. If they are small and have a small head and they are alcohol exposed, then you could make a diagnosis. The average age of diagnosis I believe is seven, and it is usually when kids go to school. In one cohort it was shown to be seven, and it is usually when they go to school and they are having trouble. Another study found an average age of diagnosis in their cohort as three years of age; so that is where they are more aware and looking more actively for it. But childhood is the most common time of diagnosis; and the facial features can look more pronounced in childhood than they did in infancy or will later in adulthood.

**The CHAIR:** Is it likely to be picked up at the three-year-old check, if children are having that?

**Dr Fitzpatrick:** If people are looking for it. I do not want to get off track, but the maternity notification forms do not have a tick box for alcohol use in pregnancy at this stage. I do not think it is on people's radars. That can change. That is easy to change, and it needs to change. Just moving on quickly to the second term of reference—the factors influencing positive or negative childhood development from birth to year 12—there is obviously foetal alcohol spectrum disorder, which we will talk about more in detail. Another initiative that I am personally involved with is an outback youth mentoring program called True Blue Dreaming, where we link year 9 students generally with an inspirational mentor from a university, such as Notre Dame University in Broome or UWA—

St Georges College provide mentors—and they engage in a one-on-one mentoring relationship for a year.

**The CHAIR:** Is that for students at risk?

**Dr Fitzpatrick:** Including students at risk, and certainly in the wheatbelt, where we run it, kids at risk are referred. We are just starting up in Derby, so there will be kids from the Mowanjam community involved. But we do not want to brand it amongst youth as a program for kids at risk, so we want to include them but also include kids who are not necessarily at risk. But most kids in outback communities are at risk, and it is an outback mentoring program. On the other factors influencing positive or negative child development regarding FASD, I believe that alcohol exposure in utero is as severe as a baby being shaken, but we do not take it as seriously. We certainly take exposure to smoking seriously, and there is legislation now around protecting children from exposure to cigarette smoke; however, we have not done that for alcohol yet. My thought would be that legislating that if there is known alcohol exposure during pregnancy there could be some requirement on the mother to be involved in a social work-type support or a detox-type thing as happens in heroin addiction.

**The CHAIR:** In relation to that, again because we have just come back from the conference—we have not had an opportunity yet to report back to our fellow committee members—one of the things I thought was very good that we heard was happening in some of the provinces were the mentors they had. So an Aboriginal woman in her mid-30s who had had problems earlier was working with people. I also wondered what your opinion would be if the committee were to make a recommendation that in some areas where we know alcohol is a problem that we fund shelters. In the metropolitan area we have shelters for women who have suffered domestic violence. When you look at the economics of the cost of a child born with FASD, just on the family and community, do you think it would be a good investment for us as a committee to say that in those areas shelters should be funded so that the midwife, the GP or whoever first comes in contact with that pregnant person says to them, “Do you have a problem with alcohol yourself or are you living with family members where alcohol is a problem at home and, if so would you like to go to the shelter that is now in town where you could stay throughout your pregnancy?” They could have someone coming in and working with them. For example, in South Australia we were told that child health nurses provide 32 visits within two years to children at risk. So, have you heard of those types of shelters in those areas where there is a known problem with alcohol? Do you think that would be a good suggestion to come from us as a committee?

**Dr Fitzpatrick:** I do. I think the model might be taken up differently by different communities. I definitely think that offering shelter, whether it be a physical place to live or a community-based support network and intensive support for those really high at-risk people, which is a form of shelter without moving people from their homes, is warranted. The women who have kids with FAS are women whose husbands drink at home and women who are exposed to domestic violence et cetera; so, definitely, helping those women to get out of those environments is a good idea. In the Fitzroy Valley, such a support network is being developed. We are establishing the Marulu unit and we have applied to Lotterywest for seed funding to get that up and running. That will be based at the women’s resource centre; they do have a shelter right next to that centre. You touched on mentors and community midwives. The equivalent in the Fitzroy Valley context would be what we calling Marulu workers, who are local Aboriginal people trained up in FASD whose job it is to identify and support mums at risk or mums who have already got a child with FASD—who by the way are at high risk of having another child with FASD. We have a model ready that we are hoping is part funded, to establish exactly such a shelter. If things are really bad, as currently happens, women would come and live in the women’s refuge, which is right next to the women’s resource centre. It is a great idea. It really fits in with what is in this document, which is the “Lililwan Collaboration: Inquiry into Fetal Alcohol Spectrum Disorders (FASD) Submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs”. This documents a model in the Fitzroy

Valley called the collaborative circle of community care—there is a lot of alliteration—that essentially is about providing that kind of shelter or respite for those women who are at highest risk. I would say that the principle is fantastic. I also think it would work, and it has been shown to work in other countries. I know the key worker program in Canada, for instance. But what it looks like would have to be determined by the community.

**The CHAIR:** On a regional basis?

**Dr Fitzpatrick:** Yes, or even a community-by-community basis. What works in Fitzroy Crossing might not work in Halls Creek or Narrogin. The concept and the resourcing should be available, but what it looks like should be the community's call because that is what has made this project work in the Fitzroy Valley: the community has owned it and designed it.

**The CHAIR:** It is like someone taking out to the community: "This is the problem. These are the current options or you might like to come up with another alternative that you think would work in this area."

**Dr Fitzpatrick:** But have some guidelines around it that stipulated it was for pregnant women, women who may become pregnant or may be at risk of drinking in pregnancy, so to target it as FASD prevention, absolutely. Look there will be a model that is developed over the next 12 to 18 months in the Fitzroy Valley that could be taken as a model of promising practice.

**The CHAIR:** The work you have been doing there is world renowned now.

**Dr Fitzpatrick:** It is. Our team—minus me because I am getting married soon—is in the US.

**Mr P.B. WATSON:** You can still work after you get married!

**Dr Fitzpatrick:** Yes, but you cannot go to the United States eight weeks before your wedding! They are presenting to the United Nations this week, so it is very high profile. It is working.

**Mr P.B. WATSON:** Keep up the good work, and good luck for the wedding.

**Dr Fitzpatrick:** You too.

I have pretty much finished my introductory spiel, so maybe it is best to receive questions.

**The CHAIR:** You mentioned before that the cut-off point for funding for FASD, for schools plus, was often an IQ of less than 70. Can children with FASD qualify for other benefits? What if they do not have an IQ of less than 70? We were told by one school principal that he thought that 25 per cent of his students—in fact, it was in the Fitzroy Valley—possibly had FASD, and he could not get funding for them. What are the other mechanisms, because you have worked in the area, or what advice can you give us that we can put in our report for other people so that if they suspect a child may have FASD what should they be asking? Should they be asking their family doctor to refer them to a paediatrician to look up what-and-what so that funding can be made available to help those children?

**Dr Fitzpatrick:** I have thought of this a lot over the last couple of years working in the schools. I do not know if it was the Bayulu school principal who mentioned that to you. His a chap named Ken Molyneux; he is a wonderful guy. He is an Aboriginal bloke himself, a principal of a remote community school. He says that the most useful thing for him would be, not to have a special aide per child, because it is impractical and no government could afford that, but he said that if in the classes where he thought there were high rates of kids with FASD—which is all his classes; if there was at least one or maybe two Aboriginal education workers who could be part of that class and just help those kids with one-on-one assistance when they melted down and could not cope any more or sat in with a group of one or two or three kids who are struggling with the work and gave them a bit of assistance, then the teacher of that class could focus on educating all the kids to the level that they needed to be educated to, rather than putting out fires and, from the other kids point of view, being slowed down to the lowest common denominator of ability to function in class. My thought is

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that schools in communities where there is a prevalence of as FASD—I am not sure if you would say greater than 15 per cent, 10 per cent or five per cent—should be eligible for additional funding for these types of positions. That will solve the problem quickly, because we are not going to get an interdisciplinary team out to every school to see every kid that people are concerned about in the next five years. I believe where there is reasonable suspicion of high rates of FASD, these schools should be eligible for specific funding for exactly that purpose—to look after kids with special needs in the class. I do not think FASD is everything that happens out there. There are kids who were not exposed to alcohol who have high needs as well, but those kids are not being looked after. That is a general strategy. A specific one, I believe, would be, first of all, to build a diagnostic capacity. We already have doctors, nurses allied health professionals around the state; they need to be aware of FASD and know how to diagnose it and, importantly, know how to develop management plans for those kids in school and at home.

[4.00 pm]

So that needs to happen, and once we know which children do have FASD, I believe that if a child does have a diagnosis and has significant learning or behavioural problems that prevent them from getting ahead in class, even if their IQ is greater than 70, that they should be eligible for Schools Plus funding. It may already be happening with these changes to eligibility. I believe that relaxing the criteria from 70 to 75 will help all of those kids who just do not get there, but then having a second trigger for eligibility, as Peter mentioned, such as low scores on a scale of adaptive functioning, which means a child's ability to do their activities of daily living like dress themselves, shower themselves, and feed themselves, to sit and focus in a school environment, to stay out of trouble in a home environment; it is very broad, but it is a better snapshot of what that child is actually like than the IQ, which is just one of many assessments of a child's overall function. I think if there was an and/or trigger there, with the low IQ and/or the low adaptive functioning, then that would give clinicians the flexibility to get help to the kids who really need it but just do not meet our eligibility criteria.

**The CHAIR:** We also heard that the teachers are using—obviously not the depth that you as a specialist would use—questions that they can put, that they can tick, and then refer off to the GP or the paediatrician, so maybe tools like that could be used here for the teachers then to be able to say, “Well, X number of my students have failed this test,” and maybe we could use something like that as a start.

**Dr Fitzpatrick:** I think that is a great idea. We do not have a screening tool or a referral tool at the moment in Australia; a group of us at the Telethon Institute and around the country are working on a national diagnostic tool, but I think something like that. We could use a screening tool that has been validated in another country, and I know they are out there. We in the health in schools modelling in the Fitzroy Valley over the next few years should develop or adopt a referral process that teachers can use, and even community members can use, so if they are concerned, they refer this child for this interdisciplinary assessment, and then we actually have a team that can come and visit them, because that is the other team; the health service is inadequate to actually assess these kids. But what I would propose to the committee is that, once the Kimberley model of child health assessments in schools is established over the next six or 12 months, that there is additional funding allocated to pilot this model of FASD referral diagnosis and management. The private grant that we have, it is \$150 000 a year for three years, and it is money, but in the remote communities it does not go a long way, and it is only for three years, so we would really love to test it robustly, prove that it works, and then back to your point on prevention being a good investment with the women's shelters. Every child with FASD who is diagnosed early and receives intervention will—sorry; I have introduced this the wrong way. FASD, across the lifetime, leads to what we call secondary disabilities like trouble with the law, 60 per cent; mental health problems, 80 per cent; alcohol and drug abuse, 60 per cent or so; school failure, 60 per cent; sexual abuse or vulnerability in about 30 per cent. So we know that is where these kids are going if we do not diagnose and manage them

early, but if we do diagnose and manage them early, we can reduce those secondary outcomes twofold to fourfold, so it is very much worth the investment at the top of the cliff, with the prevention, such as those shelters, and early diagnosis and management, such as a diagnostic team that is actually powered to do what it needs to do.

**The CHAIR:** So this project that you have \$150 000 for over the next three years, is it confidential, or can you supply us with information about that so that we can get Brian and Lucy to look at it carefully and maybe give us a summary for that so that the committee could then consider making a recommendation for that?

**Dr Fitzpatrick:** Absolutely; it is not confidential, I have been singing it from the hills, and I will leave this document, which is our proposal to fund that. It is for that first clinical researcher position, and we could build something around that position that really made it a powerhouse.

**The CHAIR:** One of the other things I was a bit surprised by was that we were told that in Manitoba they now have opened a school—I cannot think of the name now—specifically for children with FASD. For lots of other children with disabilities, we used to have schools, and a decade ago the decision was made that it was not advantageous for those children, and to move those children into mainstream education. So it was surprising to hear that there is now a school in Manitoba purely for FASD children. Are you aware of the debate that has been going on as to, I guess, separation or amalgamation in relation to FASD?

**Dr Fitzpatrick:** No, I am not, and it surprises me that a school like that has been opened. Philosophically, it is not something that I support, and intellectually I cannot imagine it being the best way of doing things. In some of these remote-community schools, I think that is the ideal environment for these kinds of kids, because you have small classes and a teacher who knows the child, knows their family and knows their community, and particularly with the independent schools, where it is a community school, the community knows the business of the school. I think that that is a great model for supporting these kids, as long as the teachers are adequately supported with information on how to look after kids in school. Another thing I will leave is just a link to a document called “Teaching Students with FASD — Building Strengths, Creating Hope”, which is an Alberta province document. It is the one that our occupational therapist thinks is the best, so that is the one I would recommend. But no, I do not think the Manitoba model you have just proposed makes a lot of sense, but I am not an educationalist; you are.

**The CHAIR:** It makes more sense to me having children amalgamated in the schools, because then that child is part of the community. But at the conference I was not able to meet with anyone who was involved with that school to see what arguments they were putting up in terms of that type of model.

**Dr Fitzpatrick:** We have a wonderful psychologist with us named Heather Carmichael Olson, who is from Washington state. I think I forwarded details on to Brian. She worked with us for about five months during the project, and was very interested in interventions. Certainly, her mantra was keeping the kids in the mainstream environment, but making accommodations for them specifically so they could do well in that environment. There were simple things, like not having the walls too stimulating for the kids—not too many colours or pictures or words, so they are not distracted, and little time-outs. Some of these strategies, they are not rocket science and they are not super expensive, but we are just not using them, because people do not know about them. I am a big believer in quite simple and, where possible, inexpensive solutions to problems. I think what we are going to hopefully do with this position up in the Kimberley is to provide some of those intervention strategies for teachers and parents, and our plan is to measure the child’s functioning at the beginning of all this, and then a couple of years down the track. We have already got great baseline data from our study last year, and hopefully we will see some positive outcomes.

**The CHAIR:** The other thing I was going to ask about was the economics. This is an area that Lisa might be particularly interested in, given her background. We have read some papers. To start with,

we are a long way behind some of the things that are happening in Canada, because the University of Washington came up with a diagnosis and the fact that the Canadians have been using that diagnosis, so they have been able to get the funding. Because we do not have that diagnosis, there is no funding there, but we know from Canada that they would equate a child born with FASD to 10 new replacements or six cardiac operations. So, yes, we need that diagnosis, so I guess one question I am going to ask you in a minute is how far you have got. We heard about the diagnostic tool that went to the government when we went to South Australia at the end of last year, so that seems to have been sitting with whoever for a long time. We would like to know where that tool has got to, but going back to the economics, would we, as a committee, look at DRGs and then, say, from research that has been done in America and Canada, would we try to compare the value of the dollar here and the value of the dollar there and say, “They’ve said it’s six new replacements; the equivalent here would be this”? They said in Canada—I am not quite sure what the total population is—they had almost a million children diagnosed with FASD. We do not know what the figures are here, but at the federal committee hearing that Professor Elliott presented to in Sydney, it was interesting that the federal committee said, “Would this work?” and “This is a tsunami that is going to hit our healthcare system.” Could we maybe discuss a diagnostic tool? Whose tray is it sitting in, and why is it still sitting there? And then can we maybe discuss the economics? I believe that if we can put the economic argument, we would possibly be more likely to have the government consider putting funding in sooner rather than later.

**Dr Fitzpatrick:** First of all, the diagnostic tool. The history to that is that the Department of Health put out a tender for a group to develop a national screening and diagnostic tool for FASD in 2010. Myself and Liz Elliott are on that working group. Professor Carol Bower at the Telethon Institute is the chief investigator there; probably Carol and Liz are the two chief investigators. Carol has overseen a process where we have run a survey called the Adelphi process; we run the survey with Australian clinicians and consumers and international clinicians and consumers, looking at what they felt a diagnostic tool should look like, and we went through two rounds of that survey, and we have refined —

**The CHAIR:** So that is basically where you tick which things, and then back again, and tick which things again?

[4.15 pm]

**Dr Fitzpatrick:** Exactly, and it is just sort of bringing us to a point. The questions are quite focused and they try to get consensus around certain diagnostic features. That has taken a long time, as it should have, that process. What we have done, just in the last couple of weeks, is drafted a diagnostic tool and a brief guide to go with that diagnostic tool. We have not invented anything new in Australia; what we have pretty much done is got the University of Washington tool—Susan Astley’s tool—and the Canadian tool, and we have said, “Okay, in Australia we think ours should look sort of like this”, and it looks very much like both of them. It is nothing ground-breaking. But it has not yet been submitted to government, so Carol Bower—I believe she will be coming next week—will be the person to speak with. Raewyn Mutch and Amanda Wilkins are the other paediatricians working on that. I do not think it will be too far off. Carol will know exactly what is happening. Carol believes there is a new person driving things in Canberra on this project, and that they do not want to hold things up, whereas they have been held up in the past. That said, I could go out tomorrow with our team and diagnose FASD with kids, so I do not think things have to wait in Australia for us to have that, but when we do have the tool, we have to disseminate that quickly and have people educated about its use. That will take resources, and really the energising of the whole health service around the fact that FASD exists, that it is a big problem, and that they can feel comfortable diagnosing it. So that is the diagnostic tool.

As to the economics, the most recent paper I read, which was a US paper, I think it stated a figure of \$22 000 per year on average in educational and health supports for people anywhere on the FASD

spectrum. That will be a lot higher if you are in the foetal alcohol syndrome end of the spectrum. The lifetime cost was in the millions; I cannot remember the number so I am not going to state it, but I can forward through the paper. What I have done with those figures is looked at the prevalence numbers in Fitzroy Valley and just extrapolated how many people might be living with FASD in the whole Fitzroy Valley, and looked at what that is going to cost us per year; it is massive. Some other economic modelling has been done to show that for every case of FAS that you prevent, you save the health and education systems \$500 000. There are lots of different models out there, but all of them say it is a very expensive problem and that preventing it, or minimising its impact by early diagnosis, is a wise investment. I would be very happy to give you as much information as I can find on the economics of it, but there will be more out there that I have not seen.

**The CHAIR:** We actually brought back with us a book with a chapter on—I cannot remember; what was the economics group? Who were they? I have made contact with someone who specialises in that area. But when we do our FASD report, that is obviously a really important chapter.

**Dr Fitzpatrick:** Huge.

**The CHAIR:** Because that is going to help sell the prevention.

**Dr Fitzpatrick:** Absolutely.

**The CHAIR:** If we can show the government that this is the likely cost in five years, 10 years or 20 years, we might get funding.

**Dr Fitzpatrick:** Absolutely. They often do not take into account the justice system costs or the lost productivity, so there are other costs that are not picked up in some of that modelling.

**The CHAIR:** It was the Institute of Health Economics, Edmonton, Alberta, I think that we got the figures from. Could you tell us, then, where is the Lililwan project going to now?

**Dr Fitzpatrick:** The Lililwan project itself is the prevalence study, so measuring the size of the problem and providing specific management strategies to those children who participated in the study. The way I see it is that the Marulu strategy—the community strategy—is ongoing, and that a small but significant part of it is the Lililwan project. So our job in running the prevalence study was to find out the prevalence, which we have done. However, we are not able to release the data yet because that needs to go back to the community first, and then be published and submitted to inquiries and put into reports.

**The CHAIR:** When do you think that data is likely to be ready at a state that we can possibly use it as a committee?

**Dr Fitzpatrick:** I think July, and I think—is November the time that you need to —

**The CHAIR:** We are hoping to present our FASD in August.

**Dr Fitzpatrick:** Yes. So, look, I certainly hope that it is done by then, because it is my job to do it and I change jobs in August—I start at Princess Margaret hospital again—so I will be pushing for it. What I will say is that we expected, at the start of this study, that somewhere between 20 and 40 per cent of children would be affected by FASD, and our findings are likely to reflect that. Importantly, we have found a large number of children at the more severe end of the spectrum. As well as children with FASD in Fitzroy Valley, we have also found a large number of children with neurodevelopmental problems—so problems in three or more of those learning or behavioural domains—who were not exposed to alcohol. So it will be important to get the message about FASD out there, but also to make it clear that there are other causes for neurodevelopmental problems, and they need to be supported.

**The CHAIR:** Some of those other causes could be?

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**Dr Fitzpatrick:** One of them is, say, environmental stressors, so early malnutrition or abuse or neglect or chronic skin infections, lung infections, ear infections, domestic violence at home, food insecurity, losing your mother, losing your father—all of those environmental stressors—and we have found very high rates of those in this community. That kind of stress has a physiological effect; it can increase certain stress hormones and prevent the proper development of the brain. We have found that a lot of kids were exposed to early life trauma, so that is one cause. With a lot of it we do not know the cause, but then there are other things like syndromes—like Down's syndrome, fragile X et cetera—that are not more common in places like the Kimberley but still exist. Yes, for a lot of the problems with development an exact cause or factor cannot be found.

**The CHAIR:** Maybe we could go back to the hearing problems, because we were fortunate in that four members of the upper house last week put on a breakfast for members of Parliament specifically looking at hearing problems with children. We were then made aware that there had been a federal inquiry into that two years ago. Recently, when we went to the Kimberley and the Pilbara, we saw firsthand the sound boards and the microphones, and heard about the Auslan teachers, and what was suggested to us by Dr —

**Dr Fitzpatrick:** John Bolton?

**The CHAIR:** — John Bolton was that, particularly during the wet season, on a Monday morning all children in a school should have an ear check, and if they have glue ear, then they are treated with antibiotics for that week at school, and other members of the family, maybe, are then checked, and once they have had that diagnosis and treatment on two occasions they are referred to see an audiologist. Brian and I were fortunate to be sitting next to an ENT surgeon—a very dynamic young man. He was telling us that they had been considering maybe, if they could find funding—there is the bus up north at the moment that is doing hearing checks—they could have a mobile treatment unit that could go round and insert the grommets; he said it is a very quick procedure. He said for the ear infections, ideally it would be the school nurse, but if it was not the school nurse, providing they have the right equipment, someone could be trained to take the photos and telehealth could be used to zoom them down here to Perth to someone to have a look to say, “Yes, that is that; go ahead”, whatever. Do you agree with the proposition that maybe the school health nurse can do those checks and then treat with the antibiotics? Maybe we will look at supporting a mobile surgical caravan that goes around doing grommets, or do you have any other suggestions? Hearing is obviously such a big problem that has lifelong repercussions in terms of children falling behind and never catching up.

**Dr Fitzpatrick:** Absolutely. In our study we found around about 45 per cent of kids will have hearing impairment, and that has huge impacts on their ability to learn. I think one of the biggest, sort of, crises up there is this ongoing unsolved but solvable problem of chronic ear infections and hearing loss. What I will not do is speak about the value of grommets, because I do not know enough about it. I support two things you have just proposed; one is a mobile unit, like a drive in, drive out unit. That is how I ran our clinic last year. We drove into communities, we would stay sometimes for a week, get to know the place, get to know the community priorities, build rapport, work with the kids and the families, and then go on, and, ideally, we would come back. I think, out there, mobile services are a really good idea because kids from a community like Wangkatjungka—150 kilometres from Fitzroy—cannot get to Fitzroy to see the ear, nose and throat surgeon. I really believe you have to take the specialists to these kids. There are all sorts of mobile models, and I have thought very seriously about starting a business based on this because I know how to run teams in remote areas and I know it is more effective and efficient doing it that way. I think a mobile service is a good idea.

I think that having school nurses checking kids ears and aggressively treating with antibiotics, if that is warranted; antibiotics are not always indicated for all middle ear problems, but where they are, kids should get them. I am thinking of a model where we have aggressive screening—

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“aggressive” is a bad word—or very active screening of school-age kids, and on a Monday morning is a really good time, and treatment, and then you follow them up at end of the week. You should provide health education as well and encourage the breathe, blow, cough program, but you would need a trained workforce of school nurses to do that. Currently in Fitzroy Valley there is one school nurse and they very rarely get around everywhere to do this. But I think if you took this approach to ears and skin infections—so you have antibiotics that kill skin bugs and kill ear bugs—you screen kids maybe even once a month in a community and you aggressively treat all the kids who are infected, then you would not get the herd immunity, that is a vaccination term, but the carriage rate of these bugs would go down. It still does not fix the overcrowded living or chronic infection—well, it does fix chronic infections, but it does not fix the environmental problems that need to be fixed. But I think we need to do something as well, and that is to use antibiotics wisely but really proactively. All the kids I have seen in the last four years of working as a kids doctor up there, you see them and treat them once, but you do not get back to that place for eight weeks or nine weeks. The nurses are too flat out to be able to do it well and the GPs do not really do much kids health anyway, and the kid has gone for eight weeks, 12 weeks without having their ears treated. So I support both of those approaches. They would be hard to do, but I think it would be good bang for the buck. These are issues that do not need to be massaged or tickled away; they need to be slapped with a well-resourced, really proactive service that goes out, identifies the problem, deals with it, and comes back shortly thereafter and makes sure the problem is not there. If it is, then you deal with it again. Otherwise, these kids are just destined to fail at school and in every other challenge in life.

[4.30 pm]

**The CHAIR:** You said 40 per cent and we heard in some remote communities it can be much higher than that for some of the problems.

**Dr Fitzpatrick:** Yes, I am sure.

**Ms L.L. BAKER:** Do kids pick up any infections from the animals in the camps, like the prevalence of dogs?

**Dr Fitzpatrick:** Yes.

**Ms L.L. BAKER:** I have just been looking at some information on the subject—because I was just giving you a bit of time to check the next question—around the mobile clinics that are operated by the RSPCA in remote communities to sterilise dogs. That is a really good program too.

**Dr Fitzpatrick:** Yes. Look, I think any family is entitled to have a dog or 10 dogs if they want. But a good indicator of the health of an Aboriginal community, I think, is the health of the dogs there and if there are lots of really unhealthy dogs, then you can bet the kids are going to have all sorts of worms and all these general problems, so, yes, it is a problem.

**The CHAIR:** I think that is really interesting with the dogs and the worms. You said apart from hearing, there are skin problems. Before we come back to the questions that Brian wants to make sure I ask you, why are there so many skin problems? That was not something that I picked up while we were up there.

**Dr Fitzpatrick:** Skin disease is a huge problem in remote communities. The actual disease is generally often caused by scabies initially. The scabies mite sort of burrows in, breaks the skin and then we all have got bugs like staph aureus or streptococcus crawling all over our skin. Aboriginal kids happen to have heaps more crawling over their skin because they live in confined environments, do not often have the access or the routine of showering each day and certainly do not have the kind of uptightness about being spick-and-span that a lot of people in more advantaged communities have. So, there are a lot of bugs on the skin, a lot of breaks in the skin, through scabies or scratches or whatever, and then that causes a skin sore, which you would not think is that big a

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problem. But the problem with it is that the bug that causes the skin sore, particularly one called streptococcus, it releases a toxin that damages the heart and that causes rheumatic heart disease.

**The CHAIR:** That is why there is so much rheumatic heart disease up there!

**Dr Fitzpatrick:** Exactly—that is exactly why. It also damages the kidney, so it causes post-infectious kidney inflammation, which can then later in life lead to kidney failure. That is why you have got all these people dying of kidney failure and on dialysis. Healthy skin is a huge part of all of this. A mate of mine named Sam Prince who is a doctor and an entrepreneur started a group called One Disease at a Time in the Northern Territory. They are trying to eradicate scabies, which will be a huge advance. I would build on that and say that we need to be enthusiastically assessing kids' skin and preventing skin sores by giving out medicated soaps. There is one called Gamophen soap, which is really effective, and that just knocks out all of the bugs that are on your skin. We need to be treating skin sores early so that the heart and kidney problems do not occur. I believe that the role of the school nurse—I believe that if we had an army of nurses out there looking at kids' skin, ears, hearing, growth and general health, and able to make decisions, like they can in the Northern Territory with their CARPA guidelines, the standard treatment guidelines, that —

**The CHAIR:** Sorry, the —

**Dr Fitzpatrick:** The CARPA guidelines is a great standard treatment guideline that a doctor, a nurse, an Aboriginal health worker can use. But I think empowering nurses and Aboriginal health workers to do some of this front-line intervention would be really effective.

**The CHAIR:** We actually had the director general from education in this morning. She certainly was very supportive when we were discussing the hearing problems and school health nurses. It is a shame that we were not aware of the skin problems and some of the other things that you have just mentioned today, but we can certainly let her know about that because the funding currently comes from Health for the school health nurses. They are going to provide us the memorandum of understanding that they have and the formula that is used for the school health nurses.

That might be something that when we receive that the committee could possibly make a decision to send that to you so that you could have a look at that and then get back to us on what you think of that formula. You are aware of the number of schools in the community; have you ever put something together? I mean, if we would look and say there is a primary school of 200 students, if we had that pot of gold, is there something already written, or would maybe one of the researchers who are working with you be able to put to us by way of supplementary information for each school in the Kimberley, we believe that the school nurse on a weekly basis should do (1), (2), (3), (4), (5) and (6), and on a fortnightly basis the school nurse should do this, this, this, this and this. As you identify whatever those assessments are, if you were able to say if it is 200 children, these assessments, and you would anticipate it would take five minutes for this assessment, two minutes, so that we can put it together. It might be possible then for us to say that formula of one nurse to 200 students might be fine in the western suburbs, but from what we have heard in regional areas that should be one school nurse for 50 students or 40 students so that that school nurse can, over a weekly period, fortnightly period, whatever, play the following role to try and ensure that we are focusing on prevention rather than treatment.

**Dr Fitzpatrick:** Yes. I was not aware of that formula but it just makes complete sense that it needs to be adjusted for remoteness because it takes a school nurse a couple of hours to drive out to some of these communities or more in the wet season or she cannot get out there. So, I would be happy for myself and the group that I am working with to be approached to do that kind of work with you. What it would also do for us is allow us to develop a bit of a template for what we will use up in the Kimberley. It would be really useful if we were funded to do that and to work with existing school nurses because they are the people that have the knowledge on the ground. We could go to them and ask them what they would be capable of and really get an accurate model. We could start doing that. There is a bit of a timing imperative here, is there not, from your perspective?

**The CHAIR:** The report where we are talking about the role of the school health nurses we are hoping to table in October, so we have a bit more time for that role than we have for the FASD. We can possibly in relation to that we could ask the Minister for Health—obviously, when I say “we could ask”, Lisa and I unfortunately are not a quorum for a committee, so we would have to put it to the whole committee. Then if the committee are in agreement, we could write to the Minister for Health and ask for a list of all the school health nurses that are working in the Kimberley—because you are just Kimberley, rather than Pilbara—and say we have discussed this with you and would they be happy for us to pass their names on to you? Obviously, we would have to go through and make sure that it is all —

**Dr Fitzpatrick:** We would not need the names of all those school nurses. Through Pete’s team in Broome, we know most of the Kimberley ones anyway, so you would not have to take that step for us. I guess the thing we would need to do is make sure we have got the capacity to undertake that project because we would want to do it well and we will have one person trying to establish clinics and the like.

**The CHAIR:** If you were to take this back to your group—I am not sure what funding options there are available at the moment now, what grants are coming up—but if there was a grant you could put in for, we could certainly take it to the committee that we could maybe then put in a recommendation to go with your grant application and say how this would be very useful for us in terms of the inquiry.

**Dr Fitzpatrick:** Fantastic.

**The CHAIR:** We would have to put that to the other committee members. What do you think, Lisa?

**Ms L.L. BAKER:** If we are allowed to do that.

**The CHAIR:** Our PRO will check and see. If we are not able to do that as a committee, then some of us can write as members of Parliament or get other members of Parliament. If we cannot do it through the committee process, then we can try and do it on an individual basis.

**Dr Fitzpatrick:** Understood, and thank you; I think that would be very helpful.

**The CHAIR:** We are going to run out of time and I know you have to disappear. I have here from Brian, you stated that child health has traditionally operated in a hospital-based clinical model that is out of step with reality. I am not sure, we may have already discussed this, but what is the Indigenous reality and what is the preferred model?

**Dr Fitzpatrick:** Can you please repeat the first part of the question?

**The CHAIR:** Child health in the Kimberley has traditionally operated, I guess, out of the model that we had here with child development services and someone being referred to child development services. You actually said, this is a quote from you, that child health care in the Kimberley has traditionally operated in a hospital-based western clinical model and this model is out of step with the reality that children exist in. So, the question to you was: what is the Indigenous reality and what is the preferred model rather than the hospital-based model?

**Dr Fitzpatrick:** I can just speak of what I have observed working in the Indigenous space about the reality of access to child health services. The reality is that, particularly in remote communities, there is a very strong family unit and that child health needs to, where possible, involve as much of that family unit as they can, and also that there is a strong overlap between the family and school unit, particularly in the very remote communities. So, the child is this unit in the centre of a school, family and health sort of triangle. At the moment, what we try and do in health is to access this child in isolation from the family and the school and it does not work. The reasons it does not work are many, partly because we run our clinics in remote communities during school time. Many children are at school during school time and we are very poor at communicating to parents that we



need to see their child and what we need to see their child for, so we do not have a lot of kids coming to our clinics. Community members, parents especially, are very busy with other family and community concerns, living on or below the poverty line, so bringing a child to a health clinic does not fit into their way of spending their day; generally, it is not their highest priority. There is the problem and there is the reality.

[4.45 pm]

The other part of that problem is that the health service up there, the child health nurses are focused on an ear health program, an immunisation program or an eye health trachoma program. They are flat out just trying to tick those boxes and get them done, but they lose the whole child in that.

The last part of the problem is that a paediatrician might come out to a remote community one week; the next week the speech therapist and occupational therapist might drive out there and see the same child, not really knowing what the paediatrician has done because the letter dictation takes a while and we do not really communicate well within health—we communicate far worse with the teachers and educators who bear the brunt of these children's complex problems, or the child bears the brunt but the teachers interact with that. It is a fractured service with poor communication.

I believe a part of the solution is to bring health and education together. I have always believed that. I am not very advanced in my career but ever since I began, it made complete sense to me. We trialled that last year by taking our clinical team to schools, working with them and engaging family through the schools. We did a really good job for these kids. They received a more comprehensive assessment than I am sure they have ever received in their life. They received it in one or two days whereas the same service in Perth or Sydney would take months because you go to a physio one day, OT the next, paediatrician the next et cetera. We were able to really understand the child from their educational perspective and from the community and home perspective because we went to their communities, sat in their schools and ran our clinics there. We had the paediatrician talking to the speech therapist, talking to the psych, doing all of this together. That fits within the reality of kids in these communities. We proved that this model works last year with the Lililwan project. We have been working on it since 2008 when I was first out there. We started trying to cobble this together, but I think we really proved it in a very well-resourced model last year. We cannot expect the same resourcing to be available in every community ongoing. What we are piloting now, with the proposal I have tabled, is this new way of doing things—coordination and taking health to schools. It is not saying that we are excluding the community clinics or the community nurses; we are inviting them to come and be a part of it. As doctors, we are not going to sit in the clinic, which is remote from the school, and wonder why no-one turns up.

**The CHAIR:** You were talking very much then about a multi-disciplinary approach. You have given us many, many positive reasons for that type of approach. What are the current barriers to that approach continuing? If you can tell us what the current barriers are—is it funding, what else is it, so that we can maybe look at what those barriers are?

**Dr Fitzpatrick:** One of the barriers within health, in the Kimberley at least, the allied health professionals and community health nurses are managed through the Kimberley Population Health Unit. The Kimberley Population Health Unit currently has a culture that will not cooperate with this interdisciplinary model based in schools. An example of that, which I have heard from the senior regional paediatrician, John Bolton, is that the child health nurse has not been permitted by their manager to join in with the paediatric clinics, full stop, let alone with the clinics we are running in the school. That does not make sense to any of us, because surely the child health nurse and the paediatrician should work hand in hand.

**The CHAIR:** They should be working very closely together.

**Dr Fitzpatrick:** Yes. However, the child health nurse has been instructed when they are there—because it is a position that is not well filled and often it is a fly in, fly out person not well

acquainted with the community—to focus on their ear health program, their immunisation program or their eye health program rather than being part of a more holistic model that has the community members, the family and the child, at its centre; not the clinic at its centre. There is a local structural barrier.

Another barrier is obviously adequacy of services. In the Kimberley we have a huge rate of complex health problems including things like foetal alcohol spectrum disorders, hearing problems et cetera. We do not have the troops on the ground to address that, particularly in terms of allied health professionals who, I believe, along with nursing staff, are the most effective members of the non-acute health team which accounts for a lot of the problems in this area; also, paediatricians who are able to do outreach clinics across the vast expanse of the Kimberley. Currently we have three full-time paediatricians whose main role is to staff the hospital in Broome—now in Broome, it used to be in Derby—and to fly the sickest babies and children to Darwin or Perth for treatment and to take care of the sickest of the sick. They are the two problems: local culture and coordination and, secondly, funding.

Onto solutions: I believe in establishing a Kimberley paediatrics and child health outreach service that works with the existing health service—allied health professionals and community health nurses—but also has its own capacity with, say, a nurse practitioner who knows all of the children in a particular region and can manage the database and the timetabling of their treatment as well as access allied health specialists such as psychologists, school or child psychologists, who are as rare as hen's teeth up there. A Kimberley paediatrics outreach service with paediatricians, nurse practitioners, and access to those specialist services—not necessarily a whole suite of staff—that is well funded, can actually keep a track of who and where these kids are, what their problems are and make sure that we get on top of their problems. At the moment it is underfunded and it is disorganised. I think organising it with some but not huge amounts of additional funding can allow us to really close the gap in child health disparity in the Kimberley.

**The CHAIR:** I am not sure if you are aware, it was only brought to my attention recently, that one of the reasons you may not be getting assistance from various areas within health is because the federal funding that comes to the Kimberley and the Pilbara is based a little bit on the English model whereby there needs to be a percentage. I cannot think what test it might be for children but, say, for women it was Pap smears and they do not reach 80 per cent, they do not get funding. Hopefully we will find out more over the next few months through the hearings that there is some funding that is specifically related to some health areas in the Kimberley. If those areas do not reach their targets, they might lose millions from the federal government. The priority has been put on those areas rather than other areas. That might be something for you to start questioning your colleagues about. I am trying to think of the name of the health care services. The WACH services up there maybe are not giving you the assistance that you should be given because they are worried they will lose this funding elsewhere. Once we can identify where those areas are, then we can write to the federal government and say, "This model may fit in Victoria, South Australia and Queensland, but it does not fit in the Kimberley or in the Pilbara." The name just came to me. There was a report that I looked at last year, if you are going to be doing some work with the school health nurses. She is currently working in public health in the Pilbara. It is Margaret Abernethy. Her name might be worth remembering.

We had more questions for you. Could we write to you with the other questions?

**Dr Fitzpatrick:** Of course.

**The CHAIR:** In which case, could I give you a few minutes to sum up for now and point us to any areas that you think we need to go into. Then we will follow up with the questions we have not asked.

**Dr Fitzpatrick:** Thank you. The second last thing I will do is mention the plan with the True Blue Dreaming mentoring in schools. It was initially a youth suicide prevention model to give young

people hope and inspiration, and attach them to a mentor who could share their journey to have goals and achieve goals. We have continued with the model but have now aligned it with the Australian curriculum in some instances. We are going to market it to schools. Hopefully there will be take-up of this program. It is WA initiated and based. I really wanted to put that on your radar and put it there as an opportunity. We found in Looma that kids who had been involved in True Blue Dreaming, one of them is completing year 12 this year. That is something that does not happen often. Looma is a remote community in the Kimberley. We are hoping that is a trend that continues through mentoring. That is enough about mentoring.

The last thing I will leave you with—I will leave all of these documents—is “The Lililwan Collaboration” submission to the federal government’s inquiry into FASD. The main priorities that we identify in there, which apply nationally and at the state level are, firstly, a prevention strategy to develop and implement a national and statewide prevention strategy around FASD, learning from the successful lessons of the smoking campaigns, and intervention; that is, to evaluate the feasibility of this interdisciplinary model of diagnosis and management. We believe the interdisciplinary model of assessment is the gold standard. The model we will be piloting up in the Kimberley is a good model for delivering that in remote areas. The third priority is management. Currently the Marninwarntikura Women’s Resource Centre has developed a plan for a collaborative model of care within the community which would include things like sheltering women who are at high risk, and educating and supporting families affected by FASD. We believe that that model should be funded, and some of that funding should come from the state government. I know Colin Barnett was up in Fitzroy last week with the women at the women’s resource centre. I am sure they have mentioned that to him. I will leave it with those three main priorities. However, there is a lot more detail in our submission.

Again, I thank you so much for this opportunity. I feel like I have had a long time to talk about what I am passionate about. I also believe that there are solutions to these problems, that there is hope that we can overcome this problem. I have seen evidence of that in the Fitzroy Valley.

**The CHAIR:** We would like to congratulate you and the people you are working with for all the hard work you are putting in. We hope when we present our report, it may assist in some way with the work you are doing.

We would like to thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for the correction of minor errors. Any such corrections must be made and the transcript returned within 10 days from 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 via these corrections and the sense of your evidence cannot be altered. Should 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. Please do keep in touch. We very much appreciate an open dialogue so we can make sure that the report has some good recommendations. Thank you very much.

**Ms L.L. BAKER:** Congratulations for all the work you are doing. It is extraordinary.

**Dr Fitzpatrick:** Thank you.

**Hearing concluded at 5.00 pm**

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