

**EDUCATION AND HEALTH
STANDING COMMITTEE**

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

**TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
MONDAY, 9 JULY 2012**

SESSION ONE

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 9.28 am**MUTCH, DR RAEWYN****Paediatrician and Post-doctoral Fellow with the Alcohol and Pregnancy Research Group of the Telethon Institute for Child Health Research, examined:**

The CHAIR: On behalf of the Education and Health Standing Committee, I 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 and other members of the committee—Peter Abetz, Lisa Baker; and also our secretariat, Brian Gordon and Loraine Abernethie. From Hansard today we have got Melissa Pilkington and Heather Willan. The Education and Health Standing Committee is a committee of the Assembly of Parliament. This hearing is a formal procedure of Parliament and therefore commands the same respect given to proceedings in the house. As a public hearing, 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 ask have you completed the “Details of Witness” form?

Dr Mutch: Yes.

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

Dr Mutch: Yes.

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

Dr Mutch: Yes, I did.

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

Dr Mutch: No.

The CHAIR: In that case, could you please state your full name and the capacity in which you appear before the committee today?

Dr Mutch: My name is Raewyn Cheryl Mutch. I am a paediatrician and I appear here in my position at the Telethon Institute for Child Health Research, but I will be referencing my clinical understanding through my roles as a paediatrician working with refugees and as a paediatrician working in the child development service.

The CHAIR: Thank you so much for coming along this morning. I know that you have looked at our terms of reference and you are the expert in this area, so —

Dr Mutch: You have had lots of experts actually come and see you.

The CHAIR: We have, and gradually we are starting to put the bits of the jigsaw together. But there is still an awful lot of pieces out there, so we really appreciate your coming along today. We might give you the floor to discuss, I guess, the points that we want to look at with this inquiry, where you believe the strengths are in WA, where you believe the weaknesses are in WA and what maybe the government could be doing to try and address some of those weaknesses.

Dr Mutch: My strong belief is that interdisciplinary diagnosis of children forms the fulcrum or the hub for any strategy that you have around any child with a developmental disability actually, but specifically for FASD. If you have standardised interdisciplinary assessment of those children, you

then understand where they come from; you understand their family functioning, their social hierarchy, their postcode, their educational opportunities, their resources in the community. So if you are going to have people arguing about the biggest bang for their buck in prevention strategies, you have already identified quite clearly where those children have originated from. By having an interdisciplinary approach to seeing these children, you understand their individual jigsaw puzzles. When children are exposed to alcohol in utero, the knockout to their brain is specific for that child as mediated by the mother's nutritional state, by the mother's environment—whether it is stressful, whether she has been exposed to domestic violence—and her genetic precept for metabolising alcohol. There are many, many issues that come into how alcohol presents for the foetus. Then there are the issues that Colleen O'Leary has already explained to you about the timing, the dose and the exposure that give differential knockouts to different parts of the brain. Although ongoing, there may be exposures that are negative to optimal brain development; the child is born, learns its world differently from another child who may have been exposed to the same dose and timing but has a whole collection of other factors, so you need to see that child as an interdisciplinary team. The core to that process is looking at their adaptive skills, their sensory functioning and their neurocognitive profile. If you do not measure that for the child, then you cannot think that you could help them achieve optimal education and you cannot help to give them the therapy and the management that they individually require. You can apply generic models of therapy and generic models of intervention, but they will fail many of those children. You can apply generic educational adaptations, but they will fail many of those children because of the specificity of how their brain has been affected by the alcohol and therefore how they function. Therefore, if you are thinking about establishing something to make a difference in their health and their education, then I think you really have to look at how you diagnose them.

I read the submission that James has made, and I worked with James up in the Kimberley on that. There is a wonderful strength in meeting with the children, understanding them in the world that they come from, measuring the things that they are good at and then using those things that they are good at to try and optimise their ability to have a positive outcome in education. If those things that they are good at are utilised to maintain their adaptive skills, maintain their self-esteem, then you know that you will have a chance at perhaps redirecting them away from justice and other negative outcomes of substance use, suicidal ideation—all the other negative outcomes that you have been told about by many of the submissions you have already had. So I see diagnosis as the centre point of a wheel and all the other things that you want to achieve will be optimised if that is your core approach.

The CHAIR: So on to adaptive, that is both their social functioning, their behaviour and maybe physical as well?

Dr Mutch: It is more about their capacity to generalise learning from one environment to another, which they struggle with. It is more about their ability to get dressed in the morning. It is more about organisational skills. It is about breaking down tasks and problem solving. It is about comprehending instructions that may be delivered; of a six-step instruction, they might either take the first or the last instruction and not have taken the whole. So it is about managing your day. You think of the things that you did this morning to get out of the house; you may have showered, you may have put your clothes on the right way—the right side out, you remembered where your keys were or you remembered where the bus stop was. Some of those factors are not easily remembered for some children, depending on how the alcohol has affected them in utero.

The CHAIR: If we wanted to read up a bit more on kind of that adaptive area and what comes in with that adaptive area for FASD children, what is the best?

Dr Mutch: Probably you should look at some of the therapeutic interventions that have occurred. We have had in our state Heather Carmichael Olson, who James mentioned in his submission. I met Heather in Seattle in 2008. She is one of the principal authors for five studies that are published—I

am sorry, I cannot remember who put the five papers together—that are the five best studies of therapeutic intervention and management of these children. They have a common approach where they essentially encircle around the child. They have quite intensive therapy, between 60 and 90 minutes at a time, repeated over many, many weeks, and they will address within that treatment regime issues of adaptive skills. To understand adaptive behaviour, you need really good OTs. So, Heather Carmichael is a clin psych and her background is also speech. She worked with Tracy Jirikowic who is an OT up there and they worked at putting in a program called Families Moving Forward. That now has a life of its own. Families Moving Forward has been replicated in other similar studies where there may also be use of e-learning issues, which I see is one of your terms of reference. They use e-learning modalities to optimise outcome. But essentially it is that one-to-one intensive, prolonged time therapy and prolonged over-application, so 60 to 90 minutes over 10 to 11 weeks has outcomes that persist for three to six months, as long as the follow-up occurred.

The CHAIR: Those five studies that you mentioned, are they the basis for Families Moving Forward, or could we by way of supplementary information ask you to send us those five studies?

Dr Mutch: I will send you the review article about those five studies, but one of those studies is Families Moving Forward and you can access that. Heather has been in our state. She did not win any funding, which is why she was able to come out and help on the Lililwan project. I have an email from Heather saying that she would happily come back here and run teaching and training. She would be fantastic for school psych, she would be fantastic for OT, she would be fantastic for speech, she would be fantastic for foster parents—she has a wealth of knowledge and would be invaluable if you were serious about looking at the next step following diagnosis about management and intervention.

The CHAIR: Sorry, where did you say she was from?

Dr Mutch: Seattle, University of Washington.

The CHAIR: Because they developed the tool, did they not?

Dr Mutch: They did, yes.

The CHAIR: The initial diagnostic tool that is being used by Canada and modified —

Dr Mutch: Well, modified for Canada. We were utilising it here and it may be modified for the Australian —

The CHAIR: We are hoping —

Mr P. ABETZ: My understanding is that in Australia we still have not got a commonly agreed upon diagnostic tool yet for FASD, is that right?

Dr Mutch: But there is no commonly agreed diagnostic tool for the planet actually. Partly that reflects, I think, egos and research agendas. There are similarities. To Susan Astley's credit, she came into the field with a scientific background, so she came and worked with Sterling Clarren before he moved up to Canada. She looked at how Sterling was looking at a fruit bowl of children essentially—they were all different but they were all similar—and she helped him understand them in a more rigorous and subclassified way. The utility of her lip-philtrum guide is acknowledged by every single diagnostic code and now has some MRI findings to support the changes that you see in the lip philtrum. I know that has been explained to you and you have travelled and learnt all about that, but I can talk about it again if you want to.

The CHAIR: Maybe just give us your summary of that, because the more we hear it, the —

Dr Mutch: I have read what Colleen told you and I have read what James has told you and they are sort of on the same page. But if you think about the foetus as it forms, so egg, sperm, and then it sort of turns into a three-layered disc of cells, and then it starts to fold in on itself to make a tube. Then the top end of that tube is the head end of the tube and then that starts to form the brain and

the face. Essentially from the midline, posteriorly you have these buds—I think some of you have a medical background—of tissue that grow forward and form significant structures in the face. So if you look at my mouth, the bud that grows forward here for the upper lip is different to the bud that grows forward and forms the jaw and the lower part of the face. Up until about 10 weeks' gestation, that process is coming forward and then fusing in the midline. When you use the lip-philtrum guide, it is graded from one to five. There is lip-philtrum guide 1 and lip-philtrum guide 2. Lip-philtrum guide 1 essentially looks like a Caucasian and lip-philtrum guide 2 looks like African-American, but they should not be called that; they should be just called 1 and 2, because they have utility in East Asian communities as well and that has been proven, and they have also been utilised in South Africa. So they are labelled 1 to 5. Number 3 is considered normal. If you compared number 3 on lip-philtrum guide 2, which looks like the African-American, that looks significantly different to the number 3 on the Caucasian lip-philtrum guide, but that is considered normal. Two and 1 are sort of verging into Angelina Jolie territory, but 3 is considered normal. Four and 5 are where you start to see the changes, so you see the thinning out of the lip laterally and you see the thinning of the lip volume; there is a loss of lip volume overall. Then from cortical to rostral you see the change in, really, the midline architecture of the face; it smooths out, so you see a thinning of the upper lip philtrum and it thins down until it is just flat and then with that you also get elongation. So Susan Astley on her MRI study found a correlate and reduction of brain volume. If you look at some of the animal model studies by Kathy Sulik, which again do not necessarily equate to the human model, that shows the same reduction in architecture in the midface and the same reduction in brain volume and brain complexity.

The CHAIR: In which case, if someone has the full features for FAS, when they are developing those full features or when things are not developing normally so those FAS features are actually developing abnormally, at the same time is that when the damage is being done to the brain, or could you have their facial features and because it hits the 22 days or 66 days—whatever it is—could you still have a normal brain? Do the two go together?

Dr Mutch: You can get a long thin philtrum with other genetic problems. That has already been mentioned to your committee so they have mentioned some of the other genetic problems that can cause that; some of the other drug exposures like valproate and so on can cause those similar problems. In fact, there is a diverse range of genetic anomalies that can cause mimicking changes in the midface. What the other genetic changes do not cause is a reduction in palpebral fissure length, which is really the size of your eye opening. If you think about it, the eye is really an extension of the brain; it is like a bit of a brain on a stalk from the main brain itself. That is where you see a diminution in size which appears to be more specific to FASD.

[9.45 am]

The CHAIR: I know you have read through and we have heard it, but my background is nursing and nobody else has the medical background, so it is quite difficult from outside. We have to get on top of it so we make sure we put it right in our report to get it through to others. So we appreciate you going back to the building blocks.

Dr Mutch: Even if the external blocks have finished building and forming without any alcohol exposure, so they look essentially normal, the underlying brain continues to grow in complexity and grow in size and volume for the remainder of gestation, however long it is. Any alcohol exposure during the rest of pregnancy can cause change. The argument is about how much and how little and what is safe; we do not know what is safe, so none is best.

The CHAIR: We saw a DVD of a presentation by Jack Shonkoff who talked about how a child was born with billions of neurons and he showed if you shake a plant, all the branches going everywhere. He showed at birth and then at six weeks and then at three years. So, if a child has FASD, are they still born with all of those kinds of branches that come off?

Dr Mutch: Some of the studies say that you do actually damage some of the essential compounds. There are some studies that show that you damage the neurotransmitters like GABA and nitric oxide and some say that you damage the Purkinje cells. The Purkinje cells are like your architectural struts to a building. You need to lay down those cells. Then the other cells that do motor function, sensory function, kind of travel up the highway of the Purkinje cells and get to where they should be to then formally function. Some studies show Purkinje cells being knocked out. Again, many studies show different things. That is really because they are studying not the same thing. If we could have the same genetic children who have been exposed to the same psychosocial environments, the same nutritional environments and the same dose and timing of alcohol—which would be an unethical study to do, but it is kind of being done out of the Murdoch Childrens Research Institute—then looked at those children, then you would perhaps more rightly make comparisons about what is there and not there versus controls.

The CHAIR: They might still be born with the billions of neurons, but they have not got the connective pathways to activate those neurons; is that what you are saying?

Dr Mutch: My understanding is that there is damage and that damage may be in having fewer interneuron connections. It might be fewer neurotransmitters. It might just be fewer cells, but there are still cells there that do the same function, but there are just less of them. The changes are as different as the dose and timing.

The CHAIR: Once they have built with them—you are saying that the 60 to 90 minutes, if they have not got these connections to start with —

Dr Mutch: That is why it takes so long. If you and I decided to learn something on the violin, it might take me six weeks; it might take you four. I do not know how long it would take you. These children can learn. They can learn and they can generalise, but they do it much slower and it takes a lot more repetition. That too is important. Deb Evensen and Jan Lutke, who did the “8 Magic Keys”, talk about how you need to have the same language in all the environments that you are in. If you tell me “Do not open the door” and then you tell me, “Please shut that”, and then you tell me, “Could someone just close that?”, you have all asked me the exact same thing. You all understand that it has been the exact same thing, but a child with FASD would have heard three different instructions. So, if you want them to learn something, you need to repeat the same thing over and over again—the same language and intonation. If they learn visually, you need a reproduction of those visual instructions at home, by the toilet, at school. You have to have exactly the same language and/or pictures to maximise the capacity for learning, because they need 200 replications to learn a thing that you and I may only take 10 replications to learn.

The CHAIR: We have heard of schools in Canada for FASD children. Should we have schools for FASD children or should we have so many hours of intensive—someone in a general school who can take children with FASD away and work with them?

Dr Mutch: I think we should have something like the Washington state model where every school nearly has their own OT. That allows those kinds of training and care to be carried out by a professional trained in that area and then frees up the teachers to teach, rather than do crowd control or sensory stimulus input. When I was in Washington, once you diagnosed the children and then you went out to the school and fed the information to the team about what these children’s strengths are and what their limitations were, you knew you were feeding that information forward to a multidisciplinary team at the school. That is sort of along the lines of what James suggested for the remote committees to have that kind of allied health group available to schools—not something we expect our children to travel to. I have had several emails last week from schools where they are dealing with children who are literally tearing their hair out—children who have profound distress who may or may not have a FASD. Therefore, that model of care would assist all children who have developmental difficulties and/or behavioural difficulties.

The CHAIR: If you kind of hierarchy-wise —

Dr Mutch: For me, the key to these children is for them to be entitled to a neuropsychological profile at a much more advanced level than is available from a clinical psych who is commonly available to children from the Department of Education or less commonly available; sometimes there is only a psych. Because the elegance of testing that neuropsychological profiling provides really delineates what these children cannot do. Sometimes it can be a quite discreet knockout that trips them up in education and does not reveal itself until they get to year 7 or 8. That is the higher functioning ones; so, they appear to be chatty. They appear to understand, but they keep not doing that well in their exams. When they get to year 10 and they fail English, they cannot go on. It is those discreet knockouts that can have quite a profound effect on whether they are successful in schooling. That is in the high functioning children. Sometimes those discreet knockouts are not necessarily picked up by standardised testing that is applied by the school psychs.

The CHAIR: Is the neuropsychological profile the diagnosis for FASD. Is that what the FASD assessment does —

Dr Mutch: For me, it is the key to making your foetal alcohol spectrum disorder diagnosis. You are talking about a spectrum. You want to know how unable these children are. What is commonly agreed with all the diagnostic codes is if they have three domains of impairment—those domains might be motor function, memory and learning, adaptive skills or impulsivity, hyperactivity. Those are considered different domains. It might be physical with impaired growth, small head. If they have three of those domains affected, you would push them into having a neurobehavioural or neurodevelopmental disorder. Then, if there is positive or proof of alcohol exposure, that would be alcohol expose. Then, if there are clinical features, they are either partial or full FAS.

The CHAIR: Coming back to the neuropsychological profile, we talked with James and we met Elizabeth and we heard about the—and you were possibly part of the team that was camping, going from one area to another, diagnosing the children.

Dr Mutch: Heather Carmichael Olson, who is a clin psych, helped them with that study. She did quite detailed testing to work out what these children do. For some of them they look like they have short-term memory; it looks like it is there, but then you do digit span recall. So, I will say to you, “Say number 1, 3, 5”. You will say, “1, 3, 5”. “Say 2, 7, 8”. You will say “2, 7, 8”. I will ask you to repeat that back to me backwards; you might not be able to do that. That inability to do recall shows you the fallout between short term into long term and then your recall; that is about the executive function loop. Looking at them unpicks this executive function loop, which these children have damage in.

The CHAIR: You are saying that the clinical psych then, who is part of the diagnostic team, did the neuropsychological profile and then said one, two, three or four areas —

Dr Mutch: She is a really core part of the team. She or he can look at how the brain functions and thinks. The OT will look at the adaptive skills and the sensory drive in these children. That is where they blend in to having autistic-like behaviours where they are sensory seeking; they might be rolling across the desk or feeling textures or being really impulsive or distracted by lights. That is those kinds of autistic or ADHD-like behaviours that you see. They are really pushed by huge sensory drives. Tactile, visual, smell, pressure—those kinds of sensory aspects are really important to be measured in the children. You have the neuro psych, the adaptive OT component and then the next is the speech and language. They can be quite chatty but their actual receptive cognition can be impaired and therefore their expression, which might sound fine, can actually not be as fine as it sounds when you bring in the learning and memory. Those three areas are incredibly important to be understood.

The CHAIR: We have all accepted, listening, I think, to James and Elizabeth, that there needs to be a diagnostic team rather than someone seeing someone now and waiting for someone for eight months to see someone else. But what we do not have, which you have introduced us today, is—James spoke to us about some videos that we could look at of the team in action. But we do not

have—Brian might slap me on the hand in a minute and tell me that we do have, but I do not think that we have as part of this team the paediatrician is looking for this; the occupational therapist is looking for this and this; the speech therapist this, this and this. That would be useful to have that information for us to then put to the government why it cannot just be done by two or three people, but why we need that team approach.

Dr Mutch: If I am allowed to submit that later, I will ask my immediate colleagues and if not I could even ask Heather if you want her to submit what she thinks is optimal. She would be happy to do that. But I could ask my proximal colleagues what they think is important for diagnostic —

The CHAIR: That would be lovely. That gives us the rationale for saying why we need these team members to do this assessment.

Dr Mutch: Rachel Fellows, who is an OT that I have worked with, she has been up to Seattle and met and work with Tracy Jirikowic and she is fully trained in that. Mindy Horseman, a social worker that I worked with, she has been up to Ira Chasnoff in Chicago and has worked with some of the early baby stuff, so she has got good information around that. That was like another component that I have not actually got to yet—is the need to hold these families. Whether it is a birth mother or a foster mother, if you have a prolonged period of time to complete the diagnostic measures for any child going through that process irrespective of what their final diagnosis is, it is very, very stressful. If you are dealing with a family who still have dependency issues, that stress is likely to make it more difficult for them to be restrained in their use of whatever substances they are dependent on. You are adding to their stress irrespective of whether you are looking for FASD or anything else.

The CHAIR: Could I also ask then, first, what the professionals do to come up with whether they have got problems with motor, memory, adaptive. But then what we need is, once someone has been identified with one or two of these, or it might be three of these, what should they have here? So we are not just saying there needs to be a diagnostic team, but if this diagnostic team comes up with problems in one area, then that needs, maybe, six months or 12 months with an occupational therapist and someone else. If they have got two areas, it might mean that they need this. So that we are not just saying these children need to be diagnosed, but we are actually giving the government some indication of what treatment should be given for those areas to make sure that we are looking after those children so that right from the very beginning they are not just giving us money for the diagnostic team, but they appreciate that then every child who is diagnosed, depending on whether they have problems in one or more domains—you know, this domain—so we can say to them it is likely—we could then work out or we could leave it to them to work out the costing for those children.

Dr Mutch: For a heads up not diagnosing children and not treating them, you have already had estimates—you are looking at—or incarcerating some—\$500 000 or more per person. Any developmental disability that has caused a fixed brain injury, which we think is what alcohol does, is lifelong.

[10.00 am]

Dr Mutch: I think children go through important transition points. From my perspective, that detailed assessment of a child cannot be completed until they are six. That is more about the tools that are applied to understand how they think. We do not have tools to work out the cognitive capacity of a six-month-old. We have tools to see what they can and cannot do but not at that executive function complex level. It is about the age of six that we can really tease that out. That is really your entry point into school. You may have already been flagged by kindy and pre-kindy and been evicted from kindy and pre-kindy, which is happening, but really at that age you can really see what this child is good at and where they are really falling down, and what world they come from. What resources need to be put in? That cannot be forgotten. Again, it is not just about the mum or the foster mum, it is about their whole world.

The CHAIR: 24-hour care.

Dr Mutch: Yes; how long it is to get to school. Do they have mould in their bathroom; do they have air conditioning; is Homeswest about to evict them; are there three people sleeping in one bed?—that sort of thing. They are all really important factors. That is a transition point.

The next transition point is the exiting of primary to high school. The normal high school environment has so many changes. These children really struggle with an expectation to transition to different classrooms rather than be educated in a classroom. There are profound challenges in a high school environment, so really measuring them as they exit primary school would be a very important time. Again, to see what they can and cannot do and then, when they exit high school, what are their skills, if any; what are their addictions; what are their vulnerabilities that they are taking into the adult sphere; and what resources are available there?

Ms L.L. BAKER: Sorry to stop you, but I wanted to check on what you said, so I understand it. Basically the best point to have definitive neuropsychological testing would be at six years of age?

Dr Mutch: The first that you can do that.

Ms L.L. BAKER: Given the potential brain development, I am assuming that FASD would not put the brakes on brain development from birth —

Dr Mutch: Up until then, no.

Ms L.L. BAKER: There would still be a capacity to cause some sort of adaptive development in the brain between zero and six? How do we pick it up there?

Dr Mutch: That huge gap—that again comes back to: where is the source of these children? Again, that is about a whole society approach about how do we optimise the health and education of our children irrespective of whether we are talking about alcohol here. It is about a whole of society approach, which I am sure you completely understand. Already, we know there are children who are born from units where women are supported for their drug and alcohol dependence. The follow-up for those babies falls off at about three to six months. Who is following them up? How quickly are they plugged into child development services? When they are plugged into child development services, is there any recording about what their exposures are? There is some on the questionnaire, but not everything—alcohol has been absent from that. There is ample room within there for there to be OT input, and speech and language input. That is occurring anyway for children who come into child development services at that age, but if you are wanting to understand them completely, if you are querying whether alcohol is a component to this and therefore how has it affected them, you cannot really measure that until you can apply the more detailed testing. You can measure the sensory profile before then and you can look at their speech and language before then —

Ms L.L. BAKER: But not the executive function?

Dr Mutch: But not the executive function before then.

The CHAIR: Which really goes to the value about pushing for more child health nurses. It is a good thing that the federal government's framework for early childhood learning with better qualified personnel in play groups and kindergartens really comes into play —

Dr Mutch: The AEDI is really almost like a child behaviour checklist. You can go through and tweak that. Look at the LIFT model. They could just look at the LIFT before they lift it perhaps! It would be quite useful. If they had time, that would be very useful. We have mentioned that. I was trying to answer Janet's question about the transition points. I was trying to raise that to then answer your question. It was about treatments.

The CHAIR: Would it be 12 hours of OT, 15 hours of this —

Dr Mutch: Yes; quantum of time. The reason why I did not go straight in to answer that is I wanted you to see that this is a life-long continuum, that no formula really applies all the time.

Different interventions are required depending on what the hierarchy of need is for that person. For the little ones, it is probably really around their impulsivity–hyperactivity, their adaptive skills and optimising their capacity to learn and then generalise that learning from one environment to another. Those are the kinds of measures that you need to put in there. By the time they get to exiting primary school into high school those factors all still apply, but then there will be secondary and tertiary deficits. There will be self-esteem issues. There may be mood disorders and there may be substance use. There are other components that have come into the model that will change what needs to be done first. If a child is substance using, you might not be able to use stimulants anymore, if they have to go on stimulants, because you have to discontinue it. There is a whole different range of treatments. They may need OT input but that is not really their principal need at that point in time. It may be mentoring. It may be someone to bring out their resilient factor. Maybe other things are needed at that stage even though ongoing help with sensory profiles, ongoing help with messaging and learning is still needed. There is layer upon layer of difficulty at those points.

The CHAIR: When a child is identified after the diagnosis at age six with FASD, and the child may need then several health professionals looking after them—who is best? If we were going to make a recommendation, who would we best recommend has case management of that child from age six to 18 to make sure that the checks and balances are being done at the right areas? We went to the Canadian conference. There, the late teenagers had mentor caseworkers working with them. Do we need a separate health professional for FASD children or do we say that the OT who comes on board when a child is this age, or could it be one of several health professionals but that health professional, if they are willing to take over responsibility for that child, they are funded so much per year, caseload wise, to follow those children wherever they go? Where are the checks and balances? How do we try to get those put in so that from diagnosis at age six onwards someone is following through with that child?

Dr Mutch: I think rather than “somebody”, there should be “something” that follows that child, like a more detailed health record that follows that child. That therefore overcomes staff leaving, and dying, and babies—maternity leave. There are complexities. It also overcomes the issue of remote and regional service delivery. Paediatricians spend their lives as air traffic controllers. We diagnose the children. We are really meant to hold them and see if all the people who should be involved in this child’s care are doing their job. We advocate—we write to schools, we liaise with our colleagues, we remember to do a blood test. Highly skilled community nurses equally do remarkable jobs with the refugee children that I see. They hold them, they get them to appointments; they really fulfil the role of a carer. I do not think GPs have the time. I do not think they are paid to have the time to do that. If you were going to make it “a” person, I am not sure; but if they had an electronic health record, there could be checks and balances in that, the same as we have for the vaccination schedule, “You’ve missed your four-year vaccines; you need to have that done.” For these children who have complex developmental disabilities, “You are really due for another psych profile, you need another psych test”, or, “We need to get the OT to meet with your teacher”, those sorts of things.

The CHAIR: Is it then child development services in WA? I do not think we have enough paediatricians to give you the added —

Dr Mutch: The people that I have worked with in the child development service, the allied health staff, are remarkable human beings. I see a lot of parallels between the refugee children that I see and the children that come through our door in the child development service. It is a different kind of war zone they are living in, but it is like a war zone they are living in. There are enormous needs that children and families in our community are facing. I see people who I work with go above and beyond what their job description is, trying to meet these needs. It is always not enough because the needs are so profound; therefore that then pushes back into a whole of society responsibility. As a society, can we conscience alcohol advertising at sporting events? Can we walk into a theatre at the Burswood Casino and see every single ad around the door of that targeting women in their child-

bearing years? Can we tolerate Facebook that allows young people to make jokes about their misuse of vodka? There are layer upon layer that we as a society take as normal. Should it be normal anymore? The feed-forward effect is quite profound. That is a much bigger debate, but it is a very important debate about how we meet the needs of children for health. If we optimise the health of a child, the psychosocial mental health of the child, the material needs of the child, then they have a chance to learn, they have a chance to be taught, and then they have a chance for a different life. We are pushing into education. We are expecting our teachers to do too much. They are teachers. They could teach beautifully if we could help our children be healthy, if we could help their family environment be healthy. There is enormous need.

The CHAIR: I am still coming back to you in terms of: we want a team, and you are going to give us the rationale for different people on that team. Hopefully you are going to give us the rationale, once you have spoken to people in terms of one or more domain, the type of support that might be needed, and then to be reviewed every six to 12 months. With that type of support and renewal, who is going to monitor that? We have the Telethon Institute, we have child development services, we have Notre Dame university saying that they would like to be the key research centre for FASD. It could be that we give the government three suggestions: that they either look at Notre Dame or they look at Telethon or look at that, but we are asking you —

Dr Mutch: Ideally, first of all you need “a” team in WA. You do not have a team. Ideally, it should be linked with universities. If it was out of TICHR, that is linked with UWA; if it is out of Notre Dame, it is Notre Dame. It does not really matter where it is housed, but if it could be linked across all campuses, including Edith Cowan, that would be a source of not only diagnosing children but a source of education. Like the Seattle model where occupational therapist students can come and sit in, nurses can come and sit in and teachers can come and sit in during the diagnostic process. They can learn and participate in it. They can learn standardised testing which they then take into their working life. That can feed forward and train teams for regional, and then that can feed form and train teams that might be sub-teams. OT, psych, and speech could be part of the mobile units. They need a place to learn first. There needs to be standardised application of what we do so that when we come up with a description of the child, I know that your description has meaning to me because it has been applied in the same way. The Seattle model really is the best. They have a centre where people can come and learn, and stay and take it away with them. Then you feed forward.

The CHAIR: The Seattle model—is that the course that people do that is three and a half days?

Dr Mutch: The Seattle is the ongoing training that you can do to get your head around the University of Washington diagnostic code. If you want to complete it, you go up there and spend time there. I have been up there, Amanda Watkins has been up there. She is a senior developmental paediatrician. She was actually heading up our FASD team, which we are not doing any more. Rachel Fellowes has been up there. It is a good place of learning. You are learning things that I think will help you apply to the Australian diagnostic tool as well.

Ms L.L. BAKER: Just to move on; I am conscious of the time. I am really interested in the work you have been doing around the judiciary and incarceration rates—did you look at recidivism as well as incarceration?

Dr Mutch: No, I have not looked at recidivism. This was simply a knowledge, attitudes and practice study. We have a core reference team which is police, head of foster care, a representative from NOFASARD and a representative from Youth Court.

[10.15 am]

They helped us design our questionnaire that we have sent out. We have sent it out to legal assistants. We have sent it out to police. The other one is currently sitting in the Department of the Attorney General’s office. It should have been completed by Easter. It is not; it is still sitting there just because of some problems. There is no obstruction; it has just been structural. We have had

Magistrate Horrigan and so on looking at the questionnaire. It was about to be sent out, but our key person went on holiday for three weeks. So, hopefully, it will be sent out in the next few weeks.

Ms L.L. BAKER: So you are actually inquiring into the attitudes of the judiciary.

Dr Mutch: The knowledge, attitudes and practice of people involved in law: “Do you understand what FAS or FASD is? If you do, does it make a difference with how you approach your client?” We have had to change the language depending on who we are talking to. Our language to police is different from our language to magistrates, which is different from our language to judges, but, essentially, we are asking the same things: “What do you know? If what you know, does it make a difference? Have you ever encountered any children or youth?” What is consistent is that even if they did, they have got no incentive to diagnose them.

Ms L.L. BAKER: In relation to what we are talking about—FASD and the judiciary and in courts and probably in the justice system in general—what data do you think needs to be collected that is currently not being collected; for instance, incarceration rates and recidivism?

Dr Mutch: Specifically for FASD you are asking?

Ms L.L. BAKER: Yes.

Dr Mutch: You may not know whether many of the children who come into custody have been alcohol exposed, so it will be hard to find that out. If you look at what Colleen has already told you, the women who are on the maternal and child database who have had an alcohol-related disorder, that is really only the tip of the iceberg of alcohol use in our community. There is no really available data to indicate have these youth been exposed to alcohol for a start. If you are inquiring about FASD and the youth, you are already on the back foot if you wanted to search data. If you have birth mothers or access to the records of the Department for Child Protection about what the world was like for that child, and you have a suspicion that there was alcohol exposure or proof that there was alcohol exposure, then they should be considered for a FASD diagnosis, and that is not happening at the moment.

Ms L.L. BAKER: So is there nothing that can be collected when, say, a child enters the juvenile justice system or looks like they might come into the justice system? Is there nothing that can be done at that point?

Dr Mutch: For the very young youth, especially when they go through adolescence and have pubertal changes to their face, you can do the facial photo for screening of their face. But once they go through pubertal changes, some of those structures can be hidden or less obvious. You probably need to speak to the people who work in the area. Mine was about knowledge, attitudes and practice with the judiciary. What has been clear from the reference group and what is clear from the questions that we have got back so far is even if we do know about it, we have nowhere to send these children for a confirmatory diagnosis. I have also been out and spoken to the clin psychs at Rangeview and Banksia Hill. They all came together one day and I gave them a talk about FASD. They are very aware of the fact that they have probably a lot of youth before them who have that, and, again, they have not been able to access diagnosis.

Ms L.L. BAKER: It would certainly restrict programs like the cognitive skills programs that prisons try to offer to juvenile offenders and to the senior offenders, would it not? There is not much point in giving a generic cog skills program to somebody in prison unless you actually understand in more detail what is the problem.

Dr Mutch: I do not know what is in that program.

Ms L.L. BAKER: Or something like that.

Dr Mutch: There is always an opportunity to learn. The content of that program might be fantastic, but it is how it is delivered that might need to be modulated. It might need to be adapted, depending on how the person before them learns.

Ms L.L. BAKER: And what should the state government be doing? Do you have any observations about what role a state government—any state government—should be playing in the parts of the puzzle that you know about?

Dr Mutch: Offering diagnostic services.

The CHAIR: In relation to diagnostic services age 6, if we are going to have this team, whether it is paediatricians or child development services—I am quite happy for you to think more about this and get back to us—once they have been diagnosed, I just want to make sure that we do not just have diagnosis and not all the treatment interventions. We have got midwives seeing children sometimes before they are born or after they are born, we have got the child health nurse seeing children, we have got GPs seeing children, and we have got people from alcohol and drug authorities seeing families with children. With all of those records for all of those people, should there be a spot where alcohol comes into it and should we have a state register? Just as we ask health professionals to notify if there has been sexual or child abuse and there is mandatory reporting, should there be mandatory reporting not in a kind of derogative way, but who should the GPs, if the mum is a heavy drinker—on some people you can smell it; for other people, you ask her when she is pregnant how much she drinks and how much the husband drinks—be notifying to try to make sure that children who might be at risk, or families who might be at risk before having other children, are given the support that maybe currently is not there at the moment? What do we want to collect and from whom?

Mr P. ABETZ: And where is it stored?

The CHAIR: Who does it go to?

Mr P. ABETZ: Who can access that information?

Dr Mutch: I think, as a duty of care, questions about alcohol use should be part of the routine prenatal screening: Are you hep B immune? Are you smoking? Are you drinking? The first question I always ask is: “Was your pregnancy planned? You know that 50 per cent of pregnancies are not planned. You know the rates of drinking in our society. Therefore, it is highly likely that if your pregnancy was not planned, you have had alcohol exposure in the early part of your pregnancy.” So my first question is: “Was your pregnancy planned?” That is always a really polite, pleasant starting point for any mother I see. Then it is easy to ask: “Did you take folic acid? Did you take up swimming? Did you stop drinking? Were you drinking? How much did you keep drinking?” It is the easiest part of a holistic health care check that is comfortable and easy.

When you start talking about different organisations recording alcohol use and listing it under syphilis or sexual abuse or domestic violence, that becomes not a heinous area, but a very difficult area because part of the reticence with people diagnosing FASD in the paediatric and medical community has been one of fear of stigmatisation, and that has come out of Jan Payne’s research that is consistent with other places. There is already a reticence to even ask, let alone bothering to diagnose. There are even people who think it is not a valid diagnosis or “What is the point of diagnosing it anyway because it can’t make a difference?” That has been quoted to me from extremely high people in health who have thought that. There is already encumbrance upon beginning to make a diagnosis. If you are wanting to list alcohol, I do not think you can do that unless you have support services for substance dependence, unless you have meaningful commitment to stand with these families, because there is a lot of evidence. It is not just about the mother drinking; it is what their partner drinks that influences whether they keep drinking or not. Whether you have got meaningful programs to meet people where they are, not at arm’s length and then you have diagnostic services and you have enough people to provide therapeutic intervention. I think it would be harmful to just start there to collect the data and then use that as an argument point for the other.

Also in that point, I think it is important that if money is being thrown only at prevention or screening, you should not screen unless you have diagnostic follow-through just to confirm or not. If you are throwing money at prevention programs, currently in the state you cannot prove whether that prevention program is working or not, because there are not enough data points in the system currently that are valid to say who has FASD and who is drinking. There is no way that you can argue that your prevention strategies are effective because you have not been collecting the data in the first place as to who has got FASD and how much they are drinking. It can be called a circular argument. I think the data has to be collected. I think the question has to be mandatory as part of holistic intervention. I think it just should be part of your routine engagement today: “How are you going? What are you doing? Are you exercising? What is your abdominal circumference? How much are you drinking?” It should be part of just routine health care at whichever interface you engage with a health professional, irrespective of their title.

Mr P. ABETZ: Given the amount of FASD that there would appear to be from what we have seen in the Kimberley and so on and also in our suburbs, these kinds of diagnostic teams are professional people and they need to be paid reasonable salaries. There is all of that cost of actually dealing with FASD. If we are really going to take it seriously, that is going to be a massive cost burden on our health budget, which would suggest that if we have got this thing moving through that is going to cost us a lot of money, that should also be a good argument for why we invest very heavily in education and reducing alcohol consumption. Is there any idea about what sorts of costs there are in following through on a FASD child in terms of their diagnosis, the interventions they need and all of that?

Dr Mutch: There is no costing for Australia. There are costings that you have already had reported on record for North America—the cost of “a” child, and it is considerable. I have had conversations with health professionals who have said, “I haven’t even got enough money to buy a biro.” I am very aware of the budget constraints. I think there is a duty of care. I think Australia’s consumption of alcohol, and in our youth, outstrips America. We know our normal consumption of alcohol is considerable. I do not think there is any excuse anymore. I saw one lot of evidence submitted to you that said there is not enough evidence. I disagree with that. There is enough evidence now to say that this is massive. When are we as a state going to have the sorts of resources financially that we currently have with what we are digging out of the ground? If we cannot do it now with the impetus and the knowledge and the federal backing and federal support, I suspect we would never do it.

Ms L.L. BAKER: Well said.

The CHAIR: I now declare this a closed hearing. That means that from now, what you have to say does not go on the internet.

[The committee took evidence in camera]
