

WORKSHOP 4

Foetal alcohol syndrome

Chair: John Wakerman

INTRODUCTION

John Wakerman

JOHN WAKERMAN: Good afternoon. We might just get started because time will run away from us. My name is John Wakerman and I'm the facilitator of this workshop. This does not look like a workshop setting to me, which is a bit unfortunate because we've left time for discussion at the end and we do want to generate discussion, but I don't think we're going to be able to put the chairs in a circle, I'm afraid.

The National Rural Health Alliance has organised this workshop around foetal alcohol syndrome, and there are a number of questions that we might ask, and some of them might be answered during this session and others may not, but we may come up with some processes for answering some of those questions.

Some of the questions that we're interested in answering are what's happening internationally in this area, what's happening around the country here in terms of diagnosis, intervention, research, evaluation of interventions, where are the gaps in knowledge about foetal alcohol syndrome, where are the gaps in implementation and evaluation, what does best practice look like, do we have a coherent national approach here in Australia and I was just asking Heather d'Antoine and Sue Miers whether they thought we had a national approach and their response was, well, there's a lot of activity, there are pockets of activity around the country and there are pockets of interest.

We know also that there's been quite a bit of work over the years in Cape York, and unfortunately we're not going to hear about that today. But there doesn't seem to be a coherent national strategy from what we can make out. Another question in my mind is what are we doing locally, what are we all doing locally? And that's particularly a question that weighs on my mind because in the Northern Territory we have the - I'm not proud to say - highest per capita alcohol consumption in the country and Australia ranks pretty highly internationally in that area as well. So, are we inadequately dealing with a major public health problem here in this region? What's happening in your region?

So those are some of the questions we'd like to get at and we'll be able to have a discussion at the end. But first we've got a number of presentations for you. The first will be actually a video from Margaret Clarke, who's a paediatrician in Calgary. She has visited here a couple of times. She knows a bit about Australia and she's going to give us an international perspective on foetal alcohol syndrome and she'll tell you that the nomenclature has changed as well.

Then we're going to hear from Sue Miers representing the National Organisation for Foetal Alcohol Syndrome and Related Disorders and Sue will give more of a community or personal perspective on this issue. Heather d'Antoine from the Telethon Institute will give a researcher's perspective and then we have Francie Turner and Nettie Flaherty, two local practitioners who

will give you a view from community workers on the ground. And then finally Nigel Stewart who's a paediatrician will give you another perspective as a practising paediatrician.

I'm going to try and keep this as tight as possible. The video is a bit long, but we're unable to edit it, and then I've got to try and keep the presentation a bit tight, so at the end we should have about 25 to 30 minutes for discussion. What I'd like you to be thinking about as you're hearing the speakers is about what sort of recommendations you'd like to put up, what sort of action you'd like to see arising from this workshop.

So it's not a talkfest, it is an opportunity for the National Rural Health Alliance, if we think this is an important issue, if we think that there are gaps in terms of action, then you need to be thinking about those and discussing those and if the group comes up with some good actions that we can put up to the Alliance, they'll take them forward to the national level. So please be action-focused in your considerations and the discussion at the end. Okay, without any further delay, we're going to get this video going, if Steven is here.

BACKGROUND AND INTERNATIONAL EVIDENCE

[Dr Margaret Clarke](#), University of Calgary (on video)

DR MARGARET CLARKE: Good afternoon, and thank you in particular to John Wakerman and Gordon Gregory for inviting me here electronically to Alice Springs, one of my favourite places in the world. I'm recording this in Canada where it's a balmy 9 degrees Celsius and of course I'm here today to give you a brief background on foetal alcohol spectrum disorders and also give you a bit of an international perspective on this very important topic.

I guess the first thing I'd like to say is there is some new information available in the area of foetal alcohol spectrum disorders and a lot of it relates to new terminology. So I'd like to move through what the various terms mean and how we now understand this information.

First of all, what is foetal alcohol syndrome? Well, first of all, it's a congenital abnormality caused by maternal ingestion of alcohol. There are three criteria that you really need to make the diagnosis of foetal alcohol syndrome. One is there's a characteristic pattern of facial characteristics; two there is often pre and postnatal growth deficiency and three, there is a characteristic pattern of diffuse brain damage.

This next slide shows you the first person in North America who was recognised as having foetal alcohol syndrome. There's an interesting story related to this young man who, at the time, was eight and is now about 30 and living in Seattle. He came in through a short stature clinic and was recognised, in addition to being very small, as having very characteristic facies but also having a particular pattern of being slower to develop and a very bright resident by the name of Christie Yuland said to her supervisor, on further inquiry, she also found that his mother had ingested considerable alcohol during the pregnancy and so together they coined the term "foetal alcohol syndrome", not even knowing in 1973 that this was the cause of this young man's abnormality, but subsequently another 10 or 12 cases in the US were identified and then another 24 cases from France and that's how foetal alcohol syndrome really got its start in the modern day.

But we now know that foetal alcohol syndrome in our communities is only the tip of the iceberg because when I see children in my clinic in Calgary, very few of them, the minority have the full foetal alcohol syndrome; most have a variant thereof and you can see the other things here below the tip of the iceberg, partial foetal alcohol syndrome, alcohol related birth defects, especially defects of the heart, the limbs and the eyes and finally, alcohol related neuro-

developmental deficit, again referring to children that may look normal, may have normal patterns of growth, but have all sort of different problems affecting their behaviour and development.

Well, what are a few alcohol effects, or FAE? This is a term that is certainly encountered or we're encouraging practitioners not to use any more. It was first, in fact, coined by a man by the name of Stirling Claren who needed a way to describe all of the people in his clinic that didn't meet four criteria for foetal alcohol syndrome, so it was an exclusionary diagnosis and one that was never meant to be a five generally. The problem with FAE is that people tend to think that it's a less severe form of FAS and, as a consequence, children often don't get the services that they need.

What is foetal alcohol spectrum disorder? Well, again, we came up with this about two and a half years ago here in North America to describe this whole broad spectrum of prenatal alcohol exposure to get away from the FAS/FAE conundrum. But again to emphasise, this is not a diagnostic term, it's an umbrella term to describe all of the diagnostic categories underneath FAS. So foetal alcohol spectrum disorders encompass all of the below. Again, partial foetal alcohol syndrome, alcohol related birth defects and alcohol related neuro-developmental disorder.

How much of FAS do we have in our communities? There have been very few good prevalence studies done, but we generally feel that FAS prevalence is probably zero point five to two per thousand and for FASD, the whole spectrum, probably more like ten per thousand. Later on in this presentation I'm going to talk to you a little bit more about some specific epidemiological studies that have been done in different communities.

The second message that I really want to talk to you about is alcohol causes a wide spectrum of deficits during pregnancy and what are some of these deficits? Well, first of all, we know that alcohol is a teratogen. It causes a wide variety of problems for the developing foetus, certainly in the more extreme form, death, but malformation, growth deficiency and a whole variety of functional deficits including brain deficit.

Why does alcohol cause such damage? Well, you can see here, it's just a tiny little molecule, a few little carbons and hydrogens connected together, but it's toxic because it's small and it gets everywhere and it can go everywhere. As soon as it hits the maternal circulation, shortly after it's in the baby's circulation and it starts causing damage from the first cell division. All kinds of mechanisms as to how alcohol does its harm and this has been a very active area of research for us here in Canada and in the US.

First of all, we know that alcohol directly will attack cell development. It makes cells smaller and malformed. The second thing is it's a by-product of alcohol metabolism, something called a CL aldehyde may also cause problems. Thirdly, we know that alcohol can affect your oxygen balance across the placenta and again less oxygen will lead to brain damage in the foetus and finally we're doing some research looking across the gland and balancing and how that may impact.

There's some interesting work that's been done that shows us where alcohol's effects are according to the trimester in pregnancy. In the first trimester, you tend to see more of the alcohol related birth defects and I've already mentioned those are things like septal defects in the heart, you can get certainly smaller eyes, a variety of kidney and limb abnormalities.

In the second trimester, you can see an increased risk of spontaneous abortion and in the third trimester if the mother continues to drink, certainly that decreased growth. The important thing to note on the far end of the slide is the effects upon the brain are throughout pregnancy

and that's again what we really know is the major long-term disability, brain damage that comes from prenatal alcohol consumption.

The message here is that you need to start understanding FASD by understanding what are the drinking patterns in your community and how can you begin to understand those and impact those so we can work to prevent FASD.

I wanted to present you with some more recent data that we looked at in Alberta, a sample of over a thousand women and they were actually part of a delayed child-bearing study and what we did in that study was ask them some specific questions about alcohol consumption prior to getting pregnant, around the time of conception and then after they became pregnant. Eight per cent were still drinking prior to pregnancy, 64 were drinking at the time of conception and again from the time that they are conceived to the time they recognise pregnancy varied between five to 10 weeks and up to 28 weeks, and 21.5 per cent reported binge drinking. When we look across Canada, we know that 16 to 25 per cent of women who are pregnant continue to report drinking during pregnancy.

Some Australian data, when I last was in Alice Springs, I was able to review the Australian Longitudinal Study on Women's Health and found in that study that 70 per cent of women report binge drinking, and remember, that's greater than five drinks per sitting, 19 per cent on a weekly basis. And again, we also know that binge drinking is frequently associated with unprotected sex and again this is going to raise the probability of foetal alcohol spectrum disorders.

So you can see here on this slide that once you get into the six to eight drink range per sitting, then that vastly increases your risks of having foetal alcohol spectrum disorder and then, of course, foetal alcohol syndrome, as you continue to drink adequate dose and quantity. Binge drinking patterns again are interesting and certainly this is one of the things that's on the rise. In our Canadian adolescents I know that in 1980 about 18 per cent of them were binge drinking. When we looking at their patterns in 1998 a full 33 per cent were binge drinking.

Binge drinking is harmful because you get a higher peak blood alcohol content which goes right to the baby, longer periods to metabolise, more damage. We also think maybe the withdrawal from the alcohol is associated with brain damage. Streissguth again has done a study, looking at a 14 year follow-up of women who reported binge drinking before they recognised pregnancy. And again, this group of children have clear differences in their performance in a number of areas, their behaviour but also their learning.

Well, what do we know about health care providers and what they're doing about FASD prevention and diagnosis. And later on you're going to hear from Heather d'Antoine, from the Telethon Institute who's going to tell you about a recent health provider survey they did in Western Australia. So I thought I'd just peak your interest and give you some information on our survey in Canada that we did in this area.

Again, we looked at about 2000 health care providers, paediatricians, obstetricians, family physicians, psychiatrists and also a group of midwives to see what they did and didn't know about this very important topic. Overall, when we looked at our Canadian health care providers, about 75 per cent agreed that the effects of alcohol were clear. Second, they almost all said that FAS occurred in all strata of society. Third, most agreed, almost 95 per cent, that prenatal alcohol exposure is a risk for permanent brain damage. And finally, and most importantly, almost 90 per cent of our practitioners agree with telling patients, "no alcohol was best in pregnancy".

What kind of alcohol advice do our physicians give? And again, we asked this of family physicians, midwives and obstetricians. Preconception, which we think is a huge area of opportunity where we could be doing better work, only about 40 per cent of our practitioners are discussing the risks of alcohol abuse and the impact on the foetus. Prenatally it changes, 94 per cent are asking about alcohol consumption and then will go back and ask about a prior alcohol history. And again, almost 90 per cent recognising no alcohol during pregnancy.

How do we determine level of risk of drinking in pregnancy? One of the things we know from other community surveys is to use a standardised screening tool such as the CAGE or the T-ACE is extremely important in primary and secondary prevention of FASD. And again, about 60 per cent of our practitioners across Canada are using some kind of a standard tool, more likely family physicians than obstetricians.

What kept practitioners from discussing alcohol with their patients? Not surprisingly a lot of us report that time is an issue. But some other interesting facts, as many also reported, that the information regarding alcohol was not in a useful form. Some people felt the clients already had enough information and a smaller group thought that patients wouldn't be interested in hearing this information. Clearly, a complex topic and an interaction between the practitioner and the person that we need to understand better.

What about diagnosis, how did our Canadian health care providers do in this area? Overall they were understanding that there were various features they needed to look for in the face but few really understood that it was the combination of the face, growth and the brain that was important. So that's an area we're going to provide further help to our practitioners in, through standardised diagnostic guidelines.

Again, some barriers to diagnosis. Most practitioners feel that a diagnosis is within their scope of practice and that's a good thing. Again, many don't think that the time is a barrier in diagnosis. So we've got this conundrum of alcohol discussions being a problem but making a diagnosis, which in fact is very time consuming, was not seen by practitioners as being a problem. Lack of training, however, was an issue that was identified by our practitioners.

Well, the next message I guess is, FASD is common and everybody is at risk. This is not something that exists just for Indigenous people or certain cultural groups, everyone is at risk. It's a leading preventable birth defect and the leading cause of mental disability in the western world. Here, you can see this is an old slide from the Centre for Diseases Control that really shows the incidence of FAS in relation to Down's syndrome and spina bifida. So you can see there that it's far more common than these two conditions.

So we've already said that we think we have about .2 to .5 to two per thousand for FAS but we know there are higher rates in certain communities, where there's higher rates of drinking. I just wanted to mention one study that I'd encourage you to read on a study of Cape Town children who were aged six and a group of researchers from South Africa and the US went in and looked for FAS and they found full blown foetal alcohol syndrome in 46 per 1000. They went to ask why and what they found is there was a higher rate of binge drinking and many of the pregnant mothers were being paid in wine rather than money from the vineyards that they were working in.

Bottom line is, everyone's at risk, you need to start screening early and aggressively, especially for our at-risk adolescent populations. I think there's a critical role for physicians. We really need to engage physicians in doing broad-based screening. We need to understand the broader help and social risks that accompany foetal alcohol spectrum disorders and we need to get creative about our community supports to help women who are drinking during pregnancy cease or cut down through lay advocacy programs.

So there are some new ways to diagnose FASD and some new diagnostic formats and I think that later on Nigel Stewart will talk to you more about the paediatrician's perspective in diagnosis, so this is just a few of the high points.

First of all, in North America and I think in Australia as well, there are two approaches that are used. There's an Institute of Medicine approach and there's a more recent approach that we use here in Alberta and in Canada called the Foetal Alcohol Syndrome Diagnostic and Prevention Network or DPN scheme. Institute of Medicine again, you've seen these terms before, there are essentially four, there's the full blown FAS, the partial FAS, alcohol related neuro developmental disorders and finally alcohol related birth defects.

The Diagnostic and Prevention Network schema looks at the individual components of the diagnosis, something they've chosen to call the Four Dot Digit Diagnostic Code. So what you can see here is there has been an individual rating for each part of the foetal alcohol syndrome diagnosis: growth; face; brain; a standardised rating of alcohol intake; and then also some recognition of pre and postnatal core morbidities.

So by way of example, if you had full blown foetal alcohol syndrome you would score across the top of Fours, prenatal and postnatal core morbidities may vary. So we have the history of prenatal alcohol exposure, growth, face and the brain. So let's look a little bit and think about this. In our clinic we rate alcohol in the following way, the most significant being confirmed high risk drinking pattern. So again, adequate quantity, volume and exposure pattern throughout pregnancy. And then everything that falls under that is a little less.

In terms of growth, we know that this is the third trimester hit in the main, if you continue to drink you tend to have a smaller baby. But there are also postnatal factors, so our children will continue to grow at a slower rate who are alcohol exposed. So here's this little guy when he grew up to be a bigger guy and you can see here, he didn't do a whole lot of growing between age 8 and 18 and again, this is growth deficiency in its most significant form in FAS.

This is the face, the typical face, of foetal alcohol syndrome and again, when we're looking at analysis of the face there are three things that we hone on in particular: the short, palpy profissures that reflects smaller orbit size, and again, eyes are just an outgrowth of brain tissue and alcohol really affects eyes and the brain tissue; a flatiltrum, again that piece between your upper lip and your nose doesn't have that furrow in it; and finally, a very thin upper lip.

The interesting thing that we now know from some work that's been done in North Carolina is that these particular things in the face will happen around day 20, post conception. The message here is many children who are alcohol exposed will not have the face. If you do have the face, it's predictive of organic brain damage and also prenatal alcohol exposure. Facial features diminish with age.

This is a young woman, again, who we first photographed at around eight years of age and again in her early adolescence and you can see how many of the facial characteristics have changed with the exception of one, is that if we measured her eyes we would still see that she had very small eyes. The landmarks for eye measurement are a source of confusion and again I just put them up here because the accuracy of measurement is extremely important in the diagnosis.

This just gives you some tools and at the back there are some resources from Washington that you can order off the internet if you want to begin to do your work using the DPN framework. There's a computer image analysis that we are using in our clinics that is also helpful in differentiating FAS from about 20 other FAS lookalikes.

Let's move on and look a little bit at how we look at the most important issue of brain damage in FASD. This would be a very extreme form of prenatal alcohol exposure. The brain on the left is from a five day old baby that did not survive his mother's drinking during pregnancy. But again, this is the exception rather than the rule. Most brains that we look at for children who are alcohol exposed are completely normal.

So there are structural deficits that we see and there is also a variety of functional deficits that we see when we're making a brain diagnosis for FASD. Alcohol can cause all kinds of damage to all areas of the brain: the cerebral cortex, the white matter, the deep cerebral nuclei, the corpus callosum; and finally, all kinds of cerebellar malformations and hypoplasia.

The functional brain injury is the thing that is harder to diagnose, you need to have a team, you need to have neuro-psychological testing. But here's a way that I remember the kinds of things that impact our children who are alcohol exposed. And I remember it through a ALARMMERS and essentially it's the following domain: attention; learning; adaptation or life skills; the reasoning which also relates to intellectual functioning; memory; motor functioning; executive functioning; regulation of state; and finally, speech and language.

This is probably the most simple way that I tell people to remember what we need to know about brain damage in foetal alcohol syndrome. In our clinic we ask individuals to look at this particular figure, which is called the Ray Complex Figure and then we ask them to draw it again immediately. And then they do something else for about 30 minutes and we ask them to come back, very unfairly, and draw it again. So here's from one of our patients.

First drawing isn't too bad, most of the components are there, not everything but certainly the basic architecture. Here's what happened 30 minutes later. Individual remembers all the various pieces but can't integrate. And I think that in a nutshell tells the story of the diffuse brain injury that comes from prenatal alcohol exposure.

Just to remember that FASD and the organic brain damage comes with a host of other problems called secondary disabilities. Mental health problems are the most common but addictions are also seen. You tend to see your children start with having attention and anxiety problems, move on to depression in adolescence and finally adulthood, all of the above plus increased risk for suicide.

Well, there are some successful interventions for children with FASD and I want to speak to you about what some of them are. First and foremost, good interventions I believe start with a good and accurate diagnosis. And when you're looking you want to use a team, a multi-disciplinary team, whoever you have in your community to help make a consistent clinical diagnosis, rule out other medical causes for why this child may not be growing and developing, look fully at what the primary disabilities of FASD are. Recognise the secondary problems, if there are any, and finally link your diagnostic needs with interventions.

Here are just some of the intervention targets and you can see here how broadly we cast our net in the area of interventions to help the patient, the mothers, the adoptive family, the foster family, the school and the community. In general the intervention strategies are all around early diagnosis and early intervention, multiple levels across a lifespan, long term and continuous, that we need to act often as external brains for alcohol affected individuals and really watch them carefully for the mental health problems and the addiction problems that often become part of the disability. A little way to remember some of the general principles of intervention: SCORES' - structure, consistency, organisation, repetition, environmental modification, sensory strategy and safety.

So what are the distilled messages and how can we take actions in our community? Aggressive prevention strategies. Everybody's at risk, we should know what risky drinking is and how it can relate to FASD. That's a message that needs to go broadly to young women and men in our communities. Identify those who are the highest risk and begin looking at them in adolescence and how we can help. Capitalise on missed prevention opportunities. I see lots of public health messages in our universities and our community colleges about drinking and driving, very rarely anything about FASD. Early identification of our children through the community programs we already have in place to identify other developmental issues.

The summary is that these are very devastating conditions although it's entirely preventable. In spite of our increased knowledge we still have children being born who are alcohol affected. It's consequences to family, society and the individual are immense. The costs are tremendous, both personally and financially and we need to make effective treatment and prevention strategies available to everybody, not just in bigger communities but smaller communities as well.

There are some internet resources here in your hand out and I'll just call your attention to a couple that I think are really worthwhile. One, the recently developed Canadian diagnostic guidelines that are just put out, that's a synopsis of everything you need to know about beginning to do this work in your community. And secondly, of course, the resources available through the University of Washington that will assist in the physical diagnosis.

So thank you very much. If you have any questions, you can email me and certainly John Wakerman knows how to get hold of me as well. I wish I could be with you for the rest of the afternoon to help. I know you will enjoy the rest of the presentations and I look forward to having a direct conversation with all of you some time in the future.

JOHN WAKERMAN: Thank you, Margaret. We really are grateful to Margaret for putting that together in her own time and at her own expense. It was a very comprehensive overview of foetal alcohol syndrome. We'll save commentary till later and I'd like to introduce Sue Miers from the National Organisation for Foetal Alcohol Syndrome and Related Disorders. Thanks, Sue.

CASE STUDY: AND WORK OF THE NATIONAL SUPPORT GROUP (NATIONAL ORGANISATION FOR FOETAL ALCOHOL SYNDROME AND RELATED DISORDERS)

Sue Miers

SUE MIERS: Good afternoon everybody. I'd firstly like to pay my respects to the Arrernte people as the traditional owners of this area.

My name is Sue Miers, I'm a spokesperson for the National Organisation for Foetal Alcohol Syndrome and Related Disorders. No, FASARD, for short, because it's a big mouthful, is Australia's first support group for parents, carers and other people interested in foetal alcohol spectrum disorder.

My journey down the FAS lane began over 20 years ago when we fostered our youngest daughter Lola. She came to us just before her second birthday, a precious, cute, curious but difficult little toddler, much loved then and even more loved now. When Lola was only eight years old her birth mother died at age 45 from alcohol related disease. Her birth father is

unknown so she has become very much our daughter and a much loved sister of our three other children.

But Lola has a history and with her permission I'd like to share this with you today in the hope that it will give you a greater understanding of not only the huge personal impact of FASD but the importance of diagnosis and how this disorder impacts on every facet of our society.

Lola was born on 23 November 1980. She was born at home, transferred to hospital by ambulance and she experienced symptoms of alcohol withdrawal. At six weeks old she was removed from her birth family and placed into emergency foster care. She came into our home when she was 21 months old, a beautiful little toddler with a cheeky personality and the most beautiful smile I've ever seen.

She had a history of recurrent ear infections but otherwise seemed very healthy. No one ever mentioned to us that her mother's alcoholism may have harmed her in any way. But even in the first few days I began to recognise behaviour patterns that were different from my other children. She was hypersensitive to loud noise, at certain times she was also hypersensitive to touch and would react with volatility at even the slightest body contact. She found new situations, crowds or a change in routine particularly upsetting and stressful yet at other times she appeared quite fearless.

When only a toddler she would clamber up a trellis on top of the shed time and time again. If she wasn't constantly supervised she would wander away from home or do a disappearing act at the supermarket. She never did understand the meaning of stranger danger. Over and over we would explain the dangers and safety rules and she would seem to understand and then go straight back and do the same thing the next day. She just did not seem to remember the rules.

Lola was small for her age and was always babied by her peers at school and as she progressed through the years she always chose to play with children much younger than herself. She loved having friends, made friends easily and was always inviting them home to play but her social skills were immature and she never developed any true peer group friendships.

By the end of grade 1 she'd made very little academic progress and she was referred for psychological assessment. The results revealed learning disabilities, especially those associated with maths but also showed discrepancies in some of the sub-tests. The validity of the testing was questioned due to the degree of anxiety Lola experienced from being in a new situation with an adult she didn't know. It was the psychologist's view that with special education help she had the potential to catch up and do well at school and he downplayed our concerns about her learning and behavioural issues.

So she received extra tuition with maths and reading and although at times she would appear to make some progress, the following week facts that she had known the previous week seemed to be totally forgotten. It was a bit like filling a bucket full of holes, as fast as the information went in it seemed to pour out. Most teachers thought this was within Lola's control and phrases such as, "she could do better if she tried", "she doesn't concentrate", "she's got attention seeking behaviour" and "disobedient" all became regular entries in her school reports.

Still concerned about her progress I sought help from a myriad of professionals but never did they suggest that prenatal alcohol exposure may have caused damage or be the reason for her difficulties.

When Lola was 10 I read an article in a magazine about FAS and it hit me in the face, they were talking about my daughter: delayed physical academic and social development, impulsivity, difficulty with friendships, difficulty separating reality from fantasy, very little understanding

of cause and effect, difficulties with boundaries and ownership of property, but all the time a loving child who seemed to want to please.

The article made so much sense to me. I believed I'd found the missing piece in the jigsaw puzzle, the key to understanding Lola's difficulties and behaviours. I immediately made an appointment with the genetics clinic at the Adelaide Womens and Childrens Hospital to confirm my diagnosis. I was stunned when the diagnosis was negative. Apparently Lola didn't have the physical indicators of foetal alcohol syndrome and didn't meet all the necessary criteria for a diagnosis.

Although they agreed that she could have been affected by prenatal exposure to alcohol, they didn't want to stigmatise her with a label or give her excuses for her behavioural problems. I was still convinced that FASD was the answer so I set about to find out more information. I contacted special education services, drug and alcohol agencies, disability agencies, child and youth health and mental health agencies. But most people I spoke to had never heard of FAS, let alone have any information they could give me.

Those that had heard of it told me it was very rare and really only a problem in Indigenous communities. It is only since scouring the internet over the last seven years that I have fully realised the true impact of FASD. My research led me to heaps of resources and also to an FAS conference in Canada and Lola's diagnosis, at age 17, of partial FAS by one of their leading experts in this area, Dr Ab Chudley.

Dr Chudley's diagnosis left me with mixed feelings. I was, of course, relieved to learn that Lola's developmental and behavioural problems were most likely based in organic brain damage rather than being intentional or the result of my poor parenting. But I also felt a great sadness as I realised the frustration she must have experienced during a lifetime of failure and being told to do better when in reality she was unable to. She was being the best she could be, despite her school reports to the contrary.

I realised my expectations of her would have to change dramatically. What a difference it could have made to her life outcomes had I had that knowledge during her formative years. During that time her teachers had seen her inappropriate behaviours as being under her control as actions that must be changed. They saw her inconsistent memory as conveniently selective and her lack of social adaptation, poor choices and lack of remorse as blatant, wilful misbehaviour.

I was guided by them and supported them in their efforts to make my bright, happy child conform to the rules of the playground and the rules of the classroom. Yet I and everyone else, without exception, had failed and Lola's self esteem plummeted in the process. The cognitive impairment of children with FASD is clearly related to the degree of exposure to alcohol.

Currently in Australia many would not be diagnosed and are in our mainstream settings. It is these children and teenagers that are at the greatest risk of secondary disabilities. They may have IQs in the normal range but their social, emotional and independent living skills are often way below their academic levels. When professionals do not have the specific training or knowledge to perceive and understand the cognitive deficits of these students, expectations are set unrealistically high and so they are set up for failure.

This is why diagnosis is so important. Diagnosis gives visibility and visibility leads to solutions for both prevention and intervention and management. Working with foetal alcohol affected children and adolescents and adults requires a reframing of perceptions and a new way of thinking about the meaning of behaviours.

It is the experience of professionals overseas who work with these individuals that many of the challenging behaviours they present cannot be changed because they have their roots in

organic brain damage. In order for them to reach any kind of sustained function, successful interventions involve adapting the environment to prevent the behaviour from occurring in the first place.

This is really hard work. It usually requires constant, total supervision, highly structured, significantly altered physical environments and time consuming interventions. This has huge ramifications for children who have been undiagnosed or misdiagnosed and are therefore being managed inappropriately. We would never ask the blind person to read without the help of Braille, yet we ask alcohol affected people to work alongside others every day without special understanding or support.

The tragedy of children born with FASD cannot be understated and neither can the cost to society in both human or economic terms. Lola's diagnosis came too late to give us the knowledge we needed to help prevent the many secondary disabilities she has since experienced. She dropped out of school early, she's been in trouble with the law on several occasions, she's had problems with employment, she's spent time in psychiatric wards of hospitals with psychotic attacks brought on by alcohol misuse, she's been sexually assaulted, she's lived in a domestic violence relationship, she was physically assaulted in her flat by two of her friends. And she's only 24.

Longitudinal studies show that one of the universal protective factors for the prevention of such secondary disabilities is diagnosis before the age of six and appropriate interventions. As I contemplated this presentation, I thought about some of the frustrations of parenting a child with FASD, frustrations also experienced by other parents in our support group. We struggle to care for our children because of a lack of understanding by professionals who do not recognise or understand the disability, nor respect our efforts to describe it. We find ourselves physically exhausted because of dealing with the challenging behaviours that are based in the disability but are often typically presumed to be the result of a dysfunctional family or other environmental factors.

We are severely hampered in our parenting efforts because of insufficient resources and services specifically for FAS. Typical behaviour modification programs do not work with these children but most professionals are not aware of this. We find ourselves in the unenviable position of assertively depending our competence as parents over and over again. When seeking help and resources from professionals we have encountered lack of services, blame, discomfort, denial and simple ignorance. Yet who knows our children better than us and who lives with the problem closest to their heart.

This range of responses reflects the relative newness in Australia of the recognition of FASD. The very limited amount of useful information and professional training available leads to professional discomfort and inadequacy. But can we really blame professionals if the training isn't there for them? I can see that individuals with FASD are some of the most difficult professionals would ever have to face but as a parent I can accept no less than maximum effort and maximum understanding. My daughter and all others with FASD deserve that.

It is my experience that resistance to change is real and normal and I'm reminded also of how long it took me to finally understand that my child couldn't change. I do believe that things can change and hopefully this conference will be one of the catalysts for that change. Overseas studies are demonstrating that diagnosis and appropriate intervention and management leads to more positive life outcomes for these individuals. Surely they should receive the same quality of care that is currently provided to those with other more visible, familiar disabilities. This is a human rights issue. Thank you.

JOHN WAKERMAN: Thanks, Sue. The next speaker is Heather d'Antoine who's a researcher from the Telethon Institute for Child Health Research in Perth. Thanks, Heather.

THE WORK OF THE TELETHON INSTITUTE FOR CHILD HEALTH RESEARCH

Heather d'Antoine

HEATHER D'ANTOINE: Thanks, John. My respects too to the Arrernte people.

Some of these results might explain Sue's frustration in trying to get a diagnosis for her daughter. What I'm going to present today is some of the findings from a survey that we've done of health professionals in Western Australia. We're trying to get this published in a peer review journal so we're very limited about how we can lead the results so if you could just bear with us.

I just want to quickly talk about the epidemiology although Margaret has already touched on that, but when we looked at the rates from overseas, in USA, and it's very difficult to get a good population prevalence study, as Margaret pointed out. In the USA the rates ranged from 0.2 through to 2; South Africa 39 - I think it was a similar study done in areas where women were being paid in alcohol and so on; Indigenous Canadians were 7.2; France 2.3; Sweden 1.6 to 2.5.

Then we looked at some of the rates from Australia and in Northern Territory through reviewing medical records, the rates were about 0.68 and Indigenous population for the Territory was 1.87. And from Western Australia from the Birth Defects Registry, the rates were 0.18 for the total population and 2.76 in the Indigenous population, which raised the question for us, why are the rates in Australia so low? Is there a real difference or is FAS less well reported in Australia? And clinicians here will know that it's very difficult to diagnose FAS and obtaining information about alcohol consumption in pregnancy can be very difficult to elicit. And there seems to be concerns about labelling and stigmatising children and families if a child really does have FAS.

This particular study is part of a three-pronged approach. One was trying to estimate the incidence of FAS in Australia and we've done this through the Australian Paediatric Surveillance Unit, trying to get a better picture on FAS nationally. The second approach was to document what information exists in Australia on current levels of alcohol consumption in pregnancy. And the third one is what I'm going to present the results on, is to find out what health professionals know and do about FAS and want to know and do about FAS. Paediatricians were surveyed separately to the other health professionals and we're not presenting their results yet because the data was finished being collected late last year.

The project was funded by Healthways in Western Australia, the participants in the survey in WA included Aboriginal health workers, allied health professionals and that included a range, psychologists, speech pathologists, social workers, occupational therapists, nutritionists, physiotherapists and community nurses including school health, child health, community health, mental health, community midwives and remote area nurses, general practitioners and obstetricians.

The response rate in total was 79 per cent and it ranged from 56 per cent for GPs to 92 per cent for allied health professionals, and that was a total number of 1143 respondents. 20 per cent of the respondents were male, 22 per cent were under the age of 35 years of age. We were

interested in the age because of when FAS was first diagnosed and was there a difference between health professionals who were trained before or after it was first diagnosed. 47 per cent were between the age of 35 and 49 and we oversampled in certain areas so that we would get a good picture state-wide, and 52 per cent were from rural practice.

In a typical week those health professionals saw 80 per cent - 80 per cent saw children and 58 per cent saw pregnant women. When we look at the essential features for FAS, 54 per cent knew that clinical nervous system issues were part of the diagnosis; 55 per cent that facial features were part of the diagnosis; 52 per cent that growth was important and alcohol - 60 per cent alcohol in pregnancy is part of the diagnosis. Only 12 per cent knew that all four of those are actually essential features for diagnosing FAS.

Five per cent had diagnosed FAS; 51 per cent had seen FAS diagnosed by another person; 34 per cent suspected but didn't diagnose FAS and 4 per cent were convinced of a diagnosis but didn't record FAS. In being prepared to deal with FAS, 2 per cent felt very prepared; 8 per cent felt fairly prepared; 23 per cent somewhat prepared; and, 66 per cent, not very prepared at all.

Sources that they obtained their knowledge about FAS, 64 per cent from professional training; 53 per cent from journals and books; 29 per cent from the mass media; 23 per cent from clients and parents; and, 20 per cent from conferences like this. Resources that they felt would help health professionals deal with FAS, providing materials to them would help them with addressing the issue, 84 per cent felt that would be useful. 79 per cent felt that there needed to be more information for actual clients; 64 per cent thought a FAS diagnostic check list would be useful and then, knowing what the referral sources are, registry of specialists, alcohol history check list and training in alcohol assessment.

85 per cent agreed it is possible to prevent FAS and we know that it's totally preventable. 82 per cent, making a diagnosis may improve treatment plans for the affected child, and, 53 per cent, the diagnosis of FAS may lead to a child or their family being stigmatised and there does seem to be some reluctance in some clinicians diagnosing. 61 per cent disagree that health professionals are sufficiently aware of FAS, so they were commenting on their colleagues.

Practice and opinions about alcohol use in pregnancy. We wanted to know, did they ask pregnant women about alcohol use in pregnancy; did they offer advice about drinking alcohol in pregnancy; did they provide information on the consequences of drinking alcohol in pregnancy and what opinions do health professionals have about drinking alcohol in pregnancy. And I should just say that this particular survey tool came from Canada and we modified it for ours.

Just to remind you about the NHMRC guidelines for alcohol consumption in pregnancy. "Women who are pregnant or might soon become pregnant, (1) may consider not drinking at all; (2) most importantly, should never become intoxicated; (3) if they choose to drink over a week should have less than seven standard drinks and on any one day", so on and so forth, "no more than two standard drinks. Should note that the risk is highest in the earlier stage of pregnancy, including the time from conception to the first missed period".

87 per cent gave out the advice of "consider not drinking at all". 29 per cent, "don't become intoxicated". 29 per cent, "about less than seven standard drinks over a week" and 41 per cent, "about spreading drinks on a particular day". Only 30 per cent knew the full NHMRC guidelines.

Do they ask about alcohol use in pregnancy? And the respondents to that question was 659. 12 per cent don't ask and it ranged from sometimes asked through to routinely asked and 45 per cent of health professionals routinely ask about alcohol use in pregnancy. Do they provide

information about consequences of alcohol use in pregnancy? 21 per cent don't provide any information; 34 per cent sometimes provide information; 30 per cent, if prospectuses are present they'll provide it; and, 25 per cent routinely provide information.

53 per cent agree that a safe level of drinking has not been established; 67 per cent agree it's not easy to ask - sorry, it's easy to ask pregnant clients about how much and how often they should drink; and, 58 per cent agree, infrequent consumption of one standard drink of alcohol during pregnancy is not harmful to the mother or foetus.

Just summing up, some of the findings: 12 per cent of health professionals identified the four essential features of FAS; 92 per cent of health professionals have never made the diagnosis of FAS, although 50 per cent have seen a child with FAS; only 2 per cent of health professionals felt very prepared to deal with FAS and 84 per cent of health professionals thought resources such as materials for how professionals - would help them to deal with FAS.

95 per cent agreed that education and information about the effects of alcohol may have on the foetus should be made available to women of child bearing age. Only 45 per cent of health professionals routinely ask about alcohol use in pregnancy. Only 25 per cent would routinely provide information about the consequences of alcohol use in pregnancy and only 12 per cent of health professionals gave advice that incorporated all of the four components of the NHMRC guidelines.

And just in conclusion, I guess there's a lot of work to do with the workforce here so that they can be best supported to health promotion education of the actual workforce, providing information that's easily available to women. The NHMRC is not followed in practice although 85 per cent said that you shouldn't drink at all, so that's - and health professionals should routinely inquire about alcohol use in pregnancy and provide information on the consequences of it.

The next steps that we're taking is developing up some of these resource materials for health professionals, looking at what's available for women. The other strategy is looking at a 24 hour information and clinical advisory service for health professionals and people in the community and developing up a register for specialists available for consultation on FAS and alcohol consumption in pregnancy. That's it, thank you.

JOHN WAKERMAN: Thanks, Heather. We'll move right along. The next paper is from Francie Turner and Nettie Flaherty, who are two practitioners here on the ground in central Australia. And it'll be presented by Nettie Flaherty.

A VIEW FROM CENTRAL AUSTRALIA

Nettie Flaherty

NETTIE FLAHERTY: Anyone who knows me knows I'm not very technologically adept. I'm doing this presentation today really on behalf of Francie who's been out bush all week but arrived back about 20 minutes before we were due to begin, but hasn't really had the opportunity I suppose to turn her head to it. But anyway, she is here and so if there are any questions, they're probably best addressed to Francie.

We were asked to provide some information about a Strong Woman, Strong Baby, Strong Culture Workshop that was held last year, by the Strong Women co-ordinators and the Strong Women workers, who work on a number of communities throughout central Australia. In the

audience we actually have some current Strong Women co-ordinators and so they could probably help me answer any questions later if people have them.

I'll just briefly tell people what the Strong Women, Strong Babies Program is because it isn't actually a program about alcohol. It's an NT-wide program whose primary focus is to support grandmother's law and to support families to care for women during pregnancy, to support women care for themselves during pregnancy and to support women care for babies and young children. And it's a community based program which is controlled by the Strong Women workers who operate on that community. And so the activities that people are engaged in and the focus that they have is very much directed by the local women.

Every year the Strong Women workers have a couple of workshops and the content of those workshops are determined by the Strong Women workers on community. In 2004 the Strong Women workers came together in February. There are about 40 to 45 women from all throughout the Central Desert and the Barkly, who really had a concern about the impact of alcohol use on their family life.

Certainly in the past, Strong Women workers have used their educational flick charts to talk about the impact of alcohol use but the received message was largely related to low birth weight and the statement that, "If you drink and smoke your baby drinks and smokes". And it was really clear that the women had some additional concerns about alcohol use and really wanted to know more about why it was important to avoid alcohol during pregnancy.

In particular they were concerned about some of the children on their community and their thinking that it was related to the fact that in their perception more women were drinking during pregnancy. Francie has had an interest in the issue of foetal alcohol syndrome for a number of years and attended Margaret Clarke's talk when she was in Alice Springs a few years ago. The discussion in this workshop really did look at the issue of foetal alcohol syndrome.

Many of the women talked about the effects that the use of alcohol was having on their families and communities. They spoke about their belief that alcohol was implicated in child abuse, including child sexual abuse and in neglect, because of the way it affected adult behaviour, especially in the way that the usual inhibitions governing that behaviour were weakened. They were also concerned that the money that's spent on alcohol is diverted from purchasing food, leaving children sometimes hungry.

And I think it's really important that we take note of the broader implications, because whilst the women were concerned about their children and what they came to understand as foetal alcohol syndrome, they really saw that as happening in a context and really felt that you couldn't consider just a woman's use of pregnancy, in the absence of looking at her in the world in which she lived. They really wanted practitioners to understand that for many women drinking during their pregnancy occurs in a context where they don't feel safe. The women at the workshop were also really aware that alcohol use in the Northern Territory, as a whole, was really high.

As part of the training about foetal alcohol syndrome the picture that Margaret Clarke had in her presentation was shown to the women by Francie. When the women saw the picture of that child, all of the women at the workshop named that child and by that I mean they named the child on their community and said, "That's Nettie". It's interesting though that their assessment that the child they named had foetal alcohol syndrome was not only based on the fact that the child physically resembled the child in the picture.

They were considering the child's behaviours and they described behaviours that were things like, "That child's got no ears because it doesn't listen to what anyone says to him/her". And because they acted impulsively and did things that made no sense, like running through camp fires and tipping over cooking pots - and everyone went hungry that night.

They identified behaviours that were disruptive to the lives of many families, not simply the family who were the parents of the children and they were particularly concerned that many of these children acted in ways that endangered themselves. And, Sue, you talked about some of those things. But climbing up on rooves and placing themselves at risk and not understanding when it was explained to them again and again. So it was the facial features, the behaviour of a child and their public knowledge of the maternal drinking history.

And I think it's really important that we recognise this because I think many health professionals do talk about the issue of labelling and stigma and these women were saying, "We know who drinks, don't kid yourself". This is a very short presentation.

The women did come up with some ideas about what they felt was needed. They were clear that knowledge about how alcohol affects the foetus was not widespread. Many people might say pregnant women shouldn't drink but were unclear about what the consequences were. Some women who had a child had had a child they thought might be affected by foetal alcohol syndrome, continued to drink during subsequent pregnancies. The women at the workshop felt pretty strongly that this would be less likely to occur when information was provided to them.

The women saw promoting awareness of the effects of alcohol use on the developing child as critical and saw that this did not mean promoting awareness just amongst them and other women and men on communities but also among doctors, health workers, nurses and teachers. None of the women could ever recall having had a conversation with a health professional that explained about foetal alcohol syndrome or what the effects of drinking might be on the developmental behaviours of the child.

They asked, "Do enough of these health and educational professionals know enough about foetal alcohol syndrome and do they feel comfortable talking about alcohol to pregnant women?" They said that they believed increasing numbers of women were drinking, especially if their husbands drank. The women were clear that for a woman to stop drinking during pregnancy, they may need help with other issues affecting their well-being. It may also mean that their partners need to be encouraged to stop drinking too.

The women at the Strong Women Workshop were clear that children needed to be assessed and diagnosed as early as possible. These women were sensitive to the issue of labelling. They didn't want families to feel bad or for women to be punished. However, they were also clear that without assistance children would be isolated within their communities, they wouldn't do well at school and they might end up in gaol. These outcomes make people feel bad. Having a child that causes disruption and not knowing what to do and having nowhere to go for help makes people feel bad.

The women were clear that people needed to know about this and change needed to happen. It was also clear that the Strong Women workers knew already which women had drunk during their pregnancy. People drank publicly and their drinking was public knowledge. By letting these Strong Women workers know about what foetal alcohol syndrome was, they actually had begun a process of informal diagnosis. They stated that with increased knowledge, most people would engage in this process. Ordinary people engaging in this process in the absence of formal diagnosis would not lead to increased services or help about how to support families to

care for their children effectively and would only lead to the label, which may or may not be helpful.

So one of the things they were saying was, “Don’t be afraid to say, ‘this child is affected by prenatal exposure to alcohol’ but make sure you’ve got some help to offer”. They said it wasn’t right to know how a problem can happen and not give people the information about how to prevent that problem or to help reduce the effects of that problem.

Families needed help now to manage children’s behaviour, especially that behaviour that placed themselves at risk or was disruptive to community and family life.

The women asked if we knew how many children there were who had been affected by maternal alcohol use and I don’t think we really did. But that’s all right, because we don’t think anyone does. They saw knowing how big the problem was and identifying those children who were affected as early as possible as keys to being able to get help for families. They were clear that without a diagnosis there would be no services to follow.

I guess the other thing, and it’s a bit of a plug for the women in the Strong Women’s Program, is that it’s really important to support programs run by women for women, like the Strong Women’s Program, but also other programs that exist. Thank you.

JOHN WAKERMAN: Thanks, Nettie and Francie. And last speaker, Nigel Stewart who’s a rural paediatrician from South Australia.

A PAEDIATRICIAN'S VIEW

Nigel Stewart

NIGEL STEWART: While John helps me, I’d also like to acknowledge the people on whose land we meet today and learn, the Arrernte people, we see a few of them down in Port Augusta as well, which is great.

I’ve enjoyed all the presentations but I think the last presentation makes me feel stronger, so those Strong Women must be doing a good job. And I like the idea of this program being embedded and a generic, holistic program. I mean, some children can sleep peacefully in Port Augusta hospital but not all of them.

Some of my thoughts about this which are pretty random are, who speaks for and supports the mothers? And I feel much more comfortable after hearing Nettie’s talk and the Strong Mothers, Strong Babies viewpoint. I mean, those mothers, in my experience - and having worked in New Zealand with Maori and Pacific Island people and recent years here in South Australia with Aboriginal families and non-Aboriginal families, whether those women are black or white or brown, they’re often young, they’re often displaced and disconnected from their family of community. They often have a lot of tragedy in their life. Often losses, they may have lost babies, they’ve lost important people in their lives. They’re often victims, which is never talked about, of either domestic violence or of abuse.

They’re often not there when people start to talk about their baby being less than perfect and they’re not able to defend themselves. We need to also ask, are the substance abuse programs out there? I mean, there are very good methodologies for women in pregnancy who are heroin addicts to go on to methadone and to reduce the amount of substance that will affect their baby. But we don’t actually have very good programs for reducing alcohol. The women who are in this situation, as somebody pointed out to me very relevantly last night, are actually

addicted to alcohol. And they're driven by things underneath that many of us in the room have little influence upon.

So I think we really need to think about the tragedy of those women and for various reasons I've sometimes been close to them, so I have quite a strong feel for that, which probably colours my approach to this.

I think some of the approaches and problems which I think would emphasise what other people have talked about is that we need to come in with a non-judgmental, non-blaming approach. I've got to say in a lot of national programs, they really lose those points pretty quickly and at another meeting today, it will be picked up by the press and it is predictable that in many situations people take a moralistic viewpoint. I don't actually like to buy into an argument that supports the moral, right wing majority at any time, but particularly in this area.

We need to think about the fact that whatever we do and I think we've started to talk about, with the Stronger Women, Stronger Babies Program, we need to avoid further abuse of those women who are mothers and of families and a loss of self esteem. Many of those women, in my experience, have self esteem that's about this high. When you start to talk about foetal alcohol, there will be something that might be going well in their life, which may not be to the rest of the world, their self esteem drops even further.

We therefore need to balance our need to spread knowledge and to change practice amongst health professionals initially and then also with the wider community because it's quite unfair to run a public campaign before we've given the professionals the knowledge to respond to people when they come in. So timing is really important. So to me, we need to balance those human factors against the need to get a national program up. And I have every confidence people like John and other people are much better than me, in a public health sense, of actually getting those messages across the right way.

In my very first rotation as a paediatric registrar in 1982-83, in New Zealand, I worked with a paediatrician who walked round and measured every baby's head and looked at them and asked the mother how much they drank. I continue to look hard for it but I think actually foetal alcohol syndrome is quite hard to see at times and to get hard evidence to go with it is also difficult. And when we don't produce that as paediatricians, when we sometimes say "life is complex" and "that many factors are affecting how a child is today", sometimes people get angry with us. It's much easier to have the simple solutions and to have a one shot, or, one event, caused this problem. The world that I work in isn't that easy.

And, I mean, I see over 2000 children a year through Medicare and over half of them would have development and behavioural problems. Our service sees about 4400 children. I mean, there will be some children with foetal alcohol syndrome among them. One or two are diagnosed. We then will have foetal alcohol effects. But it's actually embedded in a pregnancy that didn't go well, poor nutrition, alcohol, smoking marijuana excessively, a poor birthing experience compounded by often poor attachment and poor ability of parents to actually meet the needs of their children.

Men who come through their life - and many of the young men I see have never seen a good functional man in their life in my opinion and then it's often compounded by being fostered by 30 or 40 families. Alcohol is one of the contributors and the pattern of behaviour that is being described is seen by me relentlessly in many young men that I see and a smaller number of young women.

The diagnosis is important and I do accept that it can be helpful. But disability in Australia or at least in the bit that I work in in South Australia, is not funded according to diagnosis. Foetal

alcohol syndrome does not result in you moving out of a mainstream school in to a special class or a special small class. It does if your IQ is under a certain level, it does if you've got severe behavioural problems and they can't manage it any other way.

And amid behaviour and learning, foetal alcohol is not exceptional in that the pattern of problems that it has are complex and the needs of that group of children are not met in our communities. We do not have the psychologists, we do not do the measurements, not just of IQ but of executive function, that are necessary to pick up many of our children in our community who are disabled by those aspects.

We do not have in place the early intervention programs, we do not have in place the school remedial programs. We do not even specifically work very hard on our teachers doing many of the techniques that are talked about by the foetal alcohol syndrome people, that would be good for all our kids.

I think also we need to go back to whatever we do as professionals and I try and remain the humbleness and humility to acknowledge that family is fundamental to people. The children I see growing up need good, functional adults somewhere in their lives. Often they have women, many of the boys do not have men. Whether it's a football coach or a good minister and I know that good ministers are hard to find these days, or an uncle or a grandparent, a man who's prepared to step up and be there for a young man for a period of time. So family is the fundamental building block.

Professionals only slightly value-add I think it would be fair to say. The problems that are talked about of language, of ADHD, of oppositional defiance, of conduct disorder, are extremely common in our community. ADHD runs at about 5 per cent - 3 to 5 per cent in the American and Australian community; specific learning difficulties run at probably 5 per cent and often children have several of those problems.

The solutions that are suggested are actually excellent for many of our children and would benefit all children. So I think - I certainly understand the need for particular groups to develop an answer for that particular group, whether it's the group of children with Down's syndrome, with spina bifida or whatever. However, in the world that I work in, where there's short resources, then we will try and allocate resources to children according to their need, with the resources we have available. We need to be advocating for a bigger pie for this group of children if we want to make a difference, and timely intervention.

The challenge to me as a paediatrician who has worked outside urban capital city Australia is always to compromise ideal medicine to deliver workable and acceptable health strategies and not actually to make things worse for families, and to some extent, for mothers.

This tree is a symbol that Glenys Coulthard and myself have used for a number of presentations. It sits out in the Flinders Plain and it's a tree that's seen good times and bad times, droughts, floods and many small creatures hide in its shade and live in its shade. It has its roots deep in the ground and they're the sort of child health services we need to build. Equally the discussion today is about building another root or a deeper root to the whole complex of child health services and educational services we wish to develop. So I'll stop there. Thank you.

DISCUSSION

JOHN WAKERMAN: Could I just ask the speakers to come up. We're just coming to the pointy end of the proceedings and we do have a few minutes for discussion and as I sort of flagged at the beginning, we're really looking also for some action. Some of the messages coming out of these very diverse presentations - and I really want to thank the speakers because I think it was a terrific range of presentations - are that this is the most common cause of birth defects, it's a hundred per cent preventable.

I have to say it pains me when I hear that people like Sue needs to make the diagnosis or needed to make the diagnosis and then had to convince the medical community of the diagnosis and had to go to Canada to get more information about it. That narrative is very consistent with, I think, some of the data that Heather was presenting about, really, how little health professionals know about this problem and I'm not sure about the NH&MRC either in their guidelines.

Again, in the presentation from the Strong Women, Strong Babies workshop here, we've got people who we in the medical community might call our patients, probably being able to identify this problem much more readily than we health professionals are able to and asking questions about prevalence of this problem in their communities, which we really can't answer.

And, Nigel, you always surprise me, because I was expecting you to give us some clinical point of view but you gave us a social perspective on this problem. I thank you.

So that was just a few of the messages that were getting across to me. But clearly we do have a problem. I don't think it's being adequately addressed anywhere really in the country although, as Heather was saying to me earlier, you know, there are patches of activity. There are patches of good research like the research that the Telethon Institute's doing. I know that there's been good work up in Cape York in terms of community education and health promotion there for some years. You know, there's been a lone voice out there in the Cape.

But there doesn't seem to be any concerted national effort in this area. And I guess the thing that disappoints me the most is that - Margaret Clarke didn't go into it but when you look at what they are doing in Canada, they're many years ahead of where we're up to now in terms of better education for health professionals, interventions, evaluation of those interventions and so forth. So it's not like there isn't anybody in the world doing this sort of work.

We'll throw it open to comments now and I'm quite happy to keep going as long as there is discussion going. In a few minutes I'll have someone coming in vigorously telling me to wrap things up because this is where we're having dinner tonight and they want to set up the tables. But don't worry about that, I think this is an important issue and it needs to be discussed. So really, over to you. Do we have a mic?

FEMALE SPEAKER: I'll talk loudly.

JOHN WAKERMAN: Okay.

FEMALE SPEAKER: My name is ...(inaudible)...

JOHN WAKERMAN: Shout, shout.

FEMALE SPEAKER: The guidelines are really unclear about how ...(inaudible)...

JOHN WAKERMAN: Does someone want to respond to that? Alcohol guidelines.

FEMALE SPEAKER: Look, I agree. I think to deliver those guidelines in a clinical setting is really, really difficult and I think there's a push by some - some other countries just go for, no alcohol is best in pregnancy and it's left at that and that certainly is what's come out of South Australia for Aboriginal women. They've said it's much easier to get this message across than to go through those complex guidelines and I think there are some bodies - I think the AMA are calling for the guidelines to be changed and made much clearer for people in - so I agree with you.

FEMALE SPEAKER: Could I add to that? The Centre for Health Promotion at the Womens and Childrens Hospital in Adelaide have just done some focus groups and have just had a launch of an Alcohol and Pregnancy Don't Mix Campaign a couple of weeks ago. And in those focus groups - and they had I think about 10 focus groups that they took some messages to those focus groups - they had a men's group, a women's group, an older women's group, a younger women's group, pregnant women's group and very clearly all of those groups said, "If there's any chance that alcohol might cause harm, we want you to say no alcohol at all".

And that came out very clearly from those community groups. They didn't want a wishy-washy message, they didn't want something that said, "Maybe it will and maybe it won't". They said if there's any chance, we want you to say, "No alcohol is the safest choice". So that's why the South Australian Government now, has, through the Womens and Childrens Hospital, has got a campaign, they've got that, "Pregnancy and Alcohol Don't Mix" is on the back of buses, on bus shelters, on some billboards and they've got packages that have gone out to all the general practices and to all their community health services. And they're also now developing a workforce development package for health practitioners as well, and that's in the process of being developed at the moment.

But the AMA too is calling for no alcohol in pregnancy, in their press release just before Christmas, is the safest choice.

JOHN WAKERMAN: You'll have to shout, sorry, we've got no mic.

FEMALE SPEAKER: I just want to make a brief comment. ...(inaudible)... what happens in a community where somebody really is addicted to alcohol, who is told that the only message that is acceptable is zero alcohol. Does that person then turn round and say, "Well, I've got no hope, so I may as well just ...(inaudible)..."

FEMALE SPEAKER: Look, I can't answer that question because I don't know. But I do know that the way in which messages are conveyed to people, whether it's in an individual clinical situation or in a group setting and the way in which people are made to feel bad or supported, as that message is conveyed, probably goes more to what the consequences will be than the content of the message, even if the message is no alcohol. So I think process is really important. I think the content of what we say is really important but I think if you convey messages in a supportive, rather than judgmental way, like you were saying Nigel, then that gives a person hope for the possibility of change.

JOHN WAKERMAN: Sorry, you'll need to stand up and really shout.

FEMALE SPEAKER: I just have one comment ...(inaudible)...

FEMALE SPEAKER: Sorry, I didn't quite hear all of what you were saying but I think people were comfortable with raising the issue about alcohol in pregnancy but a lot of people didn't do it. Is anyone doing anything with undergraduates? There's a whole issue about workforce I think that needs to be looked at, as to what information are people getting in their undergraduate training or if they're trained to be midwives or GPs to do obstetrics and so on.

It's just sort of like, where do you start really. And this is where I think it's important to have a strategy so at least we can all bite off different sized chunks.

JOHN WAKERMAN: Sorry, can you stand up and shout?

FEMALE SPEAKER: I'm a second year undergraduate, so haven't done a lot yet ...(inaudible)...

NIGEL STEWART: I was just reflecting on what Sue was saying, the good work that the Womens and Childrens is doing in Adelaide. What is really necessary is that people who are old and gnarly like me are updated and younger ones like Cheryl are updated and also that the rural and remote communities and their health professionals get information at the same time as urban people, because this is highly likely to be a problem that is at least equal in our rural communities, if not higher, because people are disaffected.

It will be inner city people who are street people who, in a number of different ways, are likely to be disproportionately affected. So dealing with the traditional mainstream health professionals will not get the message out quickly enough. So as they develop resources, and I certainly in what position I'm doing, will be pushing the Womens and Childrens to get stuff up to our rural practitioners as quickly as the urban ones. Because the road from Port Augusta down to Adelaide is always longer than the one coming the other way. It takes them a lot more to come out of Adelaide than it does for us to go down.

JOHN WAKERMAN: Okay. Look, there's quite a bit of agitation because they want us out but one last question or comment. Christine.

CHRISTINE: One resource that's available, and I don't know if people know about it, the Drug and Alcohol Unit ...(inaudible)... in rural and remote communities has excellent staff ...(inaudible)...

JOHN WAKERMAN: Thanks, Christine. Okay, please, two things. The first one is, if you have any recommendations, please write them down, give them to the front desk or come and talk to me and give them to me, in relation to this issue. Secondly, please just let's thank the speakers today.