

# **Fetal Alcohol Spectrum Disorder (FASD): Across the Lifespan**

**Proceedings from an IHE Consensus Development Conference 2009**



**IHE** INSTITUTE OF  
HEALTH ECONOMICS  
ALBERTA CANADA

**Editors: Egon Jonsson, Liz Dennett, and Gail Littlejohn**

**Fetal Alcohol Spectrum  
Disorder (FASD): Across the Lifespan**

*Editors:*

*Egon Jonsson*

*Liz Dennett*

*Gail Littlejohn*

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## Foreword

The Institute of Health Economics (IHE) has organized a series of consensus development conferences, all held in Alberta, over the last few years. The first conference was Self-Monitoring in Diabetes, followed by Healthy Mothers, Healthy Babies: How to Prevent Low Birth Weight; Depression in Adults: How to Improve Prevention, Diagnosis and Treatment; and Fetal Alcohol Spectrum Disorder: Across the Lifespan.

This very specific type of conference is one way of engaging citizens, decision makers, clinicians and experts to jointly address complex health issues from an evidence-based perspective. The IHE conferences are modelled on the National Institute of Health (NIH) Consensus Development program in the United States. The best way to describe a Consensus Development Conference might be: “A jury trial on health policy and scientific issues.” The IHE conferences have taken a policy perspective in their deliberations and outputs and are primarily designed to inform public policy decision makers rather than clinical practitioners.

The conferences usually involve 25 or more experts who deliver scientific evidence and testimony to address five to eight specific questions on a particular health subject. They deliver this evidence directly to a jury of 12 to 15 people over two days in front of an audience of around 300 people. The consensus format offers an independent consideration of issues by an unbiased panel. The jury takes the expert testimony into consideration during a “sequestered” period each evening after the hearings and on the morning of the third day renders its recommendations in a consensus statement which is read publicly by the jury chair for the experts and audience. The statement is then widely disseminated across the Canadian healthcare system.

The consensus statement is based on publicly available data and other information provided to the jury by the experts. The statement is not intended as a legal document, practice guideline, or primary source of detailed technical information. Rather, the statement reflects the views of a panel of thoughtful people who come to understand the issue before them and who carefully examine and discuss the data available on the issue. The program for the FASD conference and the jury statement are found at the end of this book. The statement may be ordered free of charge from [info@ihe.ca](mailto:info@ihe.ca).

This book contains the expert presentations and the discussions in the 2009 IHE consensus development conference, Fetal Alcohol Spectrum Disorder: Across the Lifespan, held in October 2009 in Edmonton. The Honourable Anne McLellan served as chair of the jury, and Dr. Gail Andrew as chair of the expert group. Ms. Nancy Reynolds served as the moderator of the conference.

The conference was organised by IHE in close cooperation with the Interdepartmental Committee on FASD (Alberta Government) and the Canada West FASD Partnership. Special

thanks are extended to Ms. Denise Milne with Children and Youth Services, Alberta Government, and to Dr. Sterling Clarren, Research Director with the Canada West FASD Partnership, for the time, effort and wisdom they brought to this important project.

For the IHE, Edmonton, Alberta, September 2010

**Egon Jonsson**

**John Sproule**

**Liz Dennett**



# Fetal Alcohol Spectrum Disorder: Across the Lifespan

## ■ Opening Remarks

*The Honourable Janis Tarchuk, Alberta Minister of Children and Youth Services*

On behalf of the Government of Alberta and our FASD Cross-Ministry Committee, I am very pleased to be here and pleased that we are being joined by the Honourable Iris Evans. I can tell you that Minister Evans has been instrumental in raising awareness of FASD in this province. She has been a champion in addressing FASD across the lifespan and, most importantly, she has been a true supporter of our cross-ministry initiatives. So, Iris, on behalf of all of us, I want to thank you for that.

It is wonderful to see so many individuals here who are dedicated to preventing FASD and supporting those that live with FASD or work with individuals that do. We know that approximately one out of 9,000 Canadians is affected with FASD, and this means that in Alberta 23,000 children, youth, and adults live with FASD. The social and economic impacts of FASD are immense. Directly or indirectly, it affects every one of us. It is estimated that each child with FASD may need as much as 1.5 million dollars in special care, support, and supervision throughout their lifetime. That does not include costs related to the loss of human potential. The real tragedy is that this is a completely preventable disorder.

In Alberta, our government is steadfastly committed to the prevention of FASD and to the support of community-based solutions that help all of those affected by FASD. In recognizing that FASD touches on many aspects of an individual's life, our FASD Cross-Ministry Committee is made up of nine ministries and other agencies that are implementing our 10-year FASD strategic plan. This plan is both a call for action and a source of hope. Our strategy is to focus on targeted prevention programs, assessment, and diagnostic services and supports for individuals, families, and caregivers. We are seeing positive results. Case workers and health professionals are collaborating with our local FASD service networks to support children and others affected by FASD. This means that children are getting services in schools in their own communities — the kind of support they need to overcome their challenges and reach their full potential. The FASD learning series presenters are sharing their knowledge with other Canadians through video conferencing, thereby enabling parents and caregivers to learn about FASD in their own communities.

This conference is building on research being conducted on the prevention and treatment of FASD. Looking at the list of speakers, I am very pleased to see that so many of the experts are from Alberta. I think this demonstrates that good work is occurring in this province. We know that the work we are doing benefits greatly from collaboration with our national and international partners. Some of those experts, from Canada, the United States and abroad, are here to share their expertise. I believe that we can learn a great deal from their various perspectives on diagnosis, treatment and prevention of FASD.

The name of one speaker in particular caught my eye because I have had the privilege of knowing him for several years. Myles Himmelreich is here to share his stories and I am always inspired by his courage, his optimism, and his dignity in overcoming FASD challenges. Affected by FASD his entire life, he has become one of Alberta's greatest advocates and mentors. Myles' stories, and those shared by all the speakers at this conference, will help the conference jury develop recommendations that can provide us with valuable direction for action in the field of FASD. I certainly look forward to those recommendations.

I would like to thank the Institute of Health Economics, the conference organizers, and others who have made this event possible. Special thanks for your support go to the Honourable Anne McLellan and other members of the jury. I think we have made great strides over the last couple of years, but we know there is much to do, and this conference shows that we are up to the challenge. The work done here over the next couple of days not only will help ensure that FASD remains in the public domain as a key priority, but will help promote the development of grounded policy that can guide evidence-based practices in the field. I thank you for that and wish you well with your deliberations, and I do hope you enjoy the conference.

At this time, I would like to introduce our next speaker. She is currently Alberta's Minister of Finance and Enterprise. Since 1997, she has held several portfolios, including Municipal Affairs, Children's Services, Health and Wellness, and Employment, Immigration and Industry. She is a champion of children and families in this province, and she is a good friend to all of us. Please join me in welcoming the Honourable Iris Evans.

***The Honourable Iris Evans, Alberta Minister of Finance and Enterprise***

It is gratifying to be here and to see the level of expertise represented. Gail Andrew and Nancy Reynolds are among those people who have been with us from the very beginning in championing FASD and taking action in the field.

When I was involved in Children's Services years ago, we in the prairie provinces were really struggling to coordinate sparse resources to make sure that we got the FASD message out and did the right things the right way. We tapped the expertise of people like Sterling Clarren and Bruce Perry, who have been providing advice and leadership in this direction for many years. I see more men here today than the few who were involved in FASD earlier. This is important, because FASD is not just about women controlling what they ingest. FASD is about life partnerships that create the next generation and it is about a complete understanding by both men and women of their responsibility to that future generation. I am absolutely convinced that the happy, pregnant, cared-for mother does not ingest alcohol. She has learned already that it is risky, and she has a partner who supports her. It is certainly clear to me that women do not do this alone.

I could not have been prouder than when my dearest friend and colleague in government was given the privilege of carrying the mantle for Children's Services. In my five years in that role, I

had staff members who went home in tears at night because they had heard stories of such travesty to vulnerable children. There is just no end to the support that Children's Services needs — and deserves — for protecting vulnerable children. Yet there is no way that the government alone can protect the vulnerable, whether they are FASD children or children with other special needs. We all need to work together on this. You will have to find new ways of reaching out about the many problems related to FASD. We started this initiative in the years when I was in Children's Services, but we have not gone far enough yet. I am hoping that this jury can identify ways to communicate better. I think that often we do not sufficiently precondition our audiences to get them ready for receiving the knowledge they need. I think this is one of the challenges. You will leave this conference knowing more about FASD than anyone in your community, and you have to precondition others to your message. You have to let them know, first of all, that they are caring people in their community, and you want to build on that and tell them why this is so important.

I will never forget a roundtable discussion on family violence and bullying that I attended. It was to start at nine o'clock, but already at eight people were seated because they were so anxious to talk about the problems. FASD is the same. You have been here since early this morning and you are anxious to fill up your minds, your souls, and your spirits with everything you might learn. But know this: you have to start as if this is the first day of the rest of your life. No matter what you have learned so far, there are not enough other people out there learning it; otherwise, we would not still have the problems that we have with FASD, a truly preventable condition that we have not made sufficient inroads into. So precondition your audiences when you go away from here and tell everyone what you have learned here. Put it into an email and send it to everyone on your contact list. You must help with the challenge of protecting the vulnerable, not only by looking after FASD-affected children once they are here in physical form, but by protecting people who are about to become new mothers and new fathers and telling them what you know.

Thank you very much for the privilege of being here. I especially want to convey my appreciation to the people at the Institute of Health Economics. Dr. Egon Jonsson, a genius who has come to work here in our province, has understood that the best of health economics is when we stop bad things from happening to innocent people. Thank you.

***Nancy Reynolds, Moderator***

Thank you so much, Ministers. Those of you from other provinces can see how fortunate we in Alberta to have this kind of leadership and commitment in government. It has been sustained over a number of years and continues to this day. Thank you very much, Minister Evans and Minister Tarchuk. You have set the stage to move us forward over the next two days and given us some inspiring thoughts about individual actions we can take.

The title of this conference is Consensus Development Conference on Fetal Alcohol Spectrum Disorder (FASD). For those who have not attended such a conference, a consensus development



conference has a different format from most other conferences. The purpose of a consensus conference is to elevate the available scientific evidence on a health issue — in this case, FASD — and to develop a statement that answers a number of predetermined questions. The questions for this conference are listed in your program and will be repeated through the conference.

Thirty subject experts will present the evidence to the jury. The expert speakers have been chosen for their experience and expertise related to each of the questions. The jury is an independent, broad-based, non-government, non-advocacy group of individuals, and quite well balanced between men and women. The jury will listen to and question the experts throughout the next two days. The audience will also be given an opportunity to pose questions to the experts. The jury members have already reviewed the scientific literature on this topic. At the end of today, the jury will convene and develop answers to the first three questions. When the presentations are complete tomorrow afternoon, the jury members will prepare the answers to the final three questions and review the answers they prepared the evening before. On the third morning, the consensus statement will be read to the audience. You will receive a copy of it and will have an opportunity to question the jury members on the statement.

We are very pleased to have such a distinguished group of individuals to participate in the jury. The jury chair is the Honourable Anne McLellan, former Deputy Prime Minister and federal Minister of Health; Judith Bossé, Associate Assistant Deputy Minister of the Public Health Agency of Canada; Jennifer Coppens, medical student, University of Alberta; Raisa Deber, Professor, Department of Health Policy, Management and Evaluation, Faculty of Medicine, University of Toronto; David Elton, President of the Norlien Foundation and President of the Max Bell Foundation; Mark Hattori, Acting Assistant Deputy Minister, Program Quality and Standards, Alberta Children and Youth Services; James Hees, reporter with the Canadian Broadcasting Corporation; Malcolm King, Professor, Department of Medicine, University of Alberta, and Scientific Director of Canadian Institutes of Health Research, Institute of Aboriginal Peoples' Health; Christine Loock, Associate Professor, Department of Pediatrics, Faculty of Medicine, University of British Columbia, and developmental pediatrician with the Children's and Women's Health Centre of British Columbia; Rebecca Martell, Clinical Associate, Occupational Performance Analysis Unit (OPAU), Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta; Edward Riley, Distinguished Professor in Psychology and Director of the Center for Behavioral Teratology, San Diego State University; Honourable Marguerite Trussler, former Madame Justice Trussler, currently serving as the Chairperson of the Alberta Liquor and Gaming Commission; and Lee Ann Weaver-Tyrrell, child health researcher with long experience in children's services. Please join me in welcoming these jury members, who have committed a huge amount of their time and energy to this important issue.

I would also like to thank the organizers of this conference and the partners in this event, whose generous support makes this conference possible: the Institute of Health Economics, the Government of Alberta and the Public Health Agency of Canada.

## ■ Question 1

### *What is Fetal Alcohol Spectrum Disorder (FASD) and how is it diagnosed?*

#### **Overview of FASD**

*Gail Andrew, Member, Board of Directors, Canada Northwest FASD Research Network; Medical Site Lead – Pediatrics; Medical Director – FASD Clinical Services; and Pediatric Consultant, Pediatric Program, Glenrose Rehabilitation Hospital*

I greatly value the contributions of the researchers whose work has informed not only the prevention and diagnosis of fetal alcohol spectrum disorder (FASD), but also the supports and interventions after diagnosis. However, I especially want to thank my real teachers of the world: the children, youth, and adults who have FASD. They have, by their stories and journeys, informed the real-life picture of this disability. As a developmental pediatrician, I work across disability groups. But there is something unique about FASD. Children and youth with FASD are often raised within the foster care system or with families who are on their own journeys of healing. That in itself raises stress and exhaustion, so that at the end of the day they may not have the energy to advocate for FASD. Therefore, we who are professionals in the field have an obligation to become the voice of FASD, to speak for those whose voices are not loud enough.

I will try to cover the history and terminology of FASD, talk about prenatal exposure to alcohol as a teratogen and a risk factor, and try to explain the complexity of diagnosis. I will also talk about the multidisciplinary team that is required in assessing for evidence of organic brain damage, and how FASD presents across a lifespan.

FASD is not new. The syndrome is mentioned in the Bible, and there is historical evidence of it in works of art that depict drinking in connection with the distinctive face of FASD. The initial medical reports on FASD were published in 1968 in France and in 1973 in North America. The first consensus meeting on this topic was convened by the Institute of Medicine in the United States in 1996. Another milestone was the development of the 4-Digit Diagnostic Code by Susan Astley and Sterling Clarren. That code has gone through two revisions, the most recent having been published in 2004. The Centers for Disease Control and Prevention in Atlanta developed their latest guidelines in 2004. The Canadian guidelines for diagnosis were published in 2005 (Albert Chudley et al.). There are also international perspectives on FASD, an example being the international collaboration under Edward Riley that is looking at FASD in Russia, Italy, Northern Ireland, South Africa, Australia, and other countries.

Let me first clarify some of the terminology of FASD. FASD is considered to be an umbrella term that refers to a lifelong disability resulting from prenatal exposure to alcohol. It includes fetal alcohol syndrome (FAS), which is the full syndrome; partial FAS, which has some of the physical dysmorphology of FAS; and alcohol-related neurodevelopmental disorder (ARND), which is an invisible disability without the distinctive dysmorphic face and growth deficiency.

What is common to all three of these conditions is a confirmed history of prenatal exposure to alcohol and evidence of organic brain damage by objective testing. The Institute of Medicine has defined this brain damage as a complex pattern of behavioural or cognitive abnormalities inconsistent with the developmental level and not explained by genetic predisposition, family background or environment alone. A related term is alcohol-related birth defects (ARBD), which describes the teratogenic and damaging effects that alcohol can have on other developing cells and organs.

How does alcohol cause damage to the developing brain cells and other cells? From animal research in this area, we have learned a great deal about the biological mechanisms by which alcohol damages fetal brain cells. One mechanism is a direct effect on developing neurons: on neuron maturation, migration, and organization. Another is oxidative stress through glutathione depletion in neuron mitochondria. Another mechanism is neuroendocrine and neurotransmitter changes in the hypothalamic-pituitary axis, resulting in chronic elevations of the stress hormone cortisol and its effect on the developing brain.

Alcohol also has indirect effects. It can affect the function of the placenta, which provides nutrients to the developing fetus, by changing the placental vasoactivity. Alcohol also indirectly affects maternal health and other teratogenic exposures, as it may predispose the mother to using other substances that have a devastating effect on the developing cells. There is also the question of how alcohol use by the male partner affects the developing fetus. This may be through the stress mechanism: the mother is in a chronic state of stress, her cortisol level is raised and that affects the fetus.

This knowledge is from animal research. Experiments with humans cannot be done in quite the same way. The human experiment introduces multiple variables and the whole context of the life situation, including multiple confounding risk factors related to this complex disability. The spectrum of damage depends on the amount and pattern of alcohol use. We know that binge drinking has a particularly devastating effect. The time of gestation is also important. The face develops over only a three-day period, from day 19 to 21 in the pregnancy, whereas the brain develops throughout the pregnancy. Therefore, the dysmorphic face may not appear as a marker, but brain damage may be present anyway. There are many other maternal and fetal factors, such as genetic factors, epigenetic factors, nutrition, and other drug exposures and health factors.

The key here is that alcohol exposure is a risk; it is not a diagnosis in itself. That is why we need to find evidence for organic brain damage. Some of the human evidence we have obtained is from neuroimaging studies at the research level. Structural magnetic resonance imaging (MRI) and volumetric studies have shown changes in the corpus callosum, cerebellum, and caudate. A decrease in frontal lobe volume has been correlated with the severity of facial dysmorphism. There is new research being done on the use of fetal ultrasound to detect differences in the developing fetal brain. Functional MRIs have shown less activation in the prefrontal area with increasing complexity of task. Researchers using diffusion tensor images (DTIs), which are MRIs that look at the white matter tracks in the brain, have demonstrated differences in major

pathways. However, while this evidence may be viewed on MRIs at the research level, the structural MRIs that doctors can order are almost always normal. Therefore, MRI is not a diagnostic tool for FASD.

What are the biological markers of FASD? Do we have a screening tool or a single test to diagnose FASD? Facial dysmorphology (that mid-facial hypoplasia that develops with exposure to alcohol on day 19 to 21) is far from perfect as a diagnostic marker for prenatal alcohol exposure. For instance, in my clinic population, less than 10% of all children coming to a tertiary level institution have dysmorphic facial features that would be significant for a diagnosis of FAS or partial fetal alcohol syndrome (PFAS). Data from studies of children in foster care show a higher incidence of facial dysmorphology, but FASD is most often an invisible disability. As to growth deficiency, there are many causes of small stature; we have to do a differential diagnosis and also look at the growth patterns of the family. Analysis of meconium (earliest stools from a newborn) to identify fatty acid ethyl esters, which are markers for alcohol intake, also has limitations. Meconium does not start to form until the 13th week of gestation, resulting in many false negative tests. There are also ethical issues related to this, which time constraints do not allow me to discuss now. Saccadic eye movement is another area being researched, looking at differences in how the eye tracks; however, that is still at a very basic research level.

In summary, we do not have a single, universal diagnostic test or a definite screening tool for FASD. The screening tool at present is a confirmed history of alcohol exposure. We also need to consider the postnatal environment. It is known that adverse environments can have an impact on early brain development. These environmental factors include deprivation, abuse, neglect, and lack of appropriate stimulation. If the brain is already damaged from alcohol exposure, it is more vulnerable to these postnatal factors. We also know that there are critical times during brain development in which to optimize development, and we need to make sure that we are not missing that boat.

What diagnostic criteria are used in my clinic and in other diagnostic centres? We need a confirmed history of alcohol use from a reliable source. This is a challenge for the adult-diagnostic clinics. We look for evidence of prenatal or postnatal growth deficiency, with growth of less than 10% being significant. We look for the facial features, such as thin upper lip, flat philtrum, and short palpebral fissures, using photographic analysis. We need population norms; recently, palpebral fissure norms for the Canadian population have been published (Clarren, Chudley et al., 2010). We need evidence of brain damage, because ultimately diagnosis depends not on the face, but on the function. To capture that function requires multidisciplinary teamwork. The tool that most clinics are using is the 4-Digit Diagnostic Code developed by Astley and Clarren. That is a quantitative, objective approach to looking at all four categories that I discussed previously (growth deficiency, FAS facial features, central nervous system damage or dysfunction, and prenatal alcohol exposure). It is a time-consuming process for a multidisciplinary team to gather historical and current data through direct testing for evidence of organic brain damage and then to consider all the pre- and postnatal factors before formulating

the diagnosis. FASD is really a diagnosis of exclusion: a careful process of differential diagnosis is needed to identify what else could explain the particular condition or is possibly coexisting. Co-morbidities of a mental health nature also need to be considered, both in the diagnostic process and in interventions.

We need to develop standards and guidelines for diagnosis, and we need to train consistently in order ensure that diagnostic teams are using the same approach. Newly established teams need to be mentored by an established team in order to become competent in their own diagnoses. By using the same tools, standards, and guidelines, we will also be able to monitor incidence and prevalence of FASD and thereby develop a good surveillance system. That would make it feasible to monitor the impact of our prevention programs and continuously provide information about the results of interventions.

The current standard is to identify evidence of impairment in brain function in three areas that are not influenced by one another. This is a field in need of ongoing research. One of the important pieces of work in this field has been done by the Canada Northwest FASD Research Network. That network has identified a range of assessment tools that can be used by practitioners in each of the core disciplines: physicians, psychologists, occupational therapists, speech pathologists, and social workers. It needs to be refined; it is a work in process, a live document. Once all that information is gathered, there has to be a formulation process to get a picture of how the brain works. These are the eight key domains that we look at: 1) the intellectual domain, which is a frequent issue in the FASD population whose IQs are within the average range, as this causes a problem when standards for funding such as PDD (Persons with Developmental Disabilities) are raised; 2) academic achievement; 3) attention; 4) sensory, motor, visual, and spatial skills; 5) communication, not just at basic but at higher levels; 6) all aspects of memory — getting it in, the encoding, as well as retrieval and working memory; 7) executive functions, including judgment, inhibition, mental flexibility, problem solving, planning, sequencing, initiating, switching, and so on; and 8) adaptive functioning, or the core day-to-day functioning that affects one's ability to live independently, to be employed and to avoid being victimized.

How does FASD present across the lifespan? The newborn period is the optimal time to intervene, but it is very difficult to diagnose FASD in newborns or even to get the history of maternal alcohol use. But it is the optimal time to reach out to the birth mother. In the early years, children can present with delays in development that are not specific to FASD, although again this is the optimal time for intervention. Therefore, intervention needs to be based on functional need rather than driven by a diagnosis of FASD. Through the upper school years, we are able to do more specific testing to define this disability. However, while we can do more testing in adolescents and adults, we often cannot get at the history of alcohol use that will connect that individual's disability to prenatal alcohol exposure. These are some of the complexities in diagnosing FASD.

Why should we diagnose FASD anyway? Diagnosis enables us to reach out to the birth mother and leads to understanding the individual's requirements for support in education, community living and employability. Diagnosis also helps us shift away from blaming, to looking at FASD as acquired brain damage. We also need to evaluate the outcomes of our efforts in prevention and treatment. We need research into the longitudinal trajectory — how does this disability evolve over the lifespan? What interventions make a positive difference?

My policy recommendations for this disability, based on findings from research, are to:

- secure ongoing research into the best assessment tools for each age group;
- train multidisciplinary diagnostic teams to increase capacity and consistency;
- provide sustainable funding for diagnostic teams in both rural and urban areas;
- better identify best practices for interventions across the lifespan, and implement these interventions at local community levels;
- secure funding for longitudinal follow-up across the systems of care; and
- develop effective prevention strategies, including a health determinants approach, and link those to best practice, especially for high-risk mothers.

## A personal perspective

*Myles Himmelreich, Director of Programming, Canadian FASD Foundation*

I am going to share with you a bit about my life and growing up with FASD. I went to school and had many of the same struggles that a lot of individuals with FASD have: trying to fit in, memory issues, challenges such as being on time for school, being able to do the school work, being able to remember it when I got home and to take it back to school to hand it in. Fitting in with the kids in school was a struggle because I was already a bit different. I was being judged and kind of put out there, so it was hard to fit in with the kids. I was having problems in school and, then, after school as well.

FASD is an invisible disability. When we see people with other disabilities we often note something that stands out, whether it is a wheelchair, a hearing aid, or a seeing-eye dog — something that says, yes, this person has a disability, this person needs support and help. But in the case of somebody with FASD, there is not necessarily something that jumps out to say this person needs support and help. That was very true for me and is for many individuals with FASD. The fact is that not only can the people around a person with FASD not see or note anything special, but the individuals with FASD do not see it themselves. They do not see something that jumps out to say, “Yes, you have a disability and that is why you have these struggles; that is why you have these issues.” I could not see my disability. I looked in the mirror and did not see anything to say, “It is okay, because you have FASD; that is why you are having

these problems.” I just saw somebody that looked like a regular kid, so it did not make sense that I had all these problems.

I continued on through school until I got to high school, at which point I decided that school was not something that was going to work for me. I tried and tried, but I just was failing. I left school and went on to get a few jobs. I was not able to keep jobs for very long because I was either late showing up for them or I could not remember how to do them properly. So I would lose my job or I would simply quit. I preferred to quit, instead of looking like I was stupid or simply too dumb to do these things. It was a lot easier to just walk away from them.

I have been through many things that young children with FASD go through. I had seven or eight foster homes before I was two and a half years old. I was adopted. I did not know my biological family. I had all these struggles in school and with keeping a job. At that point in my life, I decided that what I needed to do was find my biological family. I thought that was going to make everything make sense, to tie everything together. As much as I had support and love from my adoptive family, I felt that something was missing and I thought that maybe that was it. So I went to find my biological family, to find out that there were about nine or so of us in the family. We were all separated, had grown up in different homes, and many of us did not even know of each other. My father had been murdered and my mother had died from alcohol abuse. Again, here was another point in my life that was not working out for me. Things were not really going the way that I thought life was supposed to go.

At that point, I started to learn about FASD. I learned that with FASD you would not be able to maintain a job, you would not be able to live independently, you would not be able to finish school, and that there was a high probability that you would end up in prison. A lot of that was true for me. I could not keep a job, I did not finish school, I had some problems with the law, and I was not able to properly live by myself. It was hard to hear these things, because, to me, it was all negative. I had this negative thing called FASD.

Eventually I started to get friends and I turned to drugs and alcohol. Drugs and alcohol not only got me friends, so that I felt I was being supported and accepted, but also, for once in my life, when I drank, my body felt relaxed. So whenever I was all “Oh my goodness, I can’t handle this,” I would turn to alcohol. Going through school, I had many of those situations. A lot of times my body was all over the place, so when I found something that actually calmed me down for once and which also got me friends and got me accepted, I thought, “Wow this is it, this is the ticket!” Of course, it wasn’t. I experienced a lot of depression and, of course, alcohol is a depressant, so it certainly didn’t help.

As time went on, I realized these things were not helpful or beneficial in creating the life that I wanted to live. I felt inside that I could do something big. I could make a change in this world. But I thought, “How am I ever going to be able to stand up and say that if I cannot even keep a job for a week? Who is going to believe in me?” I had a lot of doubt in myself. I ended up eventually going to a pre-employment program. I had done many of them up to that point, but this time I decided I was really going to put some effort into it. I had pretty good attendance and

ended up graduating the program. That was the first time I had finished something in my life, and that felt good. I went from there to get a job, and then decided that I was going to move out on my own.

I had heard all the statistics about somebody with FASD and how the struggles would come into play and I knew that they had up to that point. But I thought, “People are thinking that I am not going to succeed. If I do, that will be awesome; and if I don’t, I’m still where I was before.” I got a full-time job, I moved out on my own, and I started to get new friends — friends that were positive supports in my life. I started to turn to sports, which became my kind of AADAC [Alberta Alcohol and Drug Abuse Commission]. I would go do sports on weekends instead of partying and things started to change. I began to realize that I was doing things over and over again and that I needed that routine. I would make sure that my rent was paid from my first paycheque of the month. My bills would be paid from the second paycheque and what was left over was mine. I started to buy clothes and videos and a TV and stuff like that. It felt good to come to my own place and sit down and see these things. Before, it all used to be alcohol and drugs; now it was things I could see and appreciate. To some people that might seem small — that I had a house and TV — but it was a huge thing for me. I realized that techniques like routine and repetition were important and that as I was putting in a little more effort, things were going in a positive direction. Even though things were starting to change and go in that positive direction, I was still very scared, because up to that point in my life every time something good happened I ended up losing it. Every time I built myself up, I ended up falling down. I went to school, and ended up falling down from there. I had friends and ended up falling down from there. I had a family and ended up losing them. So it was hard and very difficult to accept success and hard and difficult to accept that I was growing. It was scary for me, and people did not understand that.

I ended up going to speak at a conference once, on living with FASD. It was the first time I had done that and after I finished my speech I had the same feeling I had had years ago, that I could make a change and do something good. I realized that is the direction I am supposed to go in. I continued doing public speaking and began mentoring other individuals with FASD. I realized I was able to speak to them and listen to what they were going through and that much of it I had struggled with and gone through. I was able to communicate and share the techniques I have used to live a positive life with FASD.

When you do research and education on FASD, you are trying to achieve outcomes. For me, in struggling with addiction issues, homelessness, school, jobs, and other things, a most important outcome is to have support. I did move out on my own, but I did and always will need support. I have my adoptive family who I am very close with and who are very loving and supportive. I have friends who have become very interested in FASD, who come to FASD Day and breakfast meetings. I have co-workers who understand where my limitations are, but also understand where my strengths are and go on those. We sit down and work out a schedule that works for me so that I am not overwhelmed and can do the best job that I can. I have those supports and will



continue to need them. I have FASD and I will always have FASD. It was a huge learning curve for me to understand that I need support and help and that I am going to have ups and downs and struggles because I have FASD. My main message is, however, that there is so much hope, potential and even success for everyone with FASD. I have been blessed with many talents and I have had the opportunity to go out and share and speak about some of the struggles and the successes that I have had, which I think is quite amazing. I embrace and realize that it is the whole package that makes me who I am. FASD does not make me who I am. I have FASD, but I am not FASD.

Minister Tarchuk said that it costs 1.5 million dollars to support and properly raise an individual with FASD. When supporting individuals with FASD, everyone from the teacher to the social worker to the parents, grandparents, siblings — everyone who is involved — needs to come together as a supportive team. In the community, we need to acknowledge that FASD is out there and needs to be spoken about and addressed. If we, over the next few days in this conference, can come up with techniques and ideas for supporting individuals with FASD, that would be an amazing and great thing. I think this conference shows that we can come together as a support team, everyone from the parents to the honourable ministers. A huge team effort is needed for helping people with FASD. If each individual costs 1.5 million dollars without support, we can save a lot of those costs by being supportive. If each individual costs 1.5 million dollars, that is a lot of taxpayers' money. But at the end of it, I know that they are worth it, and I know that I myself am worth that 1.5 million dollars.

## **Jury questions and answers**

*(Gail Andrew, Myles Himmelreich)*

**James Hees** – Is there something missing in the community that you think would lead others to find that they have FASD if communication was done in some better way than at present?

**Myles Himmelreich** – Awareness is a huge thing. Awareness and acceptance. I think there are some individuals who believe they might have FASD, but they are scared to step forward and say it. I think we need to stop being scared and hiding FASD, and accept it, embrace it, and support it.

**Gail Andrew** – Myles has presented a beautiful summary of why we need a system of care for individuals who have been prenatally exposed to alcohol. FASD is not a definitive diagnosis; however, if there is a history of alcohol exposure, we need to build a system of support and to let the caregivers know that the child has had that exposure, that the individual has strengths, but may have some limitations that are not evident at a very young age. We do not always have the capacity to provide ongoing support to that child and family. As Myles has said, it was not until he transitioned into adulthood that he had a more functional diagnosis.

**Marguerite Trussler** – It appears that the current diagnostic processes are cumbersome, somewhat non-specific, time-consuming and often delayed. Can you tell me what work is now being done on a specific biological or functional test?

**Gail Andrew** – Many of the biological markers are still being researched, and I will review some of them. Meconium testing for fatty acid ethyl esters, which indicate alcohol exposure in utero, was looked at as being a very hopeful diagnostic tool, but we're missing many people through false negatives. How much does it take to have a positive test? And it's only a marker; it does not tell us about brain function. In my own clinic, we see children who have had heavy exposure to alcohol, because that is the entry criterion. Around 30% do not get the diagnosis, especially at a young age. These individuals need to be reviewed over time. I don't think a single biological test will ever replace the need for a functional assessment of the individual's pattern of difficulties.

**Lee Ann Weaver-Tyrrell** – In regard to risk factors, you spoke about the ambiguity around the amount of alcohol or when it's ingested. What are your thoughts on the tolerance level, in an ideal world, for alcohol ingestion in pregnancy?

**Gail Andrew** – The current public health message is that no alcohol, either when planning pregnancy or during pregnancy, is best for the health of the fetus. Whether this is achievable is one of our big questions in developing and implementing prevention campaigns. We do know that many pregnancies, probably a majority, are not planned, and the risk of exposure can be high depending on the lifestyle of the mother. But the current public health message is zero tolerance.

## **Audience questions and answers**

**Audience, Egon Jonsson, CEO of Institute of Health Economics** – A main theme here is alcohol consumption during pregnancy. I wonder if there is scientific evidence of an impact of alcohol on the sperm and, in that case, whether the father's lifestyle may have a role in causing FASD.

**Gail Andrew** – Fetal alcohol spectrum disorder is caused by the direct teratogenic effect on developing fetal cells of alcohol from the mother through the placenta into the fetal system. Alcohol may have some effect on the sperm, such as by causing very micro deletions in DNA. However, I think the most important effect of alcohol used by the male partner is the indirect effect of his not being there to support his partner in making healthy choices. Very often birth mothers say they want to change, but feel they are pulled into the drinking culture. Alcohol use by the male partner is usually not an isolated factor; there can be many other factors in the mother's environment, such as extreme domestic violence, a chaotic lifestyle, a high stress level. So it is complex; but paternal alcohol consumption does not lead to the fetal brain damage of FASD.

**Audience, Leonora Hendson** – In the neonatal intensive-care unit (NICU), we identify families in which the mother has taken alcohol and the child is at risk of developing FASD. I'm concerned about how we support these families from the NICU, who are already a high-risk population. When these mothers go home, what programs are in place and how do we make sure that these children are followed and tested or assessed as needed? Statistics at NICU show that children born at less than 28 weeks have about an 11% chance of mental delay, cerebral palsy, and so on. But about 5% of them have FASD. So these are pre-term children who are already at

risk of disability and, in addition, 5% of them have FASD. How do we follow these children and ensure the families get the support that they need?

**Gail Andrew** – If the alcohol use is not picked up until the point of delivery, we have missed a huge window of opportunity to work with the mother to reduce harm during the pregnancy. However, if the mother has admitted to prenatal use of alcohol, the most important thing is to optimize the postnatal environment. We need to evaluate whether it is safe to let that baby go home with the mother. And if we feel that the home environment is safe, I think we have an obligation to optimize that child's development by doing developmental monitoring, because while alcohol exposure on its own is not a diagnosis, it is a huge risk factor. We can optimize the postnatal environment by arranging home visitations, by connecting the child with developmental services if we see there is a deviation in development, and then by planning full assessments around a positive diagnosis. That would be the optimal system of care. That would be another one of my recommendations, to optimize that postnatal period.

## ■ Question 2

***Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?***

### **Prevalence and incidence in Alberta and Canada**

**Suzanne Tough**, *Scientific Director, Alberta Centre for Child, Family and Community Research; Professor, Paediatrics and Community Health Sciences, University of Calgary*

I will begin by providing a definition of incidence and prevalence. I will then talk about what we need to consider in data interpretation, what we know in general about FAS and FASD in Alberta and Canada and what we know in subpopulations, where we see gaps in our data, and some opportunities and next steps.

Incidence is the number of new cases that occur during a specific time period. For FASD, incidence rates are usually reported per thousand live births. This requires a defined population and defined criteria for diagnosis. Prevalence includes all new and existing cases at any particular point in time. It can be reported retrospectively (for example, all new and existing cases in 2006) or currently (all new and existing cases right now). Prevalence rates can give us a good idea of how many people require resources and supports for living with FAS and FASD and can help us determine when and where services are most needed. Prevalence rates are more commonly reported than incidence rates.

The following are some things we need to consider when we think about the incidence and prevalence of FAS and FASD. First, when is it a new case? Theoretically, FAS can exist in a fetus for up to seven months prior to birth, and it is difficult to know exactly when a new case begins. The prevalence of FAS during certain months of pregnancy may be higher than the number of FAS cases reported at birth, due to spontaneous abortions. Also, we discover a new

case with diagnosis, but diagnosis may take place much later than the onset of the condition. This is particularly true with FASD, where abnormalities may not be prevalent or noticed at birth. This can influence incidence rates, which are calculated by the number of live births. And this depends also on the method used to collect the data. Considering this, a new case can exist without being identified for many years. This is probably why prevalence is talked about more often than incidence.

We also have to consider that diagnostic definitions of FAS will influence prevalence estimates. A study incorporating a broad definition is likely to produce higher rates than a study using a narrow definition. Finally, if recruitment for a study is based on referrals, then children who have mild effects or are unknown to the referral agency will be missed. It is helpful that we have Canadian guidelines for diagnosis of FASD. However, because of our limited capacity for comprehensive multidisciplinary diagnostic evaluation, the rate of diagnosis could be low. This means incidence and prevalence rates may be low due to under-detection. So, a low incidence or prevalence rate could mean that prevention programs are effectively targeting at-risk women. But it could also indicate that there is low identification of the disease.

There are different ways of studying incidence and prevalence, and they lead to different rates of detection. Dr. May has provided a framework for understanding the advantages and disadvantages of different ways of detecting cases. In passive surveillance, we use existing records in a particular geographic area. This has the advantage of being efficient because it uses systems, programs, and records that already exist. It costs less and it is easy to conduct. The disadvantages are that FASD can be difficult to diagnose at birth, and passive surveillance relies on diagnoses by many hundreds of non-specialized physicians.

Clinical studies that involve prenatal observation and study allow some postpartum follow-up of the outcomes. This offers the opportunity to gather data on maternal history and to study a large number of pregnancies. The disadvantage is that subjects may self-select, so that those at highest risk of FASD may be unlikely to attend a clinic.

With active case ascertainment, we actively seek, find, and recruit children who may have FASD within a particular geographic region. The advantage of this is that we can focus on finding children of appropriate ages for diagnosis and we can study an entire community or a population to ensure wide representation. When case ascertainment is comprehensive, we are likely to get more accurate prevalence rates than we would expect by some other methods. The disadvantages of this method are that the cost is high in both labour and time, it requires community support, and often such studies focus on high-risk populations.

There have been subpopulation studies of prevalence rates in northwestern Canada, in northern Canada, and in the criminal justice system. However, we cannot generalize from subpopulation data, and estimates vary from population to population. While knowledge of these rates is necessary for determining the supports and services that need to be developed, it is important to remember that they are not representative of the majority of the population.

Before I talk about rates, I will explain what we did to find out what we could about the incidence and prevalence of FAS and FASD. This is a brief summary of our methodology. We looked at all known and accessible papers and reports, we searched MEDLINE and the references of the articles on incidence and prevalence, and we looked at provincial and territorial government websites for sources related to rates. What we found is that there are no official Canadian statistics on incidence rates. As of 2004, the incidence of FASD in Canada was estimated at 9 per 1,000 births in an AADAC and Health Canada report, and the rate of FAS was estimated in an AADAC document at 1 to 3 per 1,000 live births. There were no citations for these figures, but the numbers seem to come from the rates estimated in the United States or the Western world literature.

Currently, the Alberta Children and Youth Services ministry does not gather information on FASD in any systematic way, although we have been told that a new case-management information system will provide that capability. When we looked for FAS rates in other provinces, we were able to determine the following. In British Columbia, the rate was suggested to be 0.25 per 1,000 live births among non-Aboriginal populations and 4.7 per 1,000 live births among Aboriginal populations between 1972 and 1980. The rate in Saskatchewan was estimated at 0.589 per 1,000 live births between 1988 and 1992, and a rate of 7.2 per 1,000 live births was identified in a northeast Manitoba hospital in 1994. Some of these estimates are more stable or reliable than others. The Manitoba data are likely unstable as a consequence of the methodology (small sample size and mostly Aboriginal population). This limitation was noted by the authors, not just through our careful review of the material.

When we looked at prevalence rates among children in care, we found Manitoba data suggesting that 11% of all children in care in Manitoba had an FASD diagnosis in 2004–05. The prevalence rate across 13 corrections sites in Canada was 0.087 per 1,000 in 2001–02. These were known cases reported in the files of inmates in the system. In a well-known British Columbia study in 1995–96, 23.3% of 287 youth remanded to inpatient psychiatric assessment in British Columbia over a one-year period had an alcohol-related diagnosis, of which 1% had FAS and 22.3% had FAE.

Prevalence rates have been reported among Aboriginal children living in Aboriginal communities. However, it is important to note that in a recent report by Janet Smiley there are no population-based estimates for First Nations, Inuit, or Métis children in Canada. The wide ranges of FAS (31 to 62 per 1,000) and FASD (51 to 101 per 1,000) reported for Aboriginal children in a Manitoba community reflect the instability of the methods used to obtain the data. The most stable estimates come from studies of over 36 communities, in which we see that in northwestern British Columbia FAS in Aboriginal children is estimated at 10 per 1,000 and FASD at 25 per 1,000. In the Yukon, FAS is estimated at 24 per 1,000 Aboriginal children and FASD at 46 per 1,000.

As has already been noted by Dr. Andrew, the risk of FASD is related to exposure to alcohol. If the risk of having a condition under study is related to exposure, then information on the rate of

this exposure in the population helps us better interpret our incidence information. We know that in Alberta there is a range of alcohol use during pregnancy and that 50% of first-time mothers report having consumed some alcohol before they knew they were pregnant. About 73% of these report low-risk patterns of consumption. Eighteen per cent report alcohol consumption throughout pregnancy. A further illustration of the complexity of FASD is highlighted in cases of discordance in twins. This reminds us that the development of FASD is a complex interaction between the amount of alcohol consumed, when it is consumed, fetal susceptibility to alcohol, and maternal characteristics such as age, nutritional status, genetics, and lifestyle.

It is clear that there is an absence of data on incidence and prevalence rates across Canada, within some of the provinces, and within cities and subpopulations. Many of the statistics reported today are from 1987 or earlier. There is inconsistency in diagnostic and reporting criteria and tremendous variation in study methodology. Because of issues related to case finding, sampling, diagnostic criteria, and coordination of interdisciplinary activities, establishing rates of FASD has been challenging. I will, however, make a cautious attempt. The incidence of FASD, according to the data we found, is potentially between 0.25 and 7.2 per 1,000 births, and the incidence of FASD somewhere between 2 and 9 per 1000 births. The prevalence of FAS is somewhere between 0.087 and 121 per 1,000 people, and the prevalence of FASD is somewhere between 25 and 233 per 1,000 people.

There are gaps in our knowledge of incidence and prevalence. However, we do know in which systems of care and subpopulations the prevalence is higher, such as children in foster care or youth in custody. Low incidence and prevalence could mean that prevention is working or, again, it could mean that there is poor identification of the disorder. But we have to start counting in other areas, and counting better. We want to arrive at the point where we will feel more confident that our prevention efforts are working. In the meantime, we cannot let counting get in the way of doing something. We need to intervene according to the developmental needs of these children and these young adults and adults.

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## Prevalence and incidence internationally

*Philip May, Professor of Sociology and Professor of Family and Community Medicine, University of New Mexico; Senior Research Scientist, Center on Alcoholism, Substance Abuse, and Addictions*

We do not know the exact prevalence or incidence of fetal alcohol spectrum disorders. The simple view of causation is summarized by QFT: that is, a child's traits are influenced by the quantity of alcohol consumed by the mother during pregnancy, the frequency of alcohol use, and the timing during the gestation of the child. Is there a threshold for blood alcohol concentration that will cause a particular level of FASD or FAS? It cannot be extrapolated accurately to humans from animal studies; and human research is limited because the many methods of determining a threshold scientifically are not ethical. The incidence of FASD is also affected by maternal traits and cofactors exclusive of alcohol use, which increase, mediate, or mitigate the risk for FASD in a particular child, in a particular mother, in a particular pregnancy, and in a particular community, as broad socioeconomic and public health conditions do affect the rate of fetal alcohol spectrum disorders.

I will discuss some known cofactors in the incidence and severity of FASD. This is not an exhaustive list by any means, but it gives an idea of the difficulty of trying to determine the prevalence of fetal alcohol spectrum disorders. In South African studies, the nutrition of the mother, both lifelong and during pregnancy, has been shown to be a significant factor in the degree to which features of FASD manifest in the child. The lower the nutrition of the mother, the more likely the damage will be severe. The body mass index of the mother is also significant, which we will discuss further. Genetic factors, while not fully understood even in laboratory animals, certainly play a role, particularly in alcohol metabolism. It has been shown that individuals who are deficient in alcohol dehydrogenase (ADH) and aldehyde dehydrogenase (ALDH) metabolism tend to drink less and therefore have a lower risk for producing children with fetal alcohol syndrome. The inverse is also true.

Race and ethnicity are factors, in that modal drinking patterns vary among racial and ethnic groups. But there may also be race-related physiological features, particularly the size of the mother, which influence the rate and severity of fetal alcohol spectrum disorder. There are also demographic factors. The older a mother is and the higher the gravidity (the more pregnancies she has had), the more likely we are to see children born with severe FASD. This makes birth order significant, with later-born children more likely to be damaged by alcohol exposure. Socioeconomic status is very important. In general-population studies, those in lower social classes have a much higher rate of FASD. And spirituality is an interesting factor: in some populations, women who are highly religious are less likely to be drinkers and therefore less likely to have children with fetal alcohol syndrome. Finally, there are many familial factors.

I will give an example drawn from one of our large general-population studies in South Africa. We have extremely good data in these studies because the women that we interview are very



honest in reporting risk factors. We looked at the DDD, or the number of drinks consumed per drinking day in the first, second, and third trimesters. From these data, we estimated blood alcohol concentration, determined through the BACCuS method. The study groups were mothers of children with FAS, mothers of children with partial FAS, and a control group, randomly selected. Among FAS mothers, the number of drinks per drinking day in the first trimester was 5.7, meaning that on a day that they drank, they consumed an average of six drinks. Mothers of children with partial fetal alcohol syndrome consumed about four drinks per drinking day. Approximately 24% of mothers in the control group drank, and they consumed about the same amount of alcohol as those with partial-FAS children. This pattern existed through all trimesters.

When we translate DDD into estimated blood alcohol concentration, we see in mothers of children with partial FAS the lower blood alcohol concentrations that we would expect in the mothers of unaffected children. In other words, it is not as simple as the drinks per drinking day and not as simple as how DDD is translated into the blood alcohol concentration. One reason it is not simple is that in South Africa the size of the mother is a significant factor. Mothers with FASD children are shorter and lighter, and, while their head circumference is the same in this particular study, they have a greatly reduced body mass index. That is, small mothers were more likely to have an FASD child, whereas mothers in the control group had an average body mass index of 27.4, which is in the overweight range. This one cofactor, of maternal body size, is very important in determining how the alcohol affects the child.

There are three major methods for studying the prevalence of FAS and FASD. Surveillance and record-collection systems use existing data that is captured, recaptured, or derived from birth registries. Clinic-based studies are usually done in prenatal or antenatal clinics, where good maternal histories can be obtained and an attempt is made to diagnose children as infants. Finally, active case ascertainment systems use data gathered in specialized referral clinics in outreach populations or in in-school studies.

These different methods produce different rates of prevalence. The approximately 15 surveillance studies that are readily available found an average of 0.85 children with FAS per 1,000 and a median of 0.27. Clinic-based studies, of which over 50 have been published, show a higher rate of fetal alcohol syndrome: 1.8 per 1,000 and a median of 1.9. The eight active case ascertainment studies reviewed, which exclude in-school studies, produced a rate of 15.6 per 1,000 and a median of about 9. This tremendous variation of prevalence rates can also be seen in studies of FASD. I found no surveillance studies of FASD, but clinic-based studies produced an average rate of 6 per 1,000, with a median of 5. Active case ascertainment studies, excluding in-school studies, produced an average of 38 per 1,000, with a median of about 19. We can see that higher rates are reported from active case ascertainment. However, caution is needed here, as active case ascertainment studies are usually carried out in high-risk populations and we cannot extrapolate from those to a general population. The most quoted estimate of the rate of FAS is about 0.5 to 2 per 1,000, or 0.5 to 3 per 1,000 from the Institute of Medicine report. For FASD, it is about 1%, an estimate usually derived from Sampson et al. in a longitudinal study in Seattle.

Since 1997 my colleagues and I have been doing in-school prevalence studies that provide a team of specialists access to a general population of children. Children in first grade (ages six to seven) are at an optimal age for an accurate diagnosis of FAS. Dysmorphology and growth are well known at that age and neurobehavioural testing can begin to discriminate limitations in key areas such as executive functioning. In retrospective maternal interviews, mothers generally report higher alcohol consumption than in reports given in prenatal clinics. And early identification (diagnosis by grade one) makes it possible to give FAS children the life and educational opportunities they need to prosper. One challenge is that the relationship that researchers develop with children requires active consent of the parents. In one in-school study, Sterling Clarren and colleagues in Washington were able to use passive consent in one of the two counties that they worked in. However, institutional review boards will not let us do that now, which is probably good.

I am going to report on data from South Africa, Italy, a western city in the United States, and a Head Start program in a community on the American plains. What we found in South African studies of FAS is that the average rate of prevalence is about 50 per 1,000, or 5%. Now, South Africa is a special case, where many forces have converged to create a very high-risk population. Most people do not believe that situation applies to North American populations. I think it does. I think the methods apply. I also think many of the risk factors apply and can be extrapolated to North America.

In Italy, we found prevalence rates of 5.6 and 6.8 per 1,000 for FAS. We found a rate of 2 per 1,000 in one wave of pilot screening in the western city in the United States, and 8.9 FAS per 1,000 in another screening of the same western city. In the plains Head Start school, we found 10.2 per 1,000.

Moving now to rates of FASD, in our studies in South Africa (where we combine FAS and PFAS because we are keying on dysmorphology), the estimate for FASD is about 72 per 1,000, or 7%. The rate for FAS and PFAS (again, FASD) combined was about 3% in Italy, or 30 per 1,000, and 4% in another wave in the same Italian community. These are general-population, middle class communities in Italy. In the western city, the rate of FASD was about 1.4%; it was about 2% in another wave in the western city. And FASD children represented about 2% in the plains Head Start school.

What does all this mean? Recall that the older estimates of prevalence of FAS in the general population were 0.5 to 3 per 1,000. We believe that the prevalence of FAS is closer to 2 to 7 per 1,000; and rather than FASD existing at 1%, we believe that the rates of FASD, particularly PFAS and FAS combined, the more dysmorphic forms of FASD, are between 2% and 5% in the general population of developed countries.

Is this a substantial public health problem? I have always been very much a skeptic about the prevalence of FAS, but I was working in high-risk populations and did not have the experience in the general populations that I have now. Even with active case ascertainment studies using referral, we missed many. But in-school studies have added a great deal to this area, and I believe

the prevalence rate is higher than we previously estimated. It is a very significant public health problem. If we do not actively seek FASD cases, we will not find the majority of them, especially the less severe cases. FASD is the leading cause of mental deficiency in many modern societies. We have said that for years, and I believe these in-school studies are showing that to be true.

## **Jury questions and answers**

*(Suzanne Tough, Philip May)*

**Audience** – Could you tell us how the lack of definitive incidence and prevalence rates affects the ability to get money for research?

**Philip May** – It has been very hard for me to get money to do these prevalence studies. I think what we are finding in the in-school studies will raise the priority of FASD in a number of fields. The whole area of outreach and epidemiology should be elevated, not only for FASD but also for autism and other spectrum disorders. Educational research should be enhanced to identify these children. I would hope that by looking more carefully in general populations, as we are doing in these in-school studies, we will get a larger share of the research and prevention money — because the kids are there; they really are.

**Raisa Deber** – From a policy viewpoint, we heard earlier that the current public health message is zero tolerance, that no alcohol should be consumed during pregnancy. And yet the prevalence rates that we see seem to imply that most people who drink are not producing affected children. Would you recommend a zero-tolerance strategy or a harm-reduction strategy of focusing on high consumption?

**Suzanne Tough** – A child cannot get FASD if the mother does not drink. That's it. It's that simple.

**Philip May** – I would concur. I think that no drinking during pregnancy is the best, because the more we work with maternal cofactors of risk, the more we realize that we don't completely understand the complex interactions of a number of factors or variables. For example, it is obvious that the risk of having an FASD child goes up dramatically in the third, fourth, and fifth pregnancies. However, once in awhile we see a child who is severely damaged by a seemingly minimal intake of alcohol in the first pregnancy. And animal studies are showing very clearly that identical mice and rats given identical units of alcohol have differential damage. So I agree completely that the Surgeon General's warning in 1981 in the United States was the best message.

**Suzanne Tough** – I don't think that means that we do not need harm-reduction strategies for women at risk of alcohol-exposed pregnancy. But if we are trying to communicate from a public health perspective, what the public needs is guidance in making the best possible decisions. I think they need to know exactly what all of us have been saying, that it is a complex interaction. I do not anticipate that in the foreseeable future we are going to have the scientific expertise to

give women a confident low-dose exposure limit, because of the complexity of fetal susceptibility and maternal biology and physiology.

**David Elton** – This question is for Dr. Tough. You indicated that 50% of women drink prior to pregnancy. Do we have any idea how many of those women are aware of the risk of FASD if they do drink?

**Suzanne Tough** – That's a great question and, yes, we do have some information that 99% of women are aware that they should not drink alcohol when they are pregnant. The majority of alcohol consumption that we talk about happens prior to pregnancy recognition. So at some place we have certainly conveyed the message that when you are pregnant, you should not drink. What we have been less successful at conveying is that when you think you could become pregnant, you should not be consuming alcohol. I will follow up with that, that it is true that the majority of consumption is low-dose exposure.

**Christine Looek** – All four of the speakers have brought up the importance of the context of the drinking, or the adverse childhood and community experiences. Dr. Tough, your slide on interpreting prevalence showed that in order to understand the incidence we have to understand something about the rates of exposures in populations. The studies that Dr. May presented show the variation in prevalence, whether in clinics, in schools, or in subpopulations. How will we address this in a way that recognizes that universal studies may not work because there are differences in populations that have to do with access, continuity, and equity?

**Suzanne Tough** – I don't know that I have the answer, because of all the challenges that you just identified. Women who are accessing services might not be the ones who could most benefit from more intensive intervention strategies. I think there are some measures that we should pilot test to see if we can normalize help-seeking behaviour, if we can promote better understanding of healthy reproduction and pre-conception health through early years prior to considering pregnancy. We need to think about how we reach the hardest to reach, the most vulnerable women, those who are persistently excluded.

## **Audience questions and answers**

**June Bergman** – As a primary care practitioner who has spent a good part of my life delivering babies, one of the issues that I find particularly difficult is that we tell women, “Do this, do this, do this, and you will not have a damaged baby”; and when sometimes a damaged baby occurs, these women have a huge feeling that people have failed them. I would like some comments from the panel on how you manage that in a world of “do this, don't do that” for pregnant women.

**Suzanne Tough** – Many of these women show up in our systems of care long before their first alcohol-exposed pregnancy. I think there is data showing that 72% of these women have been in contact with the foster care system and 60% have been in jail on alcohol-related charges. They come to us long before the pregnancy, with risk factors of need, and I think we do fail them. We do not identify, intervene, and follow up to prevent the pregnancy. How do we do it in a way that

is encouraging and supportive? I think we need to hear from women about how we can best do that to make it easy for them to do the right thing, because there are many environmental barriers that make it difficult for women at risk to do the right thing.

## **Extent and impact on child development**

**Ben Gibbard**, *Developmental Pediatrician, Alberta Children's Hospital; Assistant Professor, Department of Pediatrics, Faculty of Medicine, University of Calgary*

I want to begin by saying that this is one of the most challenging questions that I have had to review. In preparing for this presentation, I came across this quote by Margaret Atwood, the famous Canadian author: "The answers you get from literature depend on the questions you pose." I think in my brief presentation to you this morning I will be asking more questions than I will answer.

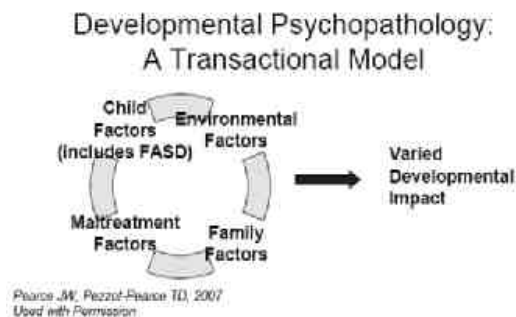
The first question I ask myself is, what exactly is the question we are asking? Are we talking about the impact and extent of prenatal alcohol exposure? Are we talking about fetal alcohol spectrum disorders? Are we talking about other cumulative risk factors? What about resilience and adaptation-promoting factors, and what about prevention and intervention as extensions of that? To answer that cluster of questions, I will step back and ask a few, more fundamental questions. What are the models of risk, resilience, and outcome that we use to understand these questions? How do we understand attribution? That is, how do we understand the place of prenatal alcohol exposure in FASD-related brain damage within the context of other cumulative risk factors? I am briefly going to mention a few core principles of child development, again as framers for this question. I will then discuss possible deficits in the FASD population and come to my final plea and thesis — that we need an individualized approach for people with cumulative risks, including FASD. That will be embedded in my policy recommendations.

Why talk about models? I think they are important because they frame attribution and they frame trajectory and expectation, including prognosis. They guide the research and programs we develop for prevention and intervention. When I first came into this field as a fellow in developmental pediatrics, the model I learned was a linear causality model. The first understanding was that prenatal alcohol exposure caused adverse outcomes. But is that the only lens for understanding outcome in this population? When I delved more deeply to see if there were other models for understanding, I came up with a few. The first is the fetal programming of adult disease model, in which a stimulus or insult at a critical period of development has lifelong effects. Dr. Weinberg is going to review this model for us in more detail. The two models that fit into my area of expertise address ways of understanding cumulative risk. The underlying thesis is that the total number of risk exposures predicts maladaptation, regardless of the specific individual risks. That model has been built into more complex ways of understanding with theories of developmental psychopathology, in which development is seen as a dynamic transaction between biologic, behavioural, psychological, and broader system or contextual variables. These models can help us begin to understand the complexity of FASD.

I will briefly sketch for you a few citations from the literature I have reviewed on the emerging work looking at cumulative risk, prenatal exposures, and environmental factors together. First, here is an early study, looking only at environmental risk and how it affects verbal IQ in four-year-olds. You can see that cumulative risk predicts blunting of IQ, and with four or more risk factors there is a remarkable blunting of IQ. This study found that no single risk factor trumped another, but it was the accumulation that was most important (Sameroff et al., 1987). There are a few studies that look at the effects of prenatal exposure to drugs and/or alcohol and compare these to the effects of environmental exposure. One study looked at developmental trajectories, using serial assessments of children aged 3 months to 57 months related to both prenatal drug and alcohol exposure and postnatal environmental exposures (Carta et al., 2001). This study found that environmental risk accounted for more variance than prenatal drug and/or alcohol exposure. There are many faults in the way the researchers case-define exposure, but this study gives us an initial suggestion that there is more at play in the lives of these children, and suggests that linear one-exposure models are too simplistic for understanding developmental outcome.

Developmental outcome is best understood by the more complex model of developmental psychopathology. A diagram of this transactional model can be found in a book by Dr. Pearce and Dr. Pezzot-Pearce, both child maltreatment specialists at the Alberta Children's Hospital (Pearce and Pezzot-Pearce, 2007). It is a conceptual model of the interaction of factors in child maltreatment; but I think it is also a good model for many individuals with FASD, where there are child-specific factors, biologic factors, environmental factors, maltreatment factors, and family factors, all of which produce varied developmental outcomes.

**Figure 1: Developmental Psychopathology: A Transactional Model**



The word ‘attribution’ was very helpful to me when I was sifting through the literature. It is defined as “how we explain causation.” Let’s take a step back and think about misattribution in FASD. Many core deficits of this population are linked to prenatal alcohol exposure, but that is not the whole story for many of the children I see in my clinic. What I see are multiple causalities interacting. Often, prenatal alcohol exposure — prenatally induced brain damage — is one of the most important factors, but not the only one at play. This is unpublished data from a study of other cumulative risk factors that we recently completed at two clinics in Alberta, a rural

clinic and the urban clinic that I practice in. The majority of the children were exposed to nicotine, half were exposed to marijuana, a third were exposed to other street drugs, two-thirds were victims of maltreatment, a third witnessed domestic violence, and over two-thirds have had multiple caregivers, the average number of caregivers being five. It is remarkable to me, when I look at the literature on FASD, how rarely other cumulative risk factors, beyond prenatal alcohol exposure, are described.

Other framers for this broad question relate to core principles of child development. A basic tenet is that children are normal until proven otherwise. That seems pretty basic, but it is remarkable to me that our diagnostic conclusion for some children seen in our FASD clinic is that they have typical development. That tells me that our process of screening and surveillance needs work. There seems to be an assumption that since a child has been exposed to alcohol prenatally, there must be an adverse outcome and therefore the child must be seen in a tertiary clinic for a possible FASD diagnosis. A related point is that it is important to think about normal variation versus maturational delay, versus transient disorders, versus persistent impairment. Children who come to my clinic are often seen only once. How do we understand trajectory in child development? Are we misattributing brain damage to something that might be a transient disorder or a maturational delay? Child development is characterized by continuity, discontinuity, and transitions. It is dynamic; it is interdependent. Different domains affect each other. Children's motor skills, for example, affect their ability to socialize. Early experiences are important, but risk and protective factors are influential throughout the lifespan. I agree that early intervention is highly important, but we should not forget about development after the preschool years. Trajectories can be altered by interventions, and those interventions can change the balance between prevention, promotion, and risk.

There is a third question that gives me pause and sends me back to Margaret Atwood's statement that the answers we get depend on the questions we ask. I have asked myself, and have asked a number of my colleagues, what are the models of neuropsychologic assessment that we use in FASD diagnosis? I ask this because the models of assessment we use in FASD are different than the models I use anywhere else in my work in general developmental pediatrics. That is interesting to me; that gives me pause. I encourage us all to think about this question. What is the model we use for assessment? Is it a brain injury model? Is it a developmental process model? Is it a strength-based model? The way we answer those questions determines the specific answers that we get about a particular child's profile and the supports and interventions the child may require.

I will turn now to the core question: What are the potential deficits in FASD? I use 'potential' here for a reason. I greatly admire the authors of the Canadian FASD guidelines for diagnosis, because I think they got so much right in that document (Chudley et al., 2005). Some of the key features from the text describing potential deficits are as follows. There is a range of cognitive and behavioural outcomes. There is no modal profile of abilities that is unique to prenatal alcohol exposure. No profile can be distinguished from that observed in other neurobehavioural

disorders. Not every deficit identified in a child with prenatal alcohol exposure may be solely the result of that one exposure. There is a lack of consensus on core deficits. Features of FASD are complex and multifaceted; they originate from organic brain damage caused by alcohol, but they interact with genetic and other influences. Over the lifespan of the affected person, these features may be exacerbated or mitigated by environmental experiences.

The list of possible functional deficits found in individuals with FASD spans every possible neuropsychological domain. I have spent months reading the literature on these possible deficits, and every single deficit on this list — every single deficit possible in human nature — has been identified in this population, including maladaptation and mental health outcomes. I considered adding stars to note the number of papers that supported each of these functional domains until I started to think that was not a good use of my time. My belief is that there is no prototypical neuropsychological profile for individuals with FASD. There have been some different assertions in the literature regarding a possible behavioural phenotype. Dr. Rutter and his colleagues in England, reviewing the literature from a complex neurodevelopmental–neuropsychiatric perspective, wondered if there are perhaps several profiles (Gray, Mukkherjee and Rutter, 2008). It has been postulated that there are specific difficulties in mathematics and aspects of attention (Jacobson and Jacobson, 2002). Recently, there have been suggestions that the phenotype is related to impairment in complex information processing and integration (Kodituwakku, 2007; Aragón et al., 2008; Kodituwakku, 2009). Other recent informants tell us there likely is no specific behavioural or neuropsychologic phenotype (Aragón, 2008). That makes sense when we look at the complexity of exposure, not only to alcohol, but also to other cumulative risk factors. I value Dr. Astley’s recent work that looked at a cohort of individuals with FASD who underwent complex neuropsychological testing as well as imaging studies (Astley et al., 2009). Her group found considerable variability in neuropsychological impairment between FASD diagnostic subgroups and within each subgroup. To summarize briefly, there are no unique developmental or psychiatric disorders in this population. The FASD profile is confounded by overlapping risks for outcome, and the research to date has a number of limitations. There are very few studies and they are a mix of independent-variable studies of “FASD versus alcohol exposure.” Many studies do not use standardized instruments, and many of the methodological shortcomings are related to not using community-referred samples or comparison groups. My plea is that we focus on an individualized-difference approach to assessment and intervention and that we place the alcohol exposure attribution in the context of cumulative risk, understanding that for many children that is the most important risk. This individualized approach will minimize incorrect assumptions about ability and limitation based on etiology. Black-and-white ways of thinking about individuals with FASD limit our ideas of their potential and of their intervention needs. Each child has a unique profile for which we need to tailor intervention related to that child’s particular strengths and challenges, developmental capacity, and family factors.

Policy recommendations derived from the information presented are as follows. Research is needed using prospective cohorts to examine the effects of cumulative risk and adaptation-



promoting variables on child developmental outcome within the Canadian context. However, this research should not distract from research and policy development related to comprehensive screening and surveillance for all children and adolescents, linked to timely assessment and intervention. Research priority should also be given to interventions for functional deficits for all children regardless of etiologic diagnosis. We also need to learn from existing deficit-intervention literature in other developmental disorders and pediatric rehabilitation medicine. There is a great deal of literature on functional impairment, and for some reason we have not made that link. We need to implement treatment-informing diagnostic approaches and to chart individual patterns of ability and disability, as well as underlying risk and adaptation-promoting factors as part of an FASD diagnostic assessment. I encourage us to learn from innovative programs that appreciate the effects of cumulative risk and emphasize intersectoral collaboration. As an example, a group of pediatricians I work with realized early on, when we spoke with them about community-based FASD clinics, that this was just one of many variables that they saw everyday in clinic. In particular, they regarded children from the child welfare system as being very challenging. They have launched an intersectoral program with Child and Family Services whereby all children who are apprehended are seen by a pediatrician who works as part of this program. Each child's cumulative risk is mapped, and they are directly linked to the FASD clinic when that is an important risk to review for diagnostic purposes. However, children in this program are referred to other services related to their risk profile — for example, mental health services, child maltreatment services, or other medical specialty clinics. An important dimension of this program is also longitudinal surveillance and follow-up for these children.

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## **Prevalence of FAS in foster care**

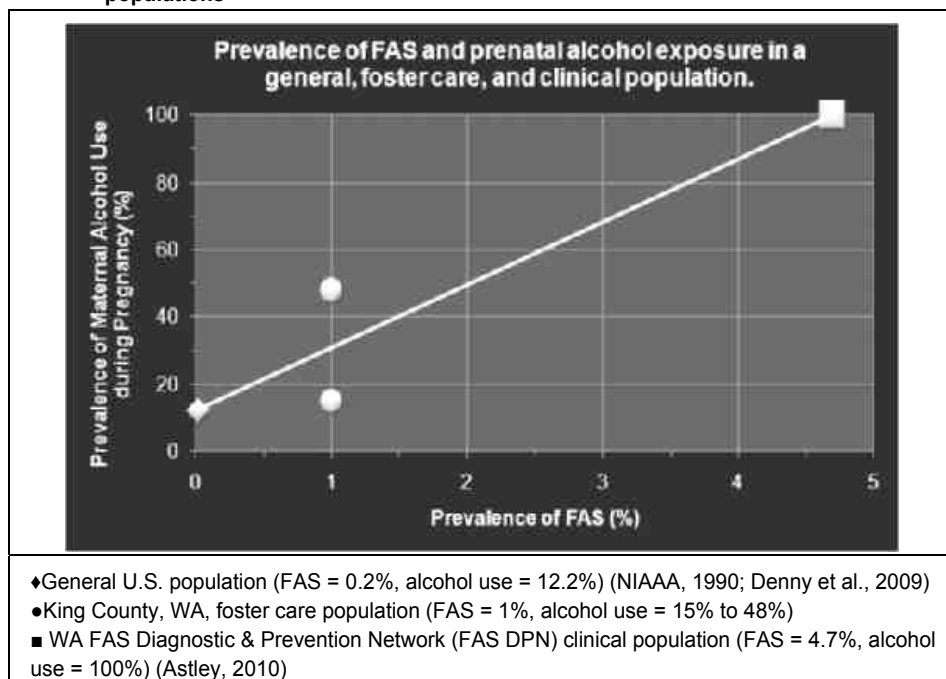
*Susan Astley, Professor of Epidemiology/Pediatrics, University of Washington; Director and Cofounder, Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network*

I am pleased to have this opportunity to present to you the Foster Care FAS Screening Program conducted jointly by the Washington State FAS Diagnostic and Prevention Network (FAS DPN) and the King County Foster Care Passport Program. This program tracked the prevalence of FAS in a high-risk population through active case ascertainment from 1999 to 2009.

The prevalence of a condition such as FAS/FASD is measured to address two important public health questions: 1) What is the prevalence of FAS/FASD at a single point in time? and 2) Is the prevalence of FAS/FASD changing over time? The answer to the first question is important for setting public health policy. What is the magnitude of the problem? What resources are needed to address the problem? The answer to the second question assesses the effectiveness of FASD prevention efforts. If prevention efforts are effective, one would expect a reduction in the prevalence of FAS/FASD over time. The methodology required to track the prevalence of FAS/FASD accurately over time is very different than the methodology required to estimate the prevalence of FAS/FASD at just one point in time. The former must be not only accurate, but also reproducible, highly efficient, and cost effective.

The Foster Care FAS Screening Program conducted by the FAS DPN provided answers to both public health questions posed above. The prevalence of FAS in foster care was 1 to 1.5 per 100, which is 5- to 10-fold greater than the estimated prevalence (1 to 3 per 1,000) in the general population (Astley et al., 2002; NIAAA, 1990). Among the foster children born between 1993 and 1998, the prevalence of FAS declined significantly in each successive birth cohort, from 7% to 2%. This reduction in FAS prevalence was significantly correlated (Pearson Correlation Coefficient 0.86,  $p = 0.028$ ) with a significant reduction in the prevalence of maternal drinking during pregnancy in Washington State across those same years (15% in 1993 down to 4% in 1998) (Astley, 2004). The maternal alcohol use data was obtained by Washington State through their participation in the Centers for Disease Control's Pregnancy Risk Assessment Monitoring System (PRAMS) (Eaglin et al., 2002). In a recent study, an interesting trend was discovered: when you plot the prevalence of maternal alcohol use and the prevalence of FAS in the U.S. general population, the Washington State foster care population, and the Washington State FAS DPN clinic population (Figure 2) (Astley, 2010).

**Figure 2: Prevalence of FAS and prevalence of maternal alcohol use during pregnancy in three populations**



There are numerous approaches one can take to estimate the prevalence of FAS and FASD. Each has significant strengths and limitations. The appropriateness of the approach depends on a multitude of factors: 1) Is the goal to estimate the prevalence of FAS only, or the full spectrum of FASD? 2) Is the goal to document prevalence at one point in time or to track the change in prevalence over time? 3) Is the goal to document prevalence in a defined high-risk subset of the general population or in the entire general population? 4) Is the goal to assess FASD prevention efforts? If yes, must we track the full spectrum of FASD across the entire general population to assess prevention efforts, or can we focus on just FAS in a high-risk subset of the general population?

The methodology used by the FAS DPN Foster Care FAS Screening Program was selected to meet the specific goals and funding parameters of the screening activity. The primary goals were to identify all children with FAS in a foster care population and link them to appropriate intervention services and foster placements. The secondary goals were to estimate the prevalence of FAS in this high-risk population and track the change in prevalence over time. This latter goal would allow us to assess Washington State's FASD-prevention efforts. The program focused on FAS (not FASD) for three important reasons:

1. A highly efficient and accurate screening tool existed to identify FAS: the FAS Facial Photographic Analysis Software (Figure 3) (Astley, 2003). All one had to do to screen for

FAS was to take a digital facial photograph. The Rank 4 FAS facial phenotype (Figure 4), as defined by the FASD 4-Digit Diagnostic Code (Astley, 2004), is over 95% sensitive and specific to FAS (Astley and Clarren, 1996). The simplicity and rigor of this screening procedure ensured its reproducibility. Reproducibility is required to accurately track a change in prevalence of FAS over time.

**Figure 3: The FAS Facial Photographic Analysis Software serves as both a screening and a diagnostic tool for FAS**

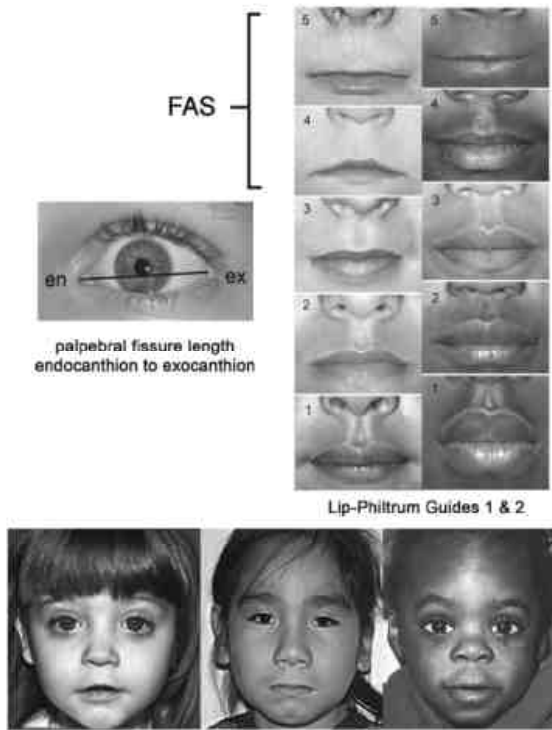


2. The number of FAS cases identified would not overwhelm the clinic's capacity to provide diagnostic and intervention services.
3. Finally, one need only track the prevalence of FAS to confirm that the state's FASD-prevention efforts are working. If prevention efforts are effectively reducing maternal drinking during pregnancy, the entire spectrum of disorders (FASD) will be reduced, not only FAS.

The program targeted a high-risk foster care population for the following reasons:

1. The higher the prevalence of FAS, the more efficient and effective the screening program. If we had targeted the general population, an estimated 1,000 children would need to be screened to identify each case of FAS. By targeting foster care, only 100 children had to be screened to identify each case of FAS. The more cases of FAS identified, the more individuals who benefit from the screening/intervention.

**Figure 4: The FAS facial phenotype is characterized by the following three minor facial anomalies**



- (1) palpebral fissure length two or more standard deviations below the mean
- (2) smooth philtrum (Rank 4 or 5 on the Lip-Philtrum Guide)
- (3) thin upper lip (Rank 4 or 5 on the Lip-Philtrum Guide)

Examples of the Rank 4 FAS facial phenotype for Caucasian, Native American, and African American children are shown. Copyright: Susan Astley, University of Washington

2. The higher the prevalence of FAS, the fewer the number of subjects that must be screened to detect significant and clinically meaningful declines in FAS prevalence over time. In other words, the higher the prevalence, the greater the statistical power to detect change.
3. By targeting children in foster care, we took advantage of an existing infrastructure and tracking system for efficient identification and enrollment of all eligible children. This greatly reduced the cost of the screening.
4. Perhaps most importantly, the foster care population was amenable to screening. A high participation rate is required to generate accurate prevalence estimates. The screening program achieved a 98% participation rate because: 1) the burden of participation placed

on the foster parent was minimized (the photographer went to the foster home to take the screening photo); and 2) the state, as legal guardian, understood the direct benefits to the child and therefore greatly facilitated the child's participation in both the screening and diagnostic evaluation phases of the activity.

As a point of clarification, the terms 'screening' and 'surveillance' are often used as if they are interchangeable. Screening and surveillance are distinct. Screening is the process of identifying individuals who are at *risk* for a condition, for the purpose of providing them with early diagnosis and intervention. Prevalence estimates can be derived from screening activities. Surveillance tracks the prevalence of a condition over time. The Washington Foster Care FAS Screening Program had both screening and surveillance components.

Before one engages in a medical screening activity, one must first ensure that screening is justified. As presented in general textbooks on the principles and practice of medical screening (Wilson and Jungner, 1968), screening is justified when the following criteria are met:

1. The condition is sufficiently prevalent or severe.
2. Early identification improves prognosis.
3. The population is willing to be screened.
4. Accurate and efficient screening tools exist.
5. Diagnostic capacity exists.
6. Effective treatment/intervention exists.

Does screening for FAS and FASD across all populations meet these criteria? Not entirely. FAS and FASD meet criteria 1, 2, and 6, but not every population is willing to be screened for FAS or FASD (criterion 3). It is understandable that families may be reluctant to have their child screened for FAS/FASD. For every child identified with FAS/FASD, there is a birth mother whose drinking during pregnancy is being implicated. For this reason, FAS/FASD screening should take place in an environment that not only affords strict medical confidentiality, but also has the expertise and capacity to support the emotional needs of the family and birth mother. The willingness (and unwillingness) of families to participate in FAS/FASD screening activities is clearly documented in the published literature. The participation rate in the foster care FAS screening was very high (98%) (Astley et al., 2002). Participation rates in FAS screening targeted to grade-school populations have been very low (< 50%) (Clarren et al., 2001; May et al., 2000). Valid prevalence estimates cannot be derived when participation is low. An accurate and efficient screening tool (criterion 4) exists for FAS: the Rank 4 FAS facial phenotype (Figure 4) (Astley and Clarren, 1996). An accurate and efficient screening tool for FASD does not exist. Screening for FAS requires the measurement of just three facial features. Screening for FASD requires confirmation of alcohol exposure and comprehensive neuropsychological assessment. Thus, FASD screening is very labour-intensive and has limited reproducibility. As for criterion 5, FAS is relatively rare in most populations and, therefore, is unlikely to exceed the

diagnostic capacity of a community. The prevalence of FASD, on the other hand, may be 5- to 10-fold higher than FAS and may exceed the diagnostic capacity of a community.

Accurate estimates of prevalence (and change in prevalence over time) require a screening tool or method that is: 1) simple and quick to administer; 2) inexpensive; 3) accurate (e.g., screen-positives have FAS/FASD, and screen-negatives do not); 4) acceptable to the target population (as reflected in high participation rates); and 5) can be implemented reproducibly year to year. When we screen for a condition, we focus on the feature that is most specific to that condition. For example, FAS is typified by growth deficiency, a unique cluster of minor facial anomalies, central nervous system (CNS) structural and/or functional abnormalities, and prenatal alcohol exposure. The only feature specific to FAS is the facial phenotype. The facial phenotype is so highly specific to FAS that one need only measure three facial features to accurately screen for FAS (Astley and Clarren, 1996; Astley et al., 2002). Collecting data on growth, CNS function, and alcohol exposure histories would greatly increase the cost of an FAS screening without increasing the accuracy. These latter features are assessed only for the small subset that screen positive for the FAS face. These assessments are conducted in the diagnostic phase of the screening.

A detailed description of the screening methodology used by the Washington State Foster Care FAS Screening Program is presented in Astley et al. (2002). Briefly, the screening program uses active case ascertainment, targets a high-risk foster care population, and focuses solely on FAS. Each week, foster care sends the FAS DPN clinic a list of all children eligible to be screened (approximately 5 to 10 children per week). The FAS DPN clinic contacts each foster parent and schedules a date when the screening photographer (an undergraduate student) will visit their home to take the child's facial photograph. Sending the photographer to the child's home is instrumental in obtaining a high participation rate. The digital photographs are analyzed by a single technician using the FAS Facial Photographic Analysis Software. It takes approximately five minutes to analyze a photo. Children who have the full FAS facial phenotype (Rank 4 as defined by the 4-Digit Diagnostic Code) screen positive. No other information is collected about the child.

The screening outcome of each child is sent to the child's legal guardian and submitted to the child's medical record. If the child screens positive, the legal guardian and foster family are invited to bring the child to the FAS DPN clinic for a full FASD evaluation. The results of the FASD diagnostic evaluation are also sent to the legal guardian and submitted to the child's medical record. If the child screens negative, a carefully worded screen-negative letter is sent to the legal guardian and the medical record, documenting that the child does not present with the FAS facial phenotype but may still be at risk for developmental delay if the child was exposed to alcohol in utero. The legal guardian is encouraged to refer a screen-negative child to the FAS DPN clinic if the child has a confirmed history of prenatal alcohol exposure.

FASD prevention efforts in Washington over the past 40 years have spanned the full continuum from public health education (e.g., warning labels on liquor bottles, pamphlets in doctors'



offices) to alcohol treatment and family planning programs designed to meet the specific needs of high-risk women (Grant et al., 1996). To assess prevention efforts, one must be able to screen and diagnose high-risk populations accurately and efficiently and track the prevalence of maternal drinking and FAS in population-based samples. In Washington state this has been accomplished through the establishment of: 1) the Pregnancy Risk Assessment Monitoring System (PRAMS) in 1993 (an annual statewide CDC survey of maternal risk factors during pregnancy, including alcohol use) (Eaglin et al., 2002); 2) the Washington State FAS DPN clinics in 1993 (Astley, 2010); 3) the FAS Facial Photographic Analysis Software in 1995 (Astley, 2003); 4) the FASD 4-Digit Diagnostic Code in 1997 (Astley, 2004); and 5) the Foster Care FAS Screening Program in 1999 (Astley et al., 2002).

One of the key goals of surveillance is to assess the effectiveness of primary prevention efforts. Tracking the prevalence of FAS over time in a high-risk foster care population offers a more accurate and efficient alternative to tracking the prevalence of FAS across a larger, more diffuse general population. If statewide prevention efforts and statewide reduction in maternal alcohol use are effectively reducing the prevalence of FAS in a foster care population, it would be difficult to argue that similar reductions are not also being realized across the entire general population. The same can be said for the impact of prevention efforts on the full spectrum of disorders caused by prenatal alcohol exposure. If maternal drinking during pregnancy is reduced, the full spectrum of disorders caused by that drinking will be reduced, not just the disorder called FAS.

The Washington State Foster Care FAS Screening Program is one example of a population-based, active case ascertainment program that has generated accurate FAS prevalence rates annually for 10 years. The change in prevalence rates has been successfully used to assess Washington state FASD-prevention efforts. The program is accurate, reproducible, quick to administer, uses existing programs and infrastructure (FAS DPN Clinic, Foster Care, and PRAMS), is cost effective, accepted by the target population (98% participation rate), and provides direct benefit to the individuals identified with FAS through linkage to intervention and therapeutic foster care placement.

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## Genetic pre-disposing factors

*Albert Chudley, Medical Director, Winnipeg Regional Health Authority Program in Genetics and Metabolism; Professor, Department of Pediatrics, University of Manitoba*

The objectives for this presentation are to review evidence of genetic influence in FASD; to review the metabolism of alcohol that may influence risk; to review, very briefly, the results of animal and human gene studies as they relate to FASD; to identify the priorities for future research; and to discuss the potential benefits and relative importance of genetic research in the field of FASD.

How do we know there are genetic influences in fetal alcohol spectrum disorders? First, not all individuals who have been exposed to alcohol during gestation show clinical effects. Second, animal studies show that there are strain differences that are determined by differences in genetic

background. A varied phenotype is observed in FASD, which may be a reflection of varied susceptibility quotients in the genetic background of individuals. We also have studies that show a high recurrence rate and risk of FASD within families: where one child is affected with FASD, there is a much higher risk of FASD in a subsequent child. In twin concordance studies, we have seen twins with differences in gene expression. Other studies have shown that identical twins are similarly affected by alcohol exposure more often than are fraternal, or non-identical, twins. Finally, ethnic differences in risk for FASD are apparent in epidemiologic studies.

That is the evidence suggesting that genetic factors influence FASD. The greatest influence is probably polymorphic variance in enzymes involved in the metabolism of alcohol. There are gene changes and polymorphisms — that is, variations in the functions of particular gene products, or enzymes — that may lead to alcohol craving and alcoholism. We also know that there are gene changes that lead to different enzyme rates and result in protection against alcoholism and FASD. Genes involved in brain and organ function and development can also be influenced by alcohol exposure. We know that some effects from genes are non-genetic in origin. We call those epigenetic influences, and I will talk briefly about that later. Finally, we know that changes in the environment may decrease the function of specific genes involved in brain and organ function, a decrease in DNA methylation with ethanol exposure being one example.

Not many gene studies have been done in humans. In case-controlled studies, we need at least two control groups, and most studies either have not included controls or have had only one control group. We need a control group of non-drinking mothers and, as a comparison group, those who drank and had no affected children. Family linkage studies have been done but in such studies we often need paternal DNA, which sometimes is not available. In addition, family linkage studies have poor success in discovering the genetic cause of complex genetic diseases because of the weak genotype–phenotype associations in multifactorial complex disorders. Finally, candidate gene association studies have been attempted. Although there have been no genome-wide or gene-expression studies done in humans to date, they have been done in animals. Select gene-targeting studies, mainly of genes involved in alcohol metabolism, have produced conflicting results.

This is a brief view of alcohol metabolism. Alcohol is metabolized to acetaldehyde and that is further metabolized to acetate, which then is excreted through the circulation and the kidneys. There are the two primary enzymes involved: alcohol dehydrogenase (ADH) and acetaldehyde dehydrogenase (ALDH). These enzymes have variable rates, depending on the genes that control them. The metabolism of alcohol produces a reactive oxygen radical that is damaging to cells. Acetaldehyde can be very toxic. Rapid production and slow metabolism of acetaldehyde leads to a phenomenon called flushing. It causes unpleasant feelings, so that people who have particular enzymes (a fast-acting ADH variant or a slow-acting ALDH variant, or both) in their bodies avoid alcohol.

The rate of birth defects in animals exposed to alcohol varies with genotype. Some genotypes result in a much higher incidence of malformations and birth defects than others.

There are seven genes in the ADH family, many of them clustered in one region of the human genome. The many polymorphisms, or variations, in these genes result in different ADH enzymes with different affinity for and effectiveness in metabolizing alcohol. There are five different classes of ADH enzymes, depending on their location within the body. Most of them are in the liver and kidney, but some are in the gut and the upper gastro-intestinal system. The majority of alcohol is metabolized by specific enzymes encoded by three genes in ADH class one and by one gene in class two. Nomenclature has changed in the last 10 years so that older studies are hard to interpret based on the new system of classification. But it is clear that the isozyme encoded by the ADH1B2 gene has a turnover rate over 80 times greater than the isozyme encoded by the gene ADH1B. That higher turnover rate leads to more rapid metabolism of and increased tolerance to alcohol. The presence of this particular allele should result in an increased rate of ethanol oxidation. ALDH is encoded by genes located in the mitochondria and is responsible for metabolizing acetaldehyde, which itself is very highly toxic, as is ethanol. One of the ALDH polymorphisms produces an enzyme with low activity. Both of these gene variants — the high-activity ADH and the low-activity ALDH — have been demonstrated to protect against the development of alcohol dependence.

This is a classification showing the number of genes involved in producing the multimeric protein ADH. People of different genetic and ethnic backgrounds have different allele frequencies. For example, 95% of Caucasians have the normal variant of ADH, or at least the normal enzyme activity; and 90% of Asians have the high-activity variant and are protected from alcoholism because of the rapid production of acetaldehyde. These variations and different enzyme activity rates are obviously going to affect the fetus in early development.

This is data from a review by Li and Warren, looking at different rates of enzyme activity in three groups: mothers who have children with FAS, children with FAS, and controls. The enzymes vary according to the category. Again, this shows that genetics has a significant influence on risk for FASD. Data in many studies by Dr. May and his colleagues have shown higher rates of FAS in African Americans and Native Americans than in non-Hispanic whites. There is a seven-fold higher rate in Blacks, after adjusting for maternal alcohol intake, chronic alcohol problems, and age. In Canada, we have not done studies of this nature, but in the United States, the southwestern Native American population has confirmed abnormal variants of enzymes with altered metabolic rates that reduce the risk for alcoholism. Protection is again presumably through the accumulation of acetaldehyde, which results in the flushing response to alcohol consumption. Other studies in that population have shown that there are several alleles and a neighboring microsatellite marker that affect the risk of alcohol dependence and are related to binge drinking. Therefore, independent of the enzyme activity, there are other factors closely linked to these genes that probably affect risk. These data strengthen the evidence that this particular gene is a candidate locus for alcohol dependence, and further research is suggested in that area.

This slide from Uddin et al. looks at what other genes might be altered by alcohol exposure. This is probably only a partial list but it shows the impact that alcohol has on the function of at least 200 genes, on the production of the gene products and enzymes, and on developmental pathways. Although we focused the first part of the talk mainly on those half dozen genes that control rates of alcohol metabolism, there are many other genes that are affected by alcohol exposure in the developing fetus and embryo.

Alcohol affects multiple cellular events, and therefore investigating a small number of candidate genes that are involved in the ethanol response may not properly identify the actual mechanisms of alcohol in the brain or the mechanisms causing teratogenic effects and FASD. Future studies to identify and prioritize candidate genes that may predict a risk for FASD will use powerful statistical hardware and a system called convergent functional genomics, which relies on animal gene-expression studies and human genetic-linkage studies, as well as human tissue data and the roles that particular genes play.

This is a partial list of the more significant genes, and pathways of genes, that have been shown or predicted to be important influences in determining risk. One is the TGF- $\beta$  signaling pathway, which plays a pivotal role during embryogenesis and development. Mutations and alterations in the signaling pathway lead to distinct characteristics that we see in FAS. Cell death from alcohol assault provides a probable explanation for the long-term central nervous system dysfunction and imaged brain size associated with FAS, and this could be mediated through this particular pathway. The second pathway is the MAPK signaling pathway, which is quite interesting in that it can lead to a wide range of cellular responses that are affected by alcohol. And, finally, we have the hedgehog signaling pathway: production of an antibody against the sonic hedgehog molecule results in a phenotype, or appearance, that mimics FAS.

Epigenetics refers to changes in appearance or gene expression by mechanisms other than changes in a DNA sequence. Alcohol is an epigenetic factor that can alter gene function, and gene function may be altered by a number of other mechanisms. A recent study by Thomas et al. shows that choline supplementation reduces the effects of prenatal alcohol exposure in rats, and that choline acts as a methyl donor. That influences both DNA methylation, which is involved in the growth of the cell, and a neurotrophic factor, acetylcholine, which is a neurotransmitter. Reducing the methylation of a particular gene region alters a growth factor that may be important as a mechanism of alcohol-induced growth retardation.

Finally, direct-to-consumer DNA testing is now available. You can test your alcohol enzyme activity to find out whether you have a slow or a fast metabolizer in those two genes and get a report determining your chance of a heart attack, your chance of developing cancer, and maybe someday your risk of having an FASD child.

Although not conclusive, it is probable that variations in genes influence the risk for and the incidence and prevalence of FASD, and these variations likely explain differences in the incidence of FASD between ethnic groups. Some genetic differences may be protective, resulting in less alcohol consumption and exposure; and certain genotypes may increase the likelihood of

binge drinking and alcoholism, resulting in a higher incidence of FASD. Further research in genetic and epigenetic factors may lead to better recognition of at-risk individuals and the development of more effective prevention strategies. Standardized approaches to determine accurate estimates of maternal alcohol intake and accurate categorized outcomes are essential in future research. Finally — and this may lead to my hanging by the jury and by colleagues in the medical genetics clinic — notwithstanding the importance of biological factors in the cause of FASD apart from alcohol and the importance of understanding mechanisms of alcohol effects, studies identifying genetic risk factors for FASD will not likely have a meaningful impact on the prevalence, treatment, or prevention of FASD.

## **Direct and indirect mechanisms for alcohol damage to the brain**

*Joanne Weinberg, Professor, Cellular and Physiological Sciences, University of British Columbia*

In talking about mechanisms underlying the effects of alcohol, I will begin with an overview and then focus specifically on the work that we are doing in our laboratory.

Animal models were developed in the 1970s, after fetal alcohol syndrome (FAS) was first described in the literature, to address the skepticism that greeted these first reports. Many doubted the suggestion that alcohol was actually a teratogen, causing the adverse effects that were being described. After all, people had been drinking for centuries, and suddenly there were reports describing something called FAS. Where did it come from? It couldn't be alcohol — it must be something else: malnutrition, liver disease, other drugs, etc. The development of a variety of animal models, however, demonstrated that the biological and behavioural effects seen in humans could be very closely paralleled in experimental animals. Thus these models were valuable tools for examining outcomes and investigating mechanisms of the effect of alcohol on the fetus.

The power of animal models is that we can very precisely control environmental and genetic variables, such as dose and timing, maternal nutrition and health, use of other drugs, and genetic background of the organism. Interestingly, even with control of genetic variables, often we see variability in phenotype. This raises the issue of gene–environment interactions and the possible role of epigenetic mechanisms in mediating the effects of alcohol. Insight into mechanisms underlying the effects of alcohol has been one of the most critical contributions of the animal models. We are getting closer to understanding mechanisms and the fact that there are likely multiple mechanisms involved. Ethanol is a very small molecule that easily crosses cell membranes, acts on multiple targets, and appears to act through multiple mechanisms. Once mechanisms can be identified, progress can be made to develop more targeted interventions. This is another key area where animal models are important.

Interaction between animal and human research has also been very critical in this field. The two inform each other. I believe it was Gail Andrew who mentioned Kathy Sulik's seminal work showing that we can reproduce the FAS facial phenotype in a mouse if we target alcohol

exposure to the time of gestation when the face is forming. In turn, outcomes in the animal models can point toward issues that could be investigated in the human studies. Together, the interactions between the animal and human studies have helped to move the field forward.

In examining mechanisms, we want to look at both direct and indirect effects. Direct toxic effects of alcohol on the embryo are well known. Alcohol readily crosses the placental and blood–brain barriers and can thus act directly on developing fetal cells. However, in mammals it is likely that interactions between direct and indirect (maternally mediated) effects of alcohol are responsible for its adverse impact (Randall, Ekblad, and Anton, 1990). Moreover, as alcohol is known to act on or modulate many different target molecules, multiple mechanisms, activated at different stages of development or at different dose thresholds of exposure, probably contribute to the diverse phenotypes seen in FASD (Goodlett et al., 2005).

Some of the mechanisms that have been described in the literature to date are as follows.

*Direct mechanisms.* Alcohol has many direct effects on cells.

1. Alcohol affects cell death through a variety of mechanisms, one of which is increasing apoptosis. The brain is particularly sensitive to direct effects of alcohol during the brain growth spurt when neurons are dividing and synapses are forming.
2. There are direct effects of alcohol on protein and DNA synthesis. We know that DNA and protein synthesis may be inhibited in the placenta, liver, kidney, and brain, resulting in fewer or smaller cells. This may account for why, in the alcohol-affected organism, the brain or other organs are smaller.
3. Alcohol disrupts specific enzymes that play a role in metabolism in the brain. Certain areas of the brain are particularly sensitive to the adverse effects of alcohol. This has been shown very clearly in animal studies and imaging studies in humans provide support for this. Brain areas, including the hippocampus, amygdale, and cerebellum, have been highlighted as being particularly sensitive.

*Indirect mechanisms.* Numerous indirect effects of alcohol have been described. These include:

1. Nutritional deprivation or malnutrition. Alcohol provides what are known as “empty calories,” i.e., calories that take the place of other nutrients. Typically with heavy drinking there is some level of nutritional deficiency, and sometimes it is fairly severe.
2. Altered calcium activity and regulation within cells. Calcium is very important in proper functioning of neurons. Therefore, alcohol-induced changes in calcium influx or efflux from the neurons can change neuronal growth and migration.
3. Alterations in prostaglandin levels. Some seminal work by Carrie Randall’s group in South Carolina has shown that prostaglandins may play a role in mediating the effects of alcohol (Randall et al., 1989). Prostaglandins are derived from arachidonic acid, which is a very important polyunsaturated fatty acid in the brain. Prostaglandins, themselves, may have teratogenic effects and effects on fetal mortality and development. Randall’s work

in a mouse model showed that if you inhibit prostaglandin synthesis, you can attenuate some of the deficits induced by prenatal alcohol exposure. Low-dose acetylsalicylic acid (e.g., Aspirin) is known to inhibit prostaglandin synthesis, and Randall's group showed that it can protect against the effects of alcohol.

4. Effects on structure and function of the placenta. Alterations in structure or function can affect the transfer of nutrients and oxygen across the placenta, which can have adverse effects on the fetus. Work has suggested, for example, that zinc and vitamin A deficiencies may contribute to alcohol effects.
5. Alcohol can alter circulatory function, which could result in changes in blood flow to the fetal brain. The umbilical artery and vein are very sensitive to the effects of alcohol on circulatory function, and a change in the flow of nutrients or oxygen will obviously have adverse effects on the fetal brain. Particular areas of the brain, such as the hippocampus, cerebellum, and basal ganglia, are especially sensitive to such alterations.
6. Disruption of cell–cell interactions or cell adhesion. In particular, it has been shown that alcohol may inhibit the functions of L1, a protein that acts as a cell-adhesion molecule, which is important in cell–cell adhesion and in the growth and proper migration of neurons. Work on L1 and other cell-adhesion molecules has been very promising in elucidating one possible mechanism underlying alcohol's adverse effects on the brain (Bearer, 2001).
7. Interference with growth factors, oxidative stress, and free radical damage are other indirect mechanisms of alcohol's actions on the CNS. Alcohol exposure can increase levels of free radicals and deplete the cell of antioxidants, leading to decreased ability to break down the free radicals resulting from metabolism of alcohol. Free radicals are, in fact, important in normal cell functioning. But when the cell is under stress, as it is with alcohol exposure, then free radicals build up and can themselves cause damage. Increased oxidative stress can deprive developing neurons of energy, thus inducing cell death. Fetal tissues generally have lower activities and levels of oxidative defenses than adult tissues and thus the fetus is highly sensitive to oxidative stress, especially early in gestation. Some promising early studies have shown that small glial proteins or peptides with neuroprotective (antioxidative and anti-apoptotic) properties may prevent alcohol-induced fetal death, growth restriction, microcephaly, and learning deficits in a mouse model of FAS (Spong et al., 2001). Further research is needed to determine if these peptides will have protective effects following fetal alcohol exposure in humans.
8. Continuous exposure to alcohol during the prenatal period is known to result in reduced numbers of serotonin neurons, deficits in cell migration, and decreased serotonin levels. Serotonin is not only an important neurotransmitter in the brain, but also a very important neurotrophic factor for normal cell development and thus for normal brain development. Imbalances in the serotonin system can affect a wide variety of functions, resulting in



mood and personality disorders, eating disorders, anxiety, and insomnia. Disruption of the serotonergic system is a very promising area of research (e.g., Sari and Zhou, 2004).

9. Disruption of endocrine balance between the mother and the fetus may be another mechanism of alcohol's actions. Changes in maternal endocrine function can have marked effects on the ability to maintain a successful pregnancy. In addition, disruption of maternal–fetal hormonal interactions could have marked effects on many aspects of offspring development.

I'm going to spend some time looking at endocrine balance, since that is a key area of research in my laboratory. How is endocrine imbalance a factor in mediating the functional changes seen in FASD? We know that among the physiological abnormalities induced by maternal ethanol intake are marked alterations in both maternal and offspring endocrine function. The endocrine system influences functions as diverse as reproduction, growth, metabolism, stress responsiveness, and behaviour, and is critical in homeostasis or balance within the body. Thus, while endocrine imbalance cannot directly result in key features of FAS, it could certainly contribute to the functional alterations observed in FASD (Anderson, 1981; Angelucci et al., 1985; Weinberg, 1993).

In our research, we have been looking at effects of alcohol on the hypothalamic-pituitary-adrenal (HPA) axis. The hypothalamus is a small area at the base of the brain. It secretes hormones that stimulate the pituitary gland, which in turn produces hormones that then stimulate the adrenal glands to release cortisol, one of the major stress hormones in the body. Cortisol itself has a many metabolic effects. Indeed, almost every aspect of metabolism is affected by cortisol. Cortisol affects the function of neurons, affects glucose and protein metabolism, has major effects on the immune system (we know that steroids have anti-inflammatory effects), and influences our ability to respond to stress. Once cortisol is released, it then feeds back to inhibit HPA activity. We have been exploring the possibility that fetal programming of the HPA axis by alcohol permanently sensitizes the adaptive mechanisms that mediate the stress response, thus making the organism hyper-reactive to subsequent life stressors and increasing vulnerability to illnesses, including depression, anxiety, and other mental health problems. We are now extending our work to look at the possibility that fetal programming of the HPA axis by alcohol may mediate the increased vulnerability to addiction or substance use disorders in individuals with FASD.

We know that children with FASD have numerous behavioural and functional problems, including a high rate of depression and anxiety disorders. These are commonly referred to as secondary disabilities. But our work, and work by others in this area, suggests the possibility that these disorders are not entirely secondary but may in fact have a primary component. That is, alcohol-induced changes in the neurobiology of the stress system may underlie the increased vulnerabilities we see (Matthews, 2002; Seckl, 2008). Studies have shown that children with FASD have increased HPA responses to stressors. Studies in animal models substantiate this finding. Prenatal alcohol exposure results in a more reactive stress system and the secretion of

higher levels of the stress hormones during the affected individual's lifetime. Changes in HPA activity and dysregulation of the HPA axis are common findings in depression. Furthermore, the HPA hyper-responsiveness and dysregulation seen in FASD are parallel in many ways to the kinds of changes in the HPA axis that are seen in depression. We know there is a strong relationship between depression in adulthood and adverse early life experiences. Moreover, brain areas involved in depression, addiction, and stress overlap to a large extent. This is where the neurobiology provides substantial evidence to suggest the possibility that alcohol-induced changes in the stress system mediate the increased vulnerability to mental health problems that we see in children with FASD. This hypothesis is in line with the stress-diathesis model of depression. That is, stress itself does not necessarily cause illnesses later in life, but stress acting on a system that is already dysregulated or already sensitized may have significant adverse effects. We know that children with FASD have a great deal of stress in their lives. It is possible that exposure to stressors later in life, acting on a sensitized neurobiological system, may mediate some of their vulnerabilities.

How do we study depression in an animal model? Key symptoms of depression in humans are depressed mood and anhedonia. Additional symptoms can include significant changes in body weight, sleep patterns, energy level, and ability to think or concentrate. In animal models, there are many measures and behavioural tests that provide an assessment of depressive or anxiety-like behaviours. We can measure body weight, performance in learning and memory, locomotor activity, social behaviour, and levels of the stress hormones under both resting and challenge conditions. There are also tests, such as the Porsolt swim test, that assess "behavioural despair" and are responsive to antidepressant treatment. The elevated plus maze is a test that measures fear or anxiety and is responsive to anxiolytic drugs.

In our studies (Hellemans et al., 2010), in the context of the stress-diathesis hypothesis, we subjected animals prenatally exposed to alcohol to a 10-day chronic mild stress regimen and then tested them on a multi-dimensional behavioural test battery to assess depressive and anxiety-like behaviours. We found that alcohol-exposed males showed increased anxiety, impaired hedonic responsivity, locomotor hyperactivity, and alterations in social behaviour, compared to controls. Alcohol-exposed females, on the other hand, showed greater anxiety, altered social interactions, and "behavioural despair."

As part of our investigation of mechanisms underlying alcohol's adverse effects, we are exploring the possibility that epigenetic mechanisms play a role in the altered behaviour and HPA activity observed in FASD. Epigenetic mechanisms are changes in hereditary information or heritable traits that do not occur through changes in the underlying DNA sequence. Due to their dynamic nature, epigenetic mechanisms may function as mediators connecting the genome to environmental signals and exposures and thus play a role in gene-environment interactions. Early life experiences, such as prenatal exposure to alcohol, may exert some of their long-lasting effects through epigenetic mechanisms that alter gene expression. We are exploring the idea that

fetal programming is a mechanism for non-genetic inheritance of a predisposition for increased risk for disorders or illnesses later in life.

Can postnatal and other environmental events modulate the effects of early life programming? Interventions based on mechanisms of teratogenesis may not fully reverse damage but may be able to improve function. Our data suggest targeting the HPA axis may provide a novel approach to intervention. Normalizing HPA activity could decrease vulnerability to stressors in later life and perhaps attenuate the increased risk for depression, anxiety, and other mental health problems in children with FASD.

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## **Jury questions and answers**

*(Susan Astley, Albert Chudley, Ben Gibbard, Joanne Weinberg)*

**Lee Ann Weaver-Tyrrell** – This question is for Dr. Gibbard. Your individualized assessment approach seems to have the potential to break down the barrier of diagnosis that exists for people receiving services. Would you say that is an accurate statement? And how well accepted is this approach in the scientific and clinical community?

**Ben Gibbard** – I work in a general developmental pediatric centre where we have general pediatric services, general behavioural pediatric services, and an FASD clinic. An interesting dialogue occurs every day with my colleagues about how we understand a heterogeneous group in the context of a specific clinic like FASD. I would be keen to support policy recommendations related to more broadly applied screening and surveillance strategies and application of intervention. I see kids in different settings with multiple exposures, where FASD is often the most important exposure but not the only one. My colleagues who do not work in the FASD clinic struggle with the question of how we take into account cumulative risk, and how that relates to specific supports and services. Did I answer your question?

**Lee Ann Weaver-Tyrrell** – Yes, and the second part is, on a national level is this much discussed?

**Ben Gibbard** – I do not think it has been discussed historically, but it is a discussion I have been hearing more and more in the last few years. In dialogue with my co-presenters leading up to this presentation, I was encouraged to hear that this is gaining acceptance.

**Edward Riley** – Given your multiple risk factor model, do you see advantages and/or disadvantages in setting up FAS diagnostic clinics as opposed to expanding developmental disability clinics?

**Ben Gibbard** – That is a very controversial question, and I am going to take the middle ground. I think FASD clinics benefit from the wisdom gained from a general pediatrics context, and the clinicians that I work with all have experience in general mental health and developmental pediatrics. That experience informs how we contextualize the diagnosis. That has been highly important in my training, and I would hope that those two things would be married.

**Gail Andrew** – As developmental pediatricians, we are not quite neurologists, not quite geneticists, not quite psychiatrists, and not quite general pediatricians, but put all those in a blender and that is what we come out as. I work across disability groups, using the same differential diagnosis approach to try to identify etiological factors, contributing co-morbidities, and companion variables in the life of every child that I see. It is a standardized approach. What I find unique about working in an FASD clinic is the opportunity to learn more about that group. This is with my research hat on now, as opposed to my clinician's hat: I would like to learn more about this particular population and be able to compare it to other populations, especially around

effective interventions. But I also feel strongly about reaching out to the birth mothers. The prevention piece is unique to this disability group — identifying a child with FASD identifies a birth mother at risk for future exposed pregnancies. Connecting her to support services may potentially prevent another child with FASD.

**Christine Looock** – Perhaps my question would apply to all four of your presentations and it relates to a pattern. Dr. Gibbard, you mentioned that there is no fingerprint or neurodevelopmental profile that presents, but that there is a pattern. Dr. Astley, you are looking at a high-risk targeted population. Dr. Chudley, you mentioned the MAPK pathway for external stress; and Dr. Weinberg, you talk about a stress-diathesis model, that there is something unique about this population. As developmental pediatricians, we see that FASD children and their mothers have more adversity in their lives than others we meet in clinical encounter. How do we approach a diagnosis recognizing that environment has played so heavily into the presentation and the severity of the outcome?

**Susan Astley** – I would start by documenting all prenatal and postnatal risk factors (not just the alcohol exposure) in the FASD diagnostic medical summary. I have never met a child whose only adverse exposure or event was their alcohol exposure. Although the vast majority of children who come to our clinic have experienced many other adverse events and exposures, there is a small handful that have not. It would be very interesting to compare these two groups to assess the impact of those additional factors on overall outcome. This assessment was recently conducted in an evaluation of the first 1400 patients with prenatal alcohol exposure who received a FASD diagnostic evaluation in the Washington FAS DPN (Astley, 2010).

**Albert Chudley** – I do not want to give the impression that I am against genetic testing or the potential of personalized medicine using genetic risk factors and predicting disease and directing treatment and drug therapy. But FAS children are different from children with autism and with nonspecific global developmental delay. Patterns of strength and weakness emerge when you look at the brain domains in these kids, and research is now starting to show patterns that separate FAS children from non-FASD children. I think there is probably still a need for a multidisciplinary approach to the FAS question; and we do make efforts to recognize that genetic and other environmental factors contribute to developmental problems. Alcohol is not alone in this, but alcohol is a significant risk factor in the disability and brain injury.

**Ben Gibbard** – In our clinic, our diagnosis list starts with functional deficits. That is the first thing we talk about. Then we talk about etiology, and then about resilience factors, if they're appropriate. Something I have never heard discussed is how we rank attribution — how we come to a formulation of the key variables of risk in a child's life. That is something that we do every day in our clinic. We come to a conclusion that alcohol is the most important risk factor for this child; but for the next child it is very significant experiences of maltreatment combined with alcohol exposure; and for the next child it is a huge genetic component related to mood instability on top of those risk factors. We do that in our clinic, we rank attribution, but it is something I have not seen well articulated.

**Joanne Weinberg** – Data suggest that alterations in the hypothalamic-pituitary-adrenal (HPA) axis may be a final common pathway for many early-life adverse events, particularly prenatal stress, and possibly prenatal alcohol exposure. Prenatal stress produces effects that overlap very significantly with the stress-related problems that we see in kids who are prenatally exposed to alcohol. Alcohol itself activates the HPA axis and increases exposure to stress hormones, and these effects may be exacerbated by alcohol-induced alterations in the maternal–fetal hormone balance. Children with FASD often have a great deal of stress in their lives. The HPA axis provides a neurobiological framework for thinking about some of these issues, including how we intervene: in this context, interventions should take into account the stress and multiple adverse factors in these children’s lives. Furthermore, as Myles Himmelreich pointed out, he had a great deal of early life stress, but a very supportive family. Having a supportive, stable environment that decreases stress does predict a better outcome. Our animal studies fit within this broader context. Understanding the underlying neurobiology provides a general framework for thinking about this common basis for problems.

**Raisa Deber** – I wonder whether there is a case for protective interventions that might keep the development from being as adverse. Several of the papers mentioned choline supplementation. Would that sort of thing — say, adding choline to prenatal vitamins — be likely to have a negative impact on people who do not need it, or might it be useful?

**Albert Chudley** – I think there needs to be research into the effect of excess choline and what the proper dose is, and then proper follow-up of children exposed. The best intervention for a woman who is drinking in her pregnancy is to try to put her in a safe environment where she can get help to stop drinking. For children who are already exposed, there is some evidence that choline has promise, but I have not seen studies with proper control groups looking at long-term benefits.

**Gail Andrew** – In understanding epigenetics and changes in methylation and where choline fits in, methionine is a critical component. Methionine contributes its methyl groups for DNA methylation, and then it is reconstituted. Choline and folate — folic acid — both play a role in providing methyl groups to reconstitute methionine. That’s why choline could be effective, but I agree with Dr. Chudley that recommending blanket choline supplementation is problematic, even though it shows great promise. Another avenue that was looked at in a large Canadian study is oxidative stress and antioxidants. The animal models seem very positive, but a trial looking at antioxidants in people showed mixed results.

**Anne McLellan** – We have heard a number of times about the importance of longitudinal work. How much longitudinal work is being done after initial diagnosis? What do we need to ensure that longitudinal work is being done? Is it more resources, human and financial? Is it a different attitude on the part of researchers and clinicians? Can the jury give a sense of the relative importance of longitudinal work, the degree to which it is being done, and, perhaps, how it should be done?

**Gail Andrew** – I see the importance of longitudinal work from two perspectives. One is the research perspective. We have many questions about how the presentation of the disability of FASD changes over time and whether interventions that target various strengths, weaknesses, and patterns can make a difference. Unless we are following an individual over time, we will not answer those research questions. We have made an attempt in the research side of my clinic, led by Dr. Carmen Rasmussen, to look at children in different age groups; but that does not tell us the whole story and it will not answer those research questions. From the perspective of the individual, I feel that when, due to financial and manpower constraints, I see a child on one occasion, make the diagnosis and then say goodbye at the end of the day, I'm not doing that child and family a service. I know that the child's needs will change, and perhaps the family's circumstances will change. Being able to provide reassessment — and it does not have to be by a whole team — at critical transition points where services change is an ethical responsibility, but not feasible at this point in time.

**Anne McLellan** – Dr. Gibbard, you have talked about transient disorders. One presumes that if you did longitudinal work, you would be able to identify how much of that which you originally diagnosed was transient, and how much of it was permanent FAS or some other permanent disability?

**Ben Gibbard** – One would hope that we would have the skill and acumen in our clinic to be able to differentiate that, but there are times when we see changes in trajectories to the positive rather than to the negative. I do think longitudinal work would be important and, to build on what Dr. Andrew said, looking at key transition points might be important. What is it like transitioning to foster care for some of these kids? What are the risk- and adaptation-promoting variables? What about that first contact with the legal system? That information would be highly important. One of the potential barriers to that research is lack of intersectoral collaboration. There are a number of systems serving children with FASD and cumulative risks: the child welfare system, the education, health and justice systems. Doing research across those systems is challenging, but that is where research needs to take place.

**Susan Astley** – Next week my team meets to begin a longitudinal study. We have conducted FASD diagnoses for 18 years and now have a dataset of several thousand patients who were diagnosed 1 to 18 years ago. This patient dataset provides quite an opportunity for longitudinal evaluation. We plan to select for follow-up interview a group of patients that reflect the full continuum of FASD, ranging in age from birth to adult, with and without other adverse pre- and postnatal experiences. We occasionally see individuals more than once in clinic. Typically, they were first seen as infants and return as adolescents when they are old enough to engage in higher-level neuropsychological assessment. It is very interesting to see how FASD manifests over time in an individual. A question I have keen interest in answering is, what are the benefits of an FASD diagnostic evaluation? Do families feel more informed? Do they feel better able to advocate for their child? Does a diagnosis under the umbrella of FASD facilitate access to services/accommodations? Is patient prognosis improved? Our patient satisfaction surveys

(distributed three months after the diagnostic evaluation) have documented over the past 18 years that there is tremendous benefit (Astley, 2010), but we would like to look further out (1 year, 5 years, 10 years down the road).

## **Audience questions and answers**

**Audience** – This question is for Dr. Weinberg or Dr. Chudley. Regarding epigenetics and changing gene expression, can these changes become crystallized in the genetics and then be passed on to the next generation so that the vulnerabilities of the people who are affected are then passed on to their children?

**Albert Chudley** – That’s an interesting and important question. My understanding is that the gametes are demethylated, so that everything is wiped clean at conception. Then several cell divisions later, methylation occurs, so that the disturbed methylation is in the individual. This is particularly true for the sperm, as there are differences in demethylation in male and female gametes. But there are questions about methylation and nutritional aspects of individuals in another generation. Does that go down to the third and fourth generation? The biology wipes the disturbed methylation clean at conception, but some of the effects on certain genes that are involved in methylation may persist. That’s an interesting question and I need help, Dr. Weinberg.

**Joanne Weinberg** – It is true that there is demethylation and remethylation *de novo* in the newborn. But animal studies suggest that epigenetic changes can be inherited — the old Lamarckian principle, but it may be through epigenetic mechanisms. Changes in HPA-axis responsivity, resulting in a higher set point or a lower set point of the stress system, can be passed on to the offspring, and those can be manipulated experimentally by adding methyl donors. By increasing or decreasing methylation experimentally in the animal model, you can reverse or bring on those effects; so certainly there is evidence that there can be some persistence to the next generation, at least of the stress system. How generalizable that is, I don’t know.

**Albert Chudley** – I have a supplementary comment. You may have changes in methylation, but you do not have FAS in another generation unless there is alcohol exposure.

**Audience, Dorothy Henneveld** – I manage some intervention programs and have a question for the two clinicians, Dr. Gibbard and Dr. Andrew. A neuropsychological multidisciplinary FASD assessment is meaningful for families and a protective factor both for individuals affected and for their families. Could you comment on the relationship between assessment and the future interventions, looking at the strengths of assessment and what that impact has protectively?

**Ben Gibbard** – Dr. McLennan has done trajectory research on outcomes of supports and services for individuals post-diagnosis. I think that for many families a diagnosis is a very helpful organizing principle. But I do not think we know enough about what that post-diagnosis phase looks like, and what the long-term trajectories following that diagnosis are. It is a bit of a black box for me as a clinician. We are building in follow-up assessments of kids, looking at trajectories, but that is so new that it is difficult to generalize any data from it.



**Gail Andrew** – I have mainly anecdotal comments from the families, quite a few of whom stay in contact with our coordinator because a relationship has been built through the process of assessment. I think that once the diagnosis is made, the caregiver often has an “ah ha!” moment, as does the affected individual. As Myles Himmelreich said, there is a feeling that “I’m not the problem; I have a problem.” I think that is powerful for the affected individual, and it helps the caregivers not to blame themselves for not being good enough parents, to realize that they are dealing with a brain that has differences. On the other hand, a diagnostic assessment is the worst thing that you can do for someone when their community, where they belong, where they came from, is not ready for it. They go back with a label that can lead to blame and shame, maybe to pulling out of services because of the attitude that FASD equals brain damage and therefore maybe we shouldn’t make all those efforts to help that individual change. I think we have a lot of work to do on the whole matter of readiness, and it should be cross-sectoral, to build on what Dr. Gibbard said.

**Nancy Whitney** – My question is for Dr. Astley. The screening that you do with faces has been quite valuable in identifying the highest-risk kids in a high-risk population and in getting them the help they need when they are in foster care. It has an unintended effect of misinforming and misguiding social welfare workers, and here I quote one of my least favourite child welfare workers: “She doesn’t have the face, so she’s fine.” Have you any thoughts about going to the next step in screening for fetal alcohol effects (FAE) in that high-risk population? How do we get to them before they end up in clinic because things have gone terribly, terribly wrong for them?

**Susan Astley** – I can address your question by sharing two important points.

1. Most individuals damaged by prenatal alcohol exposure do not have the FAS facial phenotype. When a child screened negative (e.g., did not have the FAS facial features), it did not mean they were not exposed to alcohol or not at risk for cognitive/behavioural problems. The screen-negative letter was carefully constructed to address this very important point. In the screen-negative letter, the legal guardian was instructed to refer the child to the FAS DPN clinic if they knew the child had a confirmed prenatal alcohol exposure. They were also instructed to refer the child to a neurodevelopmental clinic if they had concerns about the child’s development but did not have a confirmed prenatal alcohol exposure.
2. Even though our screening focused on FAS (not ARND) for reasons outlined in my presentation, foster care’s participation in the FAS screening increased their knowledge and awareness of the full spectrum of FASD. This heightened awareness led to a substantial increase in appropriate referrals of foster children with prenatal alcohol exposure (including those who screened negative for the FAS face) to the FAS DPN clinic. In essence, our active FAS screening program spawned a passive form of ARND screening within the foster care system.

I am often asked how one can justify screening for FAS without screening for ARND? The simple answer is, we have the tools, methods, and resources to accurately screen for FAS. We do

not have the tools, methods, and resources to accurately screen for ARND. In my opinion, it would be medically unethical to deny a population the benefits of an FAS screen just because we do not have the ability and/or resources to effectively screen for ARND.

**Sterling Clarren** – I think one summary point may have been missed by the jury. The clinics that do fetal alcohol work are responding to a need in the community. If they were not needed, they would not have been built. If general developmental clinics were serving the needs of this population, these special clinics would have never started. If general clinics were now doing the work of these clinics, they would be abandoned. So there is something else going on here that is special. And what it is, I think, is mysterious maladaptation, in that the common pathway for all of these kids — diffuse organic brain damage and all of those things that go into making them complicated — is a mystery. The only way to solve the mystery and develop a treatment approach is by doing the hard work that is done in these clinics. These are not common children, even if they are not rare. They are complicated, hard to work with, and everyone who has come into clinics over the last 15 years in pretty much every country that does this work has found that it gets harder and harder, not easier and easier. The second thing that is truly bizarre is the notion that you need to see them only once. Where else in medicine do we say that all you need is a diagnosis, and take off? It's truly interesting.

### **Reference**

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## **Question 3**

***What are the consequences of FASD for individuals, their families and society?***

### **Economic implications**

**Philip Jacobs**, *Professor, Gastroenterology Division, Department of Medicine, University of Alberta; Director of Collaborations, Institute of Health Economics*

I am going to talk about aspects of the economics, and the economic implications, of FASD. I would like to caution that while the numbers are enticing, there are many unknowns.

The key economic questions are:

1. What is the economic burden of FASD? (This does not mean personal burden. 'Economic burden' is a technical term that will be explained.)
2. What are the costs and consequences of the interventions?
3. What is the budgetary impact of government interventions?

The economic burden of a condition is a measure of the resources required to manage it. It naturally evokes questions about how our scarce resources are used and who pays for them. Treatments for FASD are very expensive over a lifetime. They often start with neonatal intensive care (80% of babies born with FASD go into an NICU) and may include institutionalization, home care, special education, social assistance, justice, and other services. Not every person with FASD receives the same treatments, but data from the United States show that in a given year the medical, education, social services, and out-of-pocket costs of treating someone with FASD is about \$20,000. Most of these costs are direct costs. Additionally, for younger people, there is a work loss, and later on in life there is a big impact on work loss as well.

If we look at the cost by age, which has been done in an American study (Stade, 2009) that was based on observational data (which may not be optimal, but is the best data available), we find that the cost does go down a little with increasing age, but FASD remains expensive throughout the lifespan. Not that we should focus only on money, but the resources we have at our disposal are scarce. The figure to keep in mind is that the *extra* cost of a person with FASD up to the age of 18 or 20 is \$21,000 per year (Stade, 2009).

Another useful figure is the lifetime cost of FASD. This morning, the Minister mentioned a figure of 1.5 million dollars. That number now seems to be closer to two million. If you multiply this by the number of people that have FASD, you arrive at the societal cost, which seems to be around six billion dollars for Canada. Note, however, that we do not know the exact number of people who have FASD. Only in economics can you take one unknown and multiply it by another unknown and end up with a very concrete number that is regularly quoted. I do not think this number itself is worth remembering. Instead, we should focus on the fact that people use resources, and it might be possible to use our resources to prevent some of these very expensive occurrences from happening.

It is also important to see if any of the interventions we use are helping to ease the burden of this very expensive condition. If nothing works, then an expensive burdensome disease must remain very expensive. There are always extra costs that result from interventions, but, ideally, there are also outcomes that make a difference to the lives of the individuals with the condition and their caregivers. The outcomes are the improvements in health-related quality of life (i.e., people feeling better and having a better life).

What do interventions for FASD cost? Without a doubt, they can be expensive. A study done in Seattle, which is one of the very few that looks at the costs of interventions, estimated that it costs \$3,800 per client for the initial visit of a home-visit program, plus social work, plus two visits per month for a year. The benefits cited were reductions in costs down the line, which were hard to prove, and improvements in the quality of life. How effective are these interventions? Determining this is a big problem. Nineteen homes were visited, and 17 of the women abstained from drinking as a result of the intervention. What this means in terms of fewer cases of FASD, we do not know. This makes it hard to determine the cost effectiveness of the intervention in preventing FASD.

The budgetary impact is \$3,800 multiplied by the number of interventions — and we need a great many interventions. It would take quite an initiative to meet the current need, and, unfortunately, I have not been able to find out what we spend now. If we do not know what we spend now, how can we know what we should spend? We should make it a priority to figure out our current expenditures.

How many interventions equal the cost of one case? If we divide \$800,000 (the extra cost of FASD during a lifetime) by \$3,800 (the cost of preventive intervention), we see that we need to prevent one case of FASD for every 210 visitation interventions. It sounds promising. Even if fewer cases than that are prevented, which would result in a net cost for the intervention, there would still be compelling benefits. We cannot focus only on reducing costs. The issue then becomes whether the extra costs are worth the extra benefits. When considering the economics, you have to focus on both: the good you are doing and the extra money you are spending.

I want to finish with a few comments. There is a submerged iceberg of need created by illness. Only a tiny fraction of the people who need it receive treatment. In colorectal cancer screening, we started a program that is very small but shows that we can have a huge effect on this very debilitating disease. Obesity is something that we are just starting to look at. There are many high-priority areas that all demand resources. Someone is going to have to make priorities, and I do not think we are doing a good job of that right now. But there are some good examples of successful prevention efforts in Canada, the reduction of smoking rates being one. It took a concerted effort, but it made a huge impact. We changed the tax system, communications, and the legal system, and there was a great deal of resistance, but Canada used its resources effectively and it had an impact internationally. Similarly, if we are to improve the treatment and prevention of FASD, a considerable effort and a great many resources will be needed.

## **Consequences for the community**

*Mary Berube, Director, Intergovernmental Initiatives, Ministry Support Services Division, Alberta Children and Youth Services*

I am going to speak about what FASD means for the community and what the community's response should be. When we use the word 'community' in this context, it is in the broadest sense: that is, the members of society and the structures we create to sustain us. In Alberta, we have many different communities: First Nations communities, rural communities, urban communities, and so on. When FASD was first identified in 1972, that discovery generated compassion in the community for infants with histories of prenatal substance exposure. This led to early prevention messaging, which, unfortunately, often encouraged anger toward the birth mothers. Since then, we have gradually gained an understanding that FASD has lifelong impacts on affected persons and their caregivers, and we have recognized FASD as a disability.

As a society, we have learned that prenatal alcohol exposure has an impact that demands a community response, and we are now moving toward an understanding that the community responses engendered by FASD and its sequelae are complex. FASD is not a simple issue to be

quickly solved. We are starting to understand our responsibility and rethink our attitudes toward pregnant substance-using women. In Nancy Poole's words, "those mothers are mothering under duress." We are wondering what it will take to mitigate the harm caused by prenatal substance abuse, who will take this on, and what it will cost.

But it is not only about money. We have a moral and ethical obligation to take on complicated issues that our fellow citizens struggle with. The community has responsibilities toward persons with FASD and their caregivers. The community has a collective responsibility to try to prevent secondary disabilities once FASD has occurred. The community has to be responsible for public health, social assistance, community safety, inclusion, and public messaging. Let us examine these responsibilities in more depth:

1. Public health – The community is responsible for diagnosis and prevention initiatives. This continuum of services includes public messaging, health promotion, and direct intervention with those who require an FASD diagnosis and with women who use alcohol during pregnancy.
2. Social assistance – The community provides social assistance, including housing and health care, for persons with disabilities. We have child welfare and child protection initiatives, education, and, sometimes, employment assistance. People with FASD use all of these services, as well as substance abuse and mental health programming and the justice system.
3. Safe communities – Safe communities need infrastructure, governance, policy design and implementation, policing, and a justice system. In all of these areas, FASD must be taken into account.
4. Community inclusion – Communities should offer equal or appropriate opportunities for all citizens and equal access to public buildings, events, and opportunities. Communities should share the burden of caring for persons with FASD, and should value diversity and celebrate the accomplishments of persons with disabilities.
5. Public messaging – Communities should provide messaging that exhibits inclusion. This includes non-blaming public awareness campaigns and unbiased language.

Here is my prescription for community management of FASD. We need the following:

- A 'diagnosis for two,' preferably in early gestation or early infancy.
- Women's centres for substance abuse interventions.
- To understand that the pregnant woman who uses alcohol is not someone to blame, but rather someone who requires our help and intervention.
- To practice harm reduction. This means having professional multidisciplinary teams that attend to the medical issues related to FASD and making available periodic screening for hearing, vision, speech, and language problems throughout the individual's development.

It also means regular screening for substance use, mental health problems, and reproductive health issues; provision of assistance to cope with relationships, parenting, and family life; and specialized intake and interventions for substance use in the mental health and justice systems.

- Family-centred care and advocacy to address the needs of children and parents.
- Support for families, including grief and loss counseling.
- Respite for caregivers in order to prevent placement breakdown, which is costly on many levels.
- Research on intervention models that work for children affected by FASD.
- To make allowances at every developmental stage and to anticipate and prepare for the challenges of each stage of development.
- Developmental assessments at every stage to inform case planning.
- Educational placement and supports to sustain students and teachers.
- Lifelong, continuous advocacy, and case management for affected individuals.
- Parent and caregiver training for every stage of development.
- To prepare individuals from an early age for meaningful work. We need to support employment, from helping with employment searches to supporting the daily work of persons with FASD.
- Increased supervision and one-on-one supports to navigate the years from 12 to 21. We need to recognize that, developmentally, the challenges of FASD grow as the child grows.
- Preplanned transitions from children's services to adult services.
- The provision of ongoing and explicit training for persons with FASD regarding socialization, employment, sexual activity, life skills, and how to accept help.
- To recognize and plan for various degrees of lifelong dependency and daily living supports for persons with FASD.

When a person with FASD is involved in a substance-use program, mental health program or justice program, we need to provide specialized interventions. FASD is unique (even though many issues associated with it overlap with other conditions), and we need specialized care and interventions that are tailored to FASD. We need to provide a range of living and housing options that are not contingent on life-management skills. In other words, individuals should have a home even if they cannot pay the rent, and they should have food to eat even if they do not manage to make their groceries last for an entire month.

Harm-reduction strategies are subject to the tides of public opinion, and right now the public is fairly open to hearing about FASD. Harm-reduction strategies are also subject to government ideology, bureaucratic will, and available monies. We need to entrench these interventions in policy so that they are less likely to be removed on a whim. The recommendations that come as a result of this conference should clearly state the best way to manage the condition and how we as a community are going to support persons with FASD and substance-using pregnant women.

It takes a whole community to manage the issue of FASD, and every community should take this on in their own way. We must recognize that as a civil society we have agreed collectively that we will take on one another's burdens, and ask what that actually means and how it can be accomplished.

## **Impact on system usage within foster care**

*Linda Burnside, Executive Director, Disability Programs, Manitoba Family Services and Housing*

I will discuss five research projects in Manitoba, dating back to 2005 when the first of them was published, involving children in foster care, and specifically children in care with FASD. While it was not our original intent to seek out children with FASD, the high rate of FASD among children in care was one of the key findings of our first study. In that study, we wanted to understand the children in care who had disability. We were very concerned that many children had disabilities, but the child welfare system in Manitoba did not have data about the nature of these disabilities. So we embarked on a time-consuming and laborious research project. We hired research associates and went to every child welfare office in Manitoba to go through files and gather information, because we had no other way of determining what kind of disabilities children had. The research associates traveled by car, airplane, boat, ferry, and snowmobile. Such is the nature of data collection in Manitoba! But we ended up with a picture of the nature and scope of disabilities affecting children in care in Manitoba.

Of the 5,500 children in foster care in 2004, one third of them (or just over 1,800) had a diagnosed disability. Seventeen per cent of children in care either had already been diagnosed with FASD or were being tested for the condition. We used stringent criteria for including FASD diagnosis or testing in our data collection. We did not include children whose files noted that they were suspected of having FASD by a social worker, foster parent, or school teacher, even though the children may have had FASD. We counted only those children who had been seen by a physician or were in the process of diagnostic testing through a medical facility or diagnostic clinic. As a result, we feel confident in the numbers that we gathered, but we think that it is an under-representation of the actual number.

In our first study (Fuchs, Burnside, Marchenski and Mudry, 2005), we found 963 children who had been diagnosed or were being tested for FASD (approximately 600 were diagnosed). Because Aboriginal children represent a high proportion of the children in care, many of the children with FASD were of Aboriginal descent. We learned that the majority of those children

were permanent wards of the child welfare system. This inspired us to look specifically at the experience of children in care who had FASD.

Our second study (Fuchs, Burnside, Marchenski and Mudry, 2007) looked at the experience and life histories of 122 children in care. We learned that children with FASD come into care at a younger age, on average, than other children in care. Because they come in at a younger age, they become permanent wards more quickly. As a result, they spend a greater proportion of their lives in care and have a higher number of placements than other permanent wards. Consequently, they experience many challenges and are intricately involved with the child welfare system.

In our third study (Fuchs, Burnside, Marchenski and Mudry, 2008), we wanted to better understand older youth with FASD who were leaving care. This was a very small study because we had only 27 individuals who met those criteria. This is partly because many older youth do not have a diagnosis of FASD and we could work only with those whom we had already identified. We discovered that only 30% of youth with FASD stayed in their longest placement until the age of majority. This means that 70% had their longest placement break down long before they reached the age of majority. In fact, we found that it was in early adolescence that most placements broke down. After their longest placement broke down, these youth tended to have a series of placements before things stabilized for them. Care was seldom extended beyond age 18, even though the provisions in Manitoba allow for care for permanent wards up to age 21. Not surprisingly, because of the length of time that these youth spend in care, they also have many social workers during that time.

We were then interested in determining how much it costs the child welfare system to provide care (Fuchs, Burnside, Marchenski, Mudry, and De Riviere, 2008). To come up with our figures, we closely examined financial records and invoices. Figure 5 is a description of the average costs that were incurred in 2006 for 400 children in care with FASD.

**Figure 5**

Average annual cost per child across all age groups was \$23,760. For each age cohort, costs averaged:	
• 0 – 5 years:	\$18,008
• 6 – 10 years:	\$20,633
• 11 – 15 years:	\$26,021
• 16 + years:	\$24,742

The numbers are relative to Manitoba’s cost of living and the amount provided to foster parents, which differs across jurisdictions. In 2006, Manitoba’s child welfare system spent 9.5 million dollars to care for these 400 children.

What is most important is that we were able to determine the impact of FASD on the cost of care by looking at the special rate. The special rate, which is unique to each child, is based on an assessment of the child’s needs and the care demands that are placed upon the foster parents. Figure 6 shows the average daily special rate for each age group. The rate increases as children grow older.



**Figure 6**

<i>Age</i>	<i>Daily rate</i>
0 – 5	\$27
6 – 10	\$35
11 – 15	\$47
16+	\$50

The average special rate for children with FASD was \$42 per day, while the average special rate for all other children in care was \$35 per day. Thus we have been able to demonstrate that FASD increases the cost of care.

This series of studies resulted in a detailed electronic database of children in care with FASD, which allowed for the opportunity to work with the Manitoba Centre for Health Policy to look at the broader economic impact of the cost of care. The fifth study (Fuchs, Burnside, De Riviere, Brownell, Marchenski, Mudry and Dahl, 2009) was an opportunity to compare several different groups, including children in care with FASD, children not in care with FASD, and children not in care and without FASD, which are briefly described in Figure 7. Data on children’s healthcare services, prescription medication, education, and subsidized child care was available through the Manitoba Centre for Health Policy in a standardized, anonymized format to protect confidentiality.

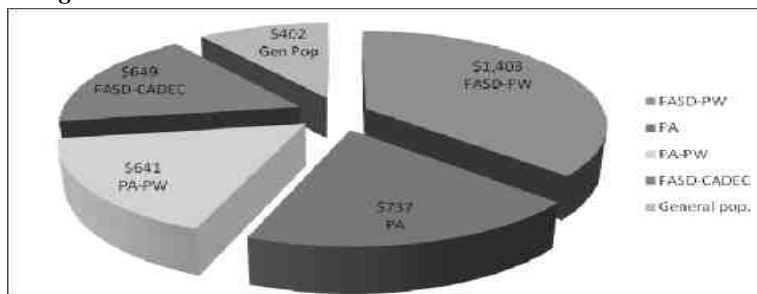
**Figure 7**

- FASD-PW: Permanent Wards with FASD (*N* = 603)
- PA: Children in temporary care whose parents have alcohol issues (*N* = 587)
- PA-PW: Permanent Wards whose parents have alcohol issues (*N* = 51)
- FASD-CADEC: Children not in care with FASD (*N* = 119)
- General Population: Children without FASD selected by random matching methodology (*N* = 4,964)

We included 603 children with FASD who are permanent wards. However, we also began to think very carefully about FASD as an end point of prenatal substance use. We wanted to consider children who are affected by parental substance use, but either do not have FASD or have not been diagnosed. We were also interested in children who are affected postnatally by parental substance use. Thus, we included both of these populations in our study. Children in the parental alcohol (PA) group were children in temporary care whose parents had presented to the child welfare system with alcohol issues, but these children did not have a recorded diagnosis of FASD. We also looked at children who were permanent wards and were affected by parental alcohol use (PA-PW). Through the Clinic for Alcohol and Drug Exposed Children (CADEC), we were able to identify 119 children with FASD who were living in the community and not currently involved with the child welfare system (FASD-CADEC). It is important to note, though, that more than half of them had previous child welfare involvement. Finally, with the help of the Manitoba Centre for Health Policy, we identified a random match sample of just under 5,000 children from the general population.

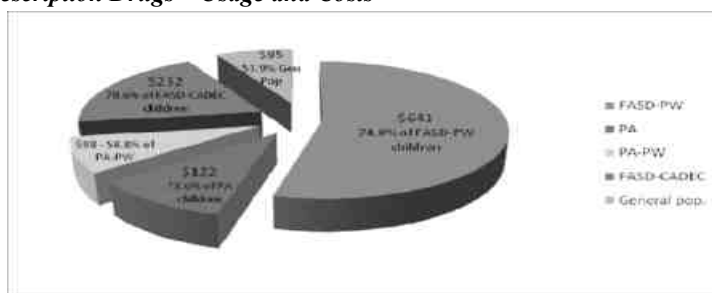
Figure 8 shows the average healthcare costs per child. The largest portion of the chart represents the population of permanent wards with FASD. They had the most significant costs in the categories of hospitalization, day procedures, physician visits, and prescription drugs. Compare that to the general population, which is the smallest part of the pie chart. You can also see the significant impact of FASD and parental alcohol use on healthcare costs for other populations.

**Figure 8: Average Healthcare Costs**



We further looked at drug prescriptions as a separate variable (Figure 9), and again the children with FASD who were permanent wards accounted for a great proportion of the cost. Seventy-four per cent of children with FASD had a prescription of some kind. Permanent wards with FASD were prescribed nervous system drugs, such as Ritalin and other ADHD drugs, at a higher rate and at a younger age than the general population. Specifically, 30% were prescribed drugs in the preschool years, up to 60% had prescriptions by the time they were school age, and the percentage increased with age.

**Figure 9: Prescription Drugs – Usage and Costs**



We wanted to know whether or not children with FASD received additional educational supports in the school system, and, in fact, they did. The top two shaded boxes in Figure 10 are reflective of the additional supports provided to permanent wards with FASD. The other two shaded boxes are for children with FASD living with families in the community. At the bottom, in the darkly shaded boxes, are the costs afforded to the general population. We can see that children with FASD needed additional supports in the school system.

**Figure 10**

	<i>Number of children enrolled</i>	<i>Children funded at Level 2</i>	<i>Children funded at Level 3</i>	<i>Total costs of education funding</i>	<i>Average costs of education</i>	<i>Incremental education costs compared to General Population</i>
<b>FASD-PW</b>	450	36.2%*	14.0%*	\$3,304,514	\$7,343	\$5,166
<b>PA</b>	311	3.2% (1)	(s)	\$ 702,458	\$2,259	\$ 82
<b>PA-PW</b>	35	17.1%*(1)	0	\$ 124,294	\$3,551	\$1,374
<b>FASD-CADEC</b>	79	38.0%*	7.6%*	\$ 460,818	\$5,833	\$3,656
<b>General population</b>	3407	1.9%	1.0%	\$7,418,198	\$2,177	

\*statistically significant difference with respect to the General Population group

(s) the estimate is suppressed due to a small count between 1 and 5 observations

(1) Statistically significant difference with respect to the FASD-PW group

We also learned that many of these youth had lower rates of high school graduation and a lower likelihood of completing sufficient credits by grade nine (which has been proven in other studies to be an indicator of high school graduation) (Brownell, De Coster, Penfold, Derksen, Au, Schultz and Dahl, 2008). They also had lower marks on standardized tests, were less likely to have written standardized tests, and had a higher rate of repeating a grade in school. Children with FASD were less likely even to be in school after age 15. And they did have incrementally higher costs, in comparison with other children.

In the area of childcare subsidies, we found that, compared to the general population, children with FASD required slightly more government assistance for accessing daycare.

Children who did not have FASD but were affected by parental alcohol abuse had the second highest rate of physician visits and hospitalizations. They also had a very high proportion of nervous system drugs prescribed, but a slightly lower rate than children with FASD. They had detrimental educational outcomes, but were less likely to receive special education funding, often because they did not have a diagnosis that made them eligible for funding.

To summarize, FASD creates significant demands for the resources of child welfare agencies, partly because of the length of time these children spend in care. Children with FASD are more likely to be permanent wards of the state, and the cost of their care is higher than for the average child in care. And we know that large numbers of children with FASD will be transitioning out of child welfare care and will need resources and supports in the adult system. We know that children with FASD are disadvantaged as they enter the child welfare system because they come into care early and are made permanent wards more quickly. They are also disadvantaged as they

leave care, in part because their placements are least stable during the time that they are making their transition to adulthood. We know that FASD significantly affects healthcare costs and utilization, education, and use of subsidized child care. Children who do not have a diagnosis of FASD but are affected by parental alcohol abuse have similarly negative outcomes, perhaps with a slight reduction in intensity.

These reports can be downloaded from the Centre of Excellence for Child Welfare website at [www.cecw-cepb.ca/catalogue](http://www.cecw-cepb.ca/catalogue).

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## Jury questions and answers

*(Mary Berube, Linda Burnside, Phil Jacobs)*

**Malcolm King** – This is a question for Mary Berube. I am thinking about the work by Chandler and Lalonde on youth suicide in British Columbia First Nations. One of their main findings was that there was no such thing as a suicide rate in First Nations communities, because it varied from zero in some communities to sky-high in others. They then went on to look at community factors that are potentially protective against youth suicide. Is there any similar study looking at community factors in First Nations, or in other communities, that affect the prevalence or incidence of FASD either negatively or positively?

**Mary Berube** – I am not aware of any studies that looked at protective factors specific to, for example, a First Nations community as opposed to other communities with respect to prevention of FASD or to managing the impacts of FASD once it is present. The closest I can come to answering your question is that there are certainly communities, both First Nations communities and others, where protective factors, if you think of it in a public health framework, are present. We know that one protective factor is paying attention to mental health, because there is a high correlation, for women in particular, between mental health problems and substance use. Women manage and cope through substance use, so if a particular community manages mental health problems well or has a very good support system for women living under duress, that will likely reduce the incidence of FASD. It is the same after FASD is present: there some instances in which the entire community seems involved in ‘taking on’ everyone in the community and helping them with their life issues. In that kind of community, where the support system would naturally be stronger, there may be fewer secondary disabilities.

**Raisa Deber** – This question is for Phil Jacobs. Your data suggested that if you prevented only one case with 210 interventions, it would be cost-neutral, and anything better than that would be cost-saving. Was your message that it is expensive, or that it is important to target?

**Phil Jacobs** – The message is that even if it is not cost neutral, that is, even if it costs more after you take into account the cost of the prevention program and any savings from preventing FASD, that does not mean you should not go ahead with it. There are health benefits that have to be taken into account as well, and they are pretty substantial.

**James Hees** – This question is for Mary Berube. Mary, you alluded to a publicity campaign that you envision. I wonder if you could explain what that might be. What message might be communicated, what media might be used, and would it be national or provincial?

**Mary Berube** – Prevention messaging is complicated because of who we are trying to reach. It seems that we have done a pretty good job of conveying to the general population that alcohol and pregnancy do not mix. Our earlier prevention campaigns had a tendency to blame pregnant substance-using women, and integral in those messages was the notion that you could just say no — that this was simple, that stopping drinking during pregnancy was as easy as knowing that it

was not a good idea to mix alcohol and pregnancy. Those public prevention campaigns have managed to help people in the low- and moderate-risk categories to stop drinking during pregnancy. Anyone who can without difficulty go nine months without using substances is able to listen to a message like that, and able to act upon it.

Pregnant substance-using women tend to have much more complicated lives, are probably using substances to cope, and may or may not know that they are pregnant. Even once they know they are pregnant and are told repeatedly that alcohol and pregnancy do not mix, they may need a great deal of support to get through a pregnancy without drinking. Some of our simple awareness campaigns are not going to manage that part. I think we need two kinds of awareness campaigns: one to promote general awareness, so that those who are able to stop will stop; and another campaign that is directly aimed at persons in the high-risk category and that looks much more like interventions that are built upon personal relationships as opposed to posters.

**Anne McLellan** – I want to ask about the yearly cost to society. People have talked about how hard it is to get a handle on this figure. Linda, you had an amount of approximately \$23,000 based on your research, and, Phil, you had \$21,000. Are we getting close to being able to do the work needed to determine what the actual yearly cost is likely to be? And, if so, is the cost in that range? Phil, you said that we do not know what we spend now in the system. Are you referring to the all-in societal cost, whether that is child welfare or what one might spend as a parent for special instruction, or whatever the case may be? And I was thinking that studies like Linda's, which focus on the child welfare costs to the province of Manitoba, are providing us with extremely useful information about what those costs are likely to be, although it is not the entire picture.

**Phil Jacobs** – I think the Manitoba cost study was very good and close, because they used actual data, but I do not think we know the program costs for prevention. Those costs are incurred across different ministries and in nonprofit organizations. Unless we get a handle on that, we may find that we are spending very little on prevention. So we need to know that, and the Manitoba study did not cover that. It covered data similar to the sort that I presented, which I got from the United States and which reflects how much we are spending now for the services. I think the Manitoba study was probably more accurate.

**Linda Burnside** – To add to that, yes, the Manitoba study certainly would be accurate because it went with actual expenditures. But of course it has limitations, because we were not able to gain access to every service and every program and every expenditure. The study therefore helps to add some clarity to the picture, but does not complete the picture, not yet.

**Christine Looek** – It was very helpful to see that services for a child in care with an FASD diagnosis cost seven dollars per day more for than for a child in care without an FASD diagnosis. If the children with FASD come into care earlier and leave later than others, we are somewhere in the range of \$400,000 to \$500,000 more for social services for each of those children. Philip, your figures looked at the service, health, and education costs of FASD for all kids with FASD, including those who did not go into care. How much does it cost to raise a kid who is using

typical support services, and do we have a comparison of costs for a kid with FASD and a kid in care with FASD? I think if we know that, we then can start to get a handle on the added burden and the added need for support for these children.

**Phil Jacobs** – That is important. These were not excess costs, but I think the excess costs would be quite substantial. In fact, the Manitoba study did compare excess costs for the services because they had a comparative sample. So their statistic was an excess cost.

## **Audience questions and answers**

**Audience** – I have a comment about the general messaging. I think we have done a pretty good job of communicating to the general population the message that if you are pregnant, you should not drink. And we are starting to add to that by saying that if you are planning to become pregnant, do not drink. The one message that we have not heard very much of yet is that if you drink, you should not get pregnant. I think we need to have a much broader comprehension that drinking is a socially acceptable, legal activity, and that anyone can get pregnant. We really need to push contraception.

**Audience** – My question is for Linda Burnside. I am curious about whether you looked at the number of children between the ages of, say, 14 and 18, who left foster care and ended up in the criminal justice system and therefore are no longer taking up dollars in the child welfare system but are now taking up dollars in the criminal justice system?

**Linda Burnside** – Because the majority of children in care with FASD are permanent wards, for the most part they are in the child welfare system until the age of majority. I believe there is going to be a presentation later that will talk about youth with FASD who are involved with Manitoba justice. That is data we were not able to access through the Manitoba Centre for Health Policy, so we have gone as far as we can right now. But, yes, we want to understand and learn more about the needs of this population.

**Gail Andrew** – One of the pieces of data that came out of the Manitoba studies is quite disturbing to me. That is the excess use of neuropharmacology for children in care. I think it raises a question. Do these children have primary organic brain differences that lead to the presentation of mental health symptoms that require medication, or are we using medications to address less than optimal environments? I do not have the answer to that but wanted to bring it forward as another controversial point.

**Christine Loock** – In working with birth families, we find that sometimes they cannot afford the medications or do not have access to the same medications available to kids whose parents have health plans or who are in care. We must balance whether it is the right treatment and whether there is equitable access to treatment. And I think that there will be errors on both sides.

## Co-morbidities with mental health for an individual with FASD

**Dan Dubovsky**, *FASD Specialist, Substance Abuse and Mental Health Services Administration (SAMHSA), FASD Center for Excellence*

I will start by reading part of a letter that I received in Alaska after doing some training at a residential treatment centre for youth with serious emotional disturbance. I received this letter from a woman who came to the training not knowing much about FASD:

“I just thought it was about infants who had mothers who drank throughout their pregnancy. But when you started to talk about your son, it was like you were talking about my son. For years, doctors have diagnosed him with several disorders. He has been diagnosed with bipolar disorder, oppositional defiant disorder, ADHD, depression, and post-traumatic stress disorder, among others. No one has been able to pinpoint what he has. I told myself that surely he could not have FASD, as I did not drink during my pregnancy. As soon as I found out I was pregnant, I stopped. But before that, I was depressed, I was in an abusive relationship, and I drank mostly to keep my husband happy around his friends.”

This woman attempted to commit suicide by taking pills, but ended up in the hospital and found out she was pregnant. She stopped drinking at that point and therefore thought that her son could not possibly have FASD. Teachers said that her son could do the work, but was lazy and just did not want to. Others complained that he was unruly and walked out of class when it was time to work. He would say he was going to the restroom and was given 5 minutes but returned in 15 minutes. The letter continues:

“He would do something to upset us and the next day he would not understand why he was being punished because he was good that day. His father thought he was just being defiant. Then he got into trouble because he was hanging around his cousin and his friends and wanted to please them by doing things they wanted him to do. One of the kids decided to commit a robbery and told my son to hold the weapon while he was running away from the police, so my son held the weapon and was caught by the police and got charged for possession of a firearm. He continues to get into trouble for the company he keeps, but they state that he is an adult now, so I have no say. He cannot get a job because he continues to lose his important documents. Whenever he has had a job, he would not follow the directions and so would lose it. His girlfriend told him to stop hanging around the gang members he has been with, because they use him to sell drugs for them, and he always gets caught because he is not good at being a criminal. He just does what he is told. So he decided to go tell these so-called ‘friends’ of his that he could not sell for them or hang around them anymore because he has a daughter now. He did not understand how dangerous that was. When he did that, he was left for dead, and a witness told the police he was beaten up by nine individuals. You could see shoe imprints all around his head and face where he was stomped on his head.”



I get many calls and letters like this. This woman's story is not unique, but it does reflect why we are all here and why it is so important to develop a consensus statement. The reason I have been in this field for almost 25 years is my son Bill. Bill was diagnosed with FAS when he was 19 years old and diagnosed with many other disorders before FAS was recognized. I am going to talk about the importance of identifying all co-occurring disorders and life and environmental issues, because only if co-occurring issues are treated simultaneously can optimal outcomes occur. While the debate continues as to whether mental health issues in people with FASD are primary or secondary, it does not really affect treatment. Regardless of whether they are primary or secondary, the way we intervene with individuals who have mental health issues co-occurring with FASD needs to be different from the way we treat individuals who have mental health issues but do not have FASD.

FASD changes the way in which information is processed by the brain, so we cannot use our typical treatments. We have heard again and again over the last few years in research that in many individuals with FASD receptive language processing seems to be more impaired than expressive language processing. Unfortunately, all of our treatment and parenting approaches, our education system, our child welfare approaches, and our justice approaches are based on receptive language processing. If we fail to diagnose FASD because we are not paying attention or because the symptoms are similar to other mental health disorders, we provide the wrong treatment and we get the wrong outcomes. We consistently set people up to fail because we are not recognizing this. We use our 'evidence-based practices,' such as motivational interviewing and cognitive-behavioural therapy techniques. However, these are based on receptive language processing, which means that they are not going to be the most effective techniques for someone with FASD. And when the techniques do not work, we say that the person is not motivated for treatment or is not ready for sobriety.

Over time, if individuals really want to do well and succeed, but keep failing and do not understand why, they start to believe that they are failing repeatedly because they are bad. They develop that self-image because that seems the only explanation for their failing over and over again. By the time they enter our systems, they have this 'bad' profile or 'bad' self-identity, and we feed into that, and they keep failing over and over again. I believe this is probably one of the reasons for the repeated foster care placements that we see. They come into foster homes, and we do not recognize the FASD and continue to use our regular approaches. John VanDenBerg did a great deal of early work in the United States around the development of 'wraparound.' The concept of wraparound is that if treatment does not work for someone, we tend to give them more of the same treatment, and all they do is fail over and over again.

Another problem is that FASD is not in the Diagnostic and Statistical Manual (DSM), and consequently clinicians often do not consider it. Whether or not it should be in the DSM is a discussion that we could have, but the important point is that we are not providing research on treatment approaches for individuals who have both FASD and mental health issues. That is something that we need to do. Clinicians tend to diagnose people based on their symptoms and

tend to treat people based on their diagnoses. A truly individualized approach is needed, but I do not believe that clinicians often do that. We look at the diagnosis and we treat based on the diagnosis. Instead, we need to look at the individual and ask what this individual needs in order to be successful, and how we as a community can help meet that need.

One explanation for the co-occurrence of mental health disorders in people with FASD is that some mental health disorders have a significant genetic link. These include schizophrenia, bipolar disorder, major depression, and ADHD. We also know that people with these disorders have very high rates of substance use. A woman who has one of these disorders and uses substances to self-medicate may give birth to a child with an FASD and a genetic vulnerability for that mental health disorder. As Joanne Weinberg said, the issue of stress and the hypothalamic-pituitary-adrenal (HPA) axis is very important. There is research that shows that the number of stressors one experiences and one's ability to cope with those stressors determines whether an underlying genetic vulnerability will develop into a full-blown disorder. If people who have been prenatally exposed to alcohol have a hypersensitive HPA axis and a genetic vulnerability to a mental health disorder, they are more likely to develop the disorder and enter our system with that diagnosis. We are likely to miss the co-occurring FASD and therefore fail to use the right approach to help them be successful. Susan Astley completed a study that speaks to this. In looking at the risk profiles of mothers of FASD children, she found that 59% of these women had a major depressive episode and 22% had a manic episode or a diagnosis of bipolar disorder. In comparison, the incidence of major depression in the general population is somewhere between 20% and 25%, and the incidence of bipolar disorder is between 1% and 2%. Seven per cent of the women had schizophrenia, while the incidence of schizophrenia in the general population is 1%. Women who have given birth to children with FASD have high rates of these genetically loaded disorders. As a result, these children already have a genetic vulnerability and are more likely to develop that mental health disorder.

The co-occurrence of mental health and substance use disorders in people with FASD can be partly explained by genetic vulnerability, peer pressure, and family traditions of drinking. Another factor may be that living with a hidden disability is very emotionally painful. It hurts to be told over and over that you are lazy, that you are not trying hard enough, that you could do it if you would only try, that you are bright enough, etc. One of the ways to block that pain is to use substances.

Mental health and other disorders likely to co-occur with FASD are schizophrenia, depression, bipolar disorder, sensory integration disorder, reactive attachment disorder, separation anxiety, post-traumatic stress, and so on. Some of them are primary and some secondary, but regardless of whether they are primary or secondary, if there is a co-occurring FASD, we need to recognize it and change our treatment approach. In psychiatry, we tend to have tunnel vision. For example, the experts in reactive attachment disorder (RAD) say, "This is how you treat RAD. It does not matter what else is going on in the individual." However, it does matter if the individual has an FASD that co-occurs with the RAD. The treatment approach needs to be different.

In addition to FASD being missed because of co-occurring mental disorders, people with FASD are often misdiagnosed because their behaviours look very similar to behaviours associated with other conditions. ADHD, oppositional defiant disorder (ODD), and conduct disorder are three possible misdiagnoses for people with FASD. We tend to treat behaviours, whereas before we intervene we should start by asking what is causing the behaviours that we are seeing. The treatment approach for a true ADHD is different from the treatment for a true ODD or a true FASD. We need to find out what is going on. We cannot say, “It looks like ADHD, so we will treat for ADHD.”

My son Bill’s misdiagnoses as he was growing up included RAD, ODD, mental retardation, ADHD, and others. He did have a number of accurate diagnoses, which included severe learning disabilities, schizophrenia, an organic tic disorder, and FAS. The problem was that he was treated for each of the misdiagnoses, and the treatments were inappropriate because the diagnoses were inaccurate. He failed with those treatments, and we just said, “He is unmotivated. He is lazy. He is not trying. When he is really motivated, he will do what he needs to do.”

The following are some implications for policy and research:

1. All persons who work in mental health or substance abuse services should be trained in FASD.
2. FASD should be considered whenever a treatment approach that works with many does not work with a certain individual.
3. All intakes in substance abuse and mental health treatment programs need to include questions about possible prenatal alcohol exposure, especially if there is a positive answer to the question about substance abuse in the family. The next question has to be, “Did your mother drink when she was pregnant with you?” If the answer to that question is, “How the heck do I know?” then we need to do some work. Seeking that information will help us understand these individuals and how to help them and their families. It is not a matter of blame, shame, or judgment; it is about providing the best possible approaches for optimal outcomes.
4. For treatment approaches to be successful, all co-occurring disorders and issues have to be addressed. FASD should be ruled in or ruled out prior to developing a treatment plan. If we develop a treatment plan and the person does not respond, the first question we need to ask is, “Are we missing something here?”
5. We do not currently have evidence-based practices for use in FASD treatment, and treatments used for other mental health disorders are not transferable to FASD. We need to fund research to develop treatments or modify existing approaches to work for people with an FASD.
6. Reward and consequence systems must not be standard for individuals with FASD, because they typically set up people to fail. Instead, we need to examine what individuals

do well, what they like to do that is safe and legal, and how we can help them do that on an ongoing basis.

7. Research must be supported in developing and testing FASD modifications of treatment protocols for post-traumatic stress disorder and other mental health disorders.
8. We need to look at modifications of treatment for substance use disorders to help individuals with FASD succeed, rather than saying that they are just not motivated for sobriety.
9. Housing approaches need to be modified for people with FASD.
10. We need to modify our methods of addressing suicide risk. Risk assessment needs to be different for people with FASD than for people without an FASD. There is wonderful work being done in Washington by Nancy Whitney and Therese Grant on the suicide risk of women with an FASD in their PCAP program.
11. We need to address sexually transmitted infections in relation to FASD, a topic we tend not to talk much about in this field.

As FASD is lifelong, services need to be available long term and need to be flexible, based on the individual's need at different times.

The last thing that I want to say is that my son Bill lost his life, due in great part to being involved in a mental health system that did not understand the interface between mental health issues and FASD and that responded to behaviours without examining their cause.

## **Consequences for the community supporting adults with FASD**

**Diane Malbin**, *Executive Director, Fetal Alcohol Syndrome Consultation, Education, and Training Services, Inc. (FASCETS)*

There is general agreement that the most debilitating aspects of FASD are effects on the developing brain. Research has established mechanisms of damage and clarified the wide range of symptoms. Less well known is what to do with all this information.

If FASD includes changes in the structure and function of the brain, then it follows that it is by definition a brain-based *physical* disability. In most cases, however, it is invisible, and behaviours are typically the only symptoms. Understanding FASD as a primary physical disability with behavioural symptoms redefines problems and solutions in a manner consistent with research. Linking brain function with behavioural symptoms establishes an alternative, neurobehavioural framework for understanding FASD and addressing it differently. This presentation briefly explores the neurobehavioural concept for its relevance in shaping the consequences of FASD to communities supporting adults with FASD.

First, a word on context: there is a gap between research and application. Few interventional studies have been conducted, and fewer still have articulated the theoretical basis of their design and thereby established congruence with research. Why are there so few studies? FASD is a

neurobehavioural condition, and the prevailing paradigm is behavioural. Current understanding of the meaning of behaviour generally fails to consider brain function, or etiology of the behaviour. This lack of a conceptual foundation on which to operationalize research helps explain the stunning dearth of theory-grounded interventional studies on FASD.

Visualize your own brain for a moment. What does it look like when it's working? When asked this question, most people realize that they are completely unaware of their brain, having the luxury of being able to be oblivious to the activities it performs. If we are unaware of our own brains, and therefore of our assumptions about brain function, how can there be a basis for comparison between our assumptions about what our own brains can do and how others' brains may work differently?

In looking at the consequences of FASD for communities, we will consider two trajectories, A and B. The first outlines current practice, and the second outlines an approach based on a neurobehavioural construct.

### ***Trajectory A: Current practice***

Trajectory A may best be illustrated by the Streissguth's study of secondary disabilities, published in 1996. Secondary disabilities are not inherent in the condition. They are defined as patterns of behaviour associated with a chronic 'poor fit' between the person and the setting. For example, if a paraplegic were punished for not performing a high jump, defensive behavioural symptoms would be normal responses to the poor fit between ability and expectation.

The power of Dr. Streissguth's study may be implicit, illuminating the limits of current practice, programs, and policies to adequately meet the needs of people with FASD. All participants in the study were diagnosed with fetal alcohol syndrome or fetal alcohol effects (the terminology at the time), and, since the study was a natural history design, all continued to receive standard services. In spite of interventions by mental health, education, and other systems, the participants had high rates of secondary symptoms. Instead of suggesting the inevitability of deterioration, what if instead this suggests the limits of current practices that are based on learning theory, and the failure of these practices to incorporate research on FASD and other brain-based conditions?

A case example from our Oregon interventional study illustrates the gap between research and practice in Trajectory A. At the time of referral, 'Fred' had been diagnosed with FASD, was seven years old and in a day treatment centre. He was in the process of being transferred to residential treatment due to tantrums that resulted in daily four-point restraints. Over the years, Fred had multiple diagnoses and numerous interventions, including consequences, suspensions, therapies, medications, and day treatment. Incrementally, each new 'failure' generated increasingly constrictive and expensive interventions. The net effect of multiple failed attempts was the belief that nothing works. Fred was viewed as having irremediable mental health and behavioural problems, which were attributed to early neglect.

Why were standard techniques ineffective with Fred? First, because even with the diagnosis of FASD, his behaviours were defined as being the problem. Interventions therefore targeted

behavioural symptoms for change. When behaviours are symptoms of brain dysfunction, this is as effective as punishing the paraplegic for ‘refusing’ to do a high jump.

Further, rewards, punishments, therapy, and other cognitive-behavioural techniques are based on learning theory, which makes assumptions about brain function that have not yet been systematically examined for their relevance to people with brain-based conditions. The poor fit between assumptions and actual abilities clarifies why so many techniques fail. Behavioural techniques based on the current theoretical foundation — learning theory — are essentially variations on one theme that does not adequately recognize the spectrum of brain function and dysfunction. The problem was not with the techniques; the problem was the poor fit between the cognitive requirements for the techniques’ efficacy and the neurobehavioural characteristics of the individual.

Negative outcomes for people with FASD are still too common. This is in part a function of the limits of the prevailing paradigm, which fails to understand and adequately address FASD and other brain-based physical disabilities. Problems are defined on the basis of superficial symptoms without regard for etiology, and solutions miss the mark, resulting in ineffective, inefficient, and increasingly expensive interventions. Trajectory A is generally characterized by multiple diagnoses, interventions that do not work, and blaming of the individual. People are seen as *being* the problem rather than *having* a problem. Consequences to communities from trajectory A are familiar: high frequencies of secondary and tertiary problems and a disproportionate representation of people with FASD in mental health, justice, and other systems.

And what of the ethical implications? Does failure to recognize a primary brain-based physical disability breach the universal ethical mandate to “first do no harm”? This question will be revisited in the discussion of the second trajectory.

The second trajectory, B, outlines consequences to communities following application of a neurobehavioural approach. First, a word on the difference between behavioural and neurobehavioural approaches. The behavioural approach exists in a moral context that interprets and assigns meaning to behavioural symptoms, and targets these behaviours for change without cognizance of brain function. The neurobehavioural approach recognizes behaviours as symptoms of underlying brain dysfunction and focuses on etiology rather than superficial symptoms. This approach redefines the problem and solutions in a manner consistent with research. The point is not to limit, enable, or excuse ‘inappropriate’ behaviours, but to understand and become more effective and efficient in addressing them. The neurobehavioural construct goes to etiology, is theoretically grounded, and operationalizes research findings on FASD and other brain-based conditions.

### ***Trajectory B: Neurobehaviourally-informed interventions***

After joining the Oregon interventive study, Fred was re-evaluated by a multidisciplinary team composed of a neuropsychologist, physician, occupational therapist, and social worker. His 4-

digit diagnosis was 1-2-3-3, static encephalopathy, alcohol-exposed. He was found to have slow auditory and cognitive processing, difficulty with memory and executive functioning, and difficulty abstracting, conceptualizing, and generalizing. He was easily overwhelmed by sensory stimuli, and at age 7 was functioning socially at 3.5 years of age developmentally.

Fred's previous assessments focused on IQ, academics, and behaviour. The neurobehavioural assessment asked different questions that provided different and more useful information about Fred. For example, when his team discussed his developmental level of functioning, the perception of this 'socially inappropriate' seven-year-old boy was reframed: Fred was actually a competent three-year-old. Treatment staff immediately pointed out a systemic problem: they were mandated to write age-appropriate treatment goals. The solution: treatment goals were rewritten and expectations adjusted to be more compatible with his actual developmental level of functioning, not his chronological age.

Neurobehavioural information helped clarify other behaviours. For example, a pattern emerged in Fred's 'inappropriate' behaviours. His tantrums were not random; they happened at the end of math class. It turned out that at the beginning of math time, his teacher gave students a worksheet with 20 math problems. At the end of the allotted time, Fred would have finished only five problems. The source of the tantrums was identified: Fred had very slow cognitive processing, difficulty 'shifting set,' or switching gears, and had what is called rigidity in perseveration. It was very difficult, if not impossible, for him to stop working on a task before he was finished. The teacher would say, "It's okay, Fred, please put your math paper away and finish it later." Fred would not just say "No." He would resist and fight, because he was not finished and he was perseverative. Fred also had a diagnosis of oppositional defiant disorder, and his treatment goal included compliance, to do what he was told when he was told. So the teacher would insist, Fred would refuse, and four-point restraints were the outcome on a daily basis.

Once the teacher understood that Fred was unable to stop, rather than simply oppositional — that he was stuck and determined to finish — the solution was simple. The next day he gave Fred five problems, and at the end of the allotted time Fred was finished. No temper tantrum. End of problem. The math accommodation was the beginning of a more systematic exploration of other problems and solutions. In a very short time, Fred was no longer defined as having behavioural problems. He was not referred to residential treatment, but rather gradually transitioned back to his local public school and not to a behaviour classroom. Fred's placement stabilized. His foster mother called his caseworker to say, "I love this kid." The key was to understand Fred differently. Although accommodations for people with FASD are often simple, simple is not simplistic; it requires a different way of thinking.

The paradox is that trying to change behaviours that are symptoms of brain dysfunction typically yields more challenging behaviours. Reframing behaviours as symptoms of underlying brain function, identifying the fit between ability and expectation or setting, and providing appropriate accommodations yields change and improvement.

The neurobehavioural approach is an alternative framework for considering human behaviours. It is very different, conceptually and theoretically, from a simple behavioural approach. It starts by considering the role of the brain, looking at strengths and limitations, and developing effective, efficient, relevant and appropriate strategies and accommodations. This is the same approach used for people with other, more obvious physical conditions. The neurobehavioural construct thus provides a way to thoughtfully apply research to theory and practice.

To summarize, the approach outlined in Trajectory A, based on learning theory, yields exacerbation rather than resolution of problems. Unfortunately, this trajectory is still far too common for those with FASD and other brain-based conditions. Trajectory B, based on a neurobehavioural approach, holds promise for realization of full human potential and prevention. Like people with other physical disabilities, people with FASD benefit from identification and conceptually congruent application of neurobehavioural principles in all settings and systems.

My vision is that the neurobehavioural approach will lead us to a paradigm shift, so that by the year 2050 our great-grandchildren will look back and say, “Can you imagine there was a time in human history when we looked at people’s behaviours and did not think about brain function?” This neurobehavioural paradigm will increase our understanding of human beings. It will help us manage the complexity associated with brain function that has historically foiled our attempts to work in a meaningful way with brain-based conditions. As a result, we are going to achieve prevention. The shift from reactivity to proactivity will mean nearly empty mental health facilities and addiction centres, less need for social services and jails. Massive retraining programs will be required for all of us whose work addresses the misery of other human beings. That is my vision.

My policy recommendations are as follows:

1. Systematically evaluate professional curricula, practice, program design, policy, and legislation for congruence with research on FASD.
2. Standardize a neurobehavioural screening tool to facilitate referral for appropriate comprehensive assessments.
3. In addition to establishing diagnostic consistency, ensure that all assessment team members share conceptual consistency and generate neurobehaviourally-informed recommendations.
4. Until FASD and the neurobehavioural construct are included in parenting and professional curricula, include an educational component in all activities, from screening through diagnosis and implementation of recommendations.
5. Evaluate to ensure sustained application of relevant, appropriate activities.



## Jury questions and answers

*(Dan Dubovsky, Diane Malbin)*

**Rebecca Martell** – Mr. Dubovsky, you mentioned the motivational interviewing model. Is there a model developed specifically for those who are affected with FASD?

**Dan Dubovsky** – Not yet. There are recommendations for modifying motivational interviewing, and some people have worked on modifications for FASD, but as far as I know, it has not been tested. Generally in motivational interviewing, the concept is that individuals do all the work themselves. The therapist's or facilitator's job is to point out discrepancies between where the person is and where they say they want to be in their life. The person then goes off and thinks about that and considers whether there are behaviours that they need to change. For someone with FASD, the work would be done by the therapist and the individual working together, rather than having the individual going off and doing it alone. It would be a longer process, and everything would be written down. All the strategies that are based on receptive language processing would need to be altered so that they use multiple senses and are repeated and reviewed repeatedly. I am hopeful that we will have an FASD-specific model in the near future, although we need more funding for research on these sorts of modifications.

**Edward Riley** – You talked about the misdiagnosis of ADHD and oppositional defiant disorder. This might be more of a semantics question, but do you think that they are really misdiagnoses or that there are etiological differences between ADHD caused by alcohol and ADHD caused by genetic factors? I mean, these kids really do have an attention problem.

**Dan Dubovsky** – They do have an attention problem and I think some of them have a co-occurring ADHD, if we want to talk about ADHD in particular. But much of the research in ADHD has shown a specific etiology of the problems in ADHD which has to do with hypoactivity in the managerial level in the frontal lobes of the brain. This seems to be from a lack of dopamine, which is why stimulants often help individuals to filter out stimuli and to focus. But if the inattention and impulsivity are not due to a lack of dopamine in that area of the brain and we use medications that increase dopamine above what it should be, then we see worsening behaviours, to which we respond by increasing the medications. So I think it is more than just semantics. I think there really is a difference. I think that some people with FASD have a co-occurring disorder, but many people with FASD have ADHD symptoms but not a true disorder. It really does affect the treatment approach. The same is true with oppositional defiant disorder. Primary oppositional defiant disorder, without other co-occurring disorders, describes conscious decisions to refuse to do what one is told to do. But in FASD, often it is an inability to remember what they were supposed to do. As they get older, it is much better to say that they did not feel like doing it than to say that they did not remember to do it. As Myles said earlier, it is much better to be seen as bad than to be seen as stupid. So I think it is more than just semantics, and I think we need to look carefully at filtering that out.

**Diane Malbin** – I would like to comment very briefly on some of the bigger issues around DSM diagnoses. The fact that there is overlap between neurobehavioural symptoms and behavioural symptoms in DSM is well established. However, one problem with the DSM is that it places clusters of presenting behavioural symptoms on Axis 1 without regard to etiology. That is a fundamental problem. If we are looking for a unifying principle in order to understand the person more holistically, then the fragmentation that results from multiple DSM diagnoses does not move us in that direction. If you have a person with prenatal exposure to alcohol and ADD, the diagnosis itself is not the problem. The bigger problem is what interventions that diagnosis generates and what it fails to recognize. What about processing pace? What about developmental level of maturity? What about sensory systems? What about executive functioning? Research has found that 80% of people with FASD may be diagnosed with ADD. Research has also found underlying neurocognitive characteristics for those with FASD/ADD to be different from ADD where there is no prenatal alcohol exposure. Shared diagnosis means reliability; validity requires etiology.

**Raisa Deber** – Do we have therapies that are likely to work? Does everyone need intensive case management for the rest of their life, or are there interventions that allow people to move on and function well?

**Diane Malbin** – We are talking about a significant shift in understanding human behaviour, and I believe that one of the gifts of FASD is to further us down that road. The shift is from trying to change the person to achieving changes by providing appropriate accommodations. In our study and in the work in British Columbia, the targets of the intervention are the systems around the person. The individual is not the one targeted for change, but rather the person-in-context. We also redefine outcomes to speak of interdependence rather than independence.

Intensive case management that focuses on changing the person is much different from creating an environment or context in which the person is able to succeed. A couple of points that Myles made today speak to that. Once someone understands that he is not the problem, but simply has a problem, esteem improves. Empowerment increases. Then we look at context. Making a few accommodations here and there in scheduling and having understanding people working with him in order to prevent problems improves things immeasurably. The goal is to move from reacting to problems to being proactive in preventing them. Just because we have the problems does not mean they have to persist.

**Dan Dubovsky** – We now call it fetal alcohol spectrum disorder, or, in the United States, fetal alcohol spectrum disorders, and it really is a spectrum. So we cannot say that there is one approach that everybody is going to need. Will there be people with an FASD who will need intensive services long term? Absolutely. Will there be people with an FASD who just need somebody to check in with them every once in a while as they get older? Absolutely. It is all about that spectrum. As we look further and recognize what is going on in the brain to cause difficulties in verbal receptive processing and difficulties in following multiple directions all at once, we alter our approaches. For example, the idea that many people with an FASD learn best

by modeling the behaviour of those around them has implications for case management. Instead of traditional case management services, which might connect the person with services and then leave it up to the person to follow through, we might provide mentorship programs. The mentor would participate in activities in programs with the person, model the behaviours at the moment, and pick up social communication issues when they occur rather than talking about them in an office a day or a week later — which to the FASD person is like a year later, because every day is a new day. This approach could be extended to programs such as foster care. For example, if you have a young parent with an FASD who is raising a child (who may or may not have FASD), instead of taking the child away for placement in foster care, let us put that parent and child together in a family foster home where a foster parent can model parenting behaviour at the moment something needs to be done. We could be very successful with this, and there is a funded program in Victoria [British Columbia] that is doing that. I think there are different approaches and modifications of approaches that are all based on the research into how the brain works in individuals with FASD.

**Frank Oberklaid** – I think all of the things that you said are absolutely unarguable, but we have heard that none of the symptoms that these young children present are unique to FASD. And a lot of the things you are talking about are, in my mind, not specific to FASD — they are just good clinical practice. They are relevant to a whole range of neurobehavioural and developmental issues. Am I missing something? I think all conditions should have that approach of individualizing, looking for etiology, trying something else if one thing does not work, etc. Are you talking about something specific to FASD, or are you talking about something that is unique to FASD rather than to all neurobehavioural issues?

**Diane Malbin** – The idea that brain equals behaviours and that brain function trumps behavioural symptoms because it goes to etiology sounds very simple. But I think if we keep that idea in mind and then revisit the behavioural symptoms currently captured in the DSM and mental health diagnoses, it can help unravel the reason that we become so reactive to behavioural symptoms. For example, I believe that frustration in response to behavioural symptoms is one of the reasons children are moved from foster home to foster home. We interpret behaviours as intentional and volitional, rather than as symptoms of brain dysfunction. Therefore, we try to stop the behaviours and they get worse.

When we talk about neurobehavioural symptoms, we have a different lens through which to view behaviours. At this point, few clinicians wear those glasses. We still view behaviours as either intentional or attention-seeking, or as symptoms of a malfunction in the family, rather than stepping back and asking a different set of questions and exploring what else is going on. How is the brain organized? Cognitive behavioural techniques may have their place in some cases of FASD, given that it is a spectrum, but in other cases they are completely counterindicated. As we step back and ask different questions, we begin to redefine not only the nature of the problem, but also our solutions.

Rather than having the person coming in and sitting in an office talking for an hour a week, the clinician realizes this is a person who has difficulty with receptive and expressive language and with integrating information and then applying it. We step back and ask, “What is the problem?” and then step back even further and explore, “Who is the person?” from a brain-based perspective. That is the first question. We need a very good neurobehavioural screening tool to help educate communities so we can build the context in which we can even consider the idea of brain function for all human beings.

**Dan Dubovsky** – I believe that in an ideal world, we would want to look at every individual and ask what that individual needs in order to be successful. That should be the focus. But I think we have to recognize the brain research that Edward Riley, Sarah Mattson, and the group at San Diego State and others have done, which indicates that our approach to FASD would be different from our approach to somebody who does not have an FASD. An example is a family that I have worked with, in which the young man has an FASD and a diagnosis of ODD and of RAD (reactive attachment disorder). When I went to visit the family one Sunday night, this 11-year-old had a friend over, and he said to his father, “Dad, can my friend stay over tonight?” His father said, “No, he cannot stay over,” and the son said “Why not?” His father said, “Because it is Sunday night, you have school tomorrow, and you still have homework to do. Maybe another time.” The son crawled onto his father’s lap, grabbed his father’s shirt with both hands and started shaking his father, saying, “Why can’t he stay overnight?” and the father calmly explained why he could not stay overnight, and the kid got more and more agitated. This went on for about 45 minutes — I was exhausted watching it — and after 45 minutes the father finally sent his son to his room. And I said to him, “You know, I do not think that is the best approach because your son does not know when it is okay to grab your shirt and when is it not okay anymore. Every once in awhile you get angry about it and then you calm down again, and that is very difficult for him. Probably the best thing would be to not let him grab your shirt at all.” And he said, “But I took him to an expert on reactive attachment disorder, and he said this is the way he attaches and I have to let him do this.” And I said, “But not if he also has an FASD.” That is something that we have to remember when dealing with this.

**Sterling Clarren** – I think that, for the jury who have not spent years in this field, there is a nomenclature problem we should put on the table because we keep tripping over it. In the field of developmental medicine, FASD is unique in that it is an etiologic diagnosis rather than a functional diagnosis. And the value of knowing that “alcohol did it” is in prevention. From the affected child’s position, it is useless. We need a second term that we do not have. We have struggled to describe this form of diffuse brain damage that leads to severe maladaptation. That is what is missing. Can other conditions cause it? Absolutely. Years ago, I recruited my wife, who is a neuropsychologist, to work with us in our field, and after a couple of weeks she very sheepishly said, “You know, honey, these kids look just like all those brain-damaged children I used to work with on physical therapy ward.” She thought I would be upset. But I was delighted, because that is the point — there are other people with other etiologies; the only difference is that we have lots of them. And alcohol is a very efficient way to find kids with a very difficult

form of brain damage. Once we figure out how to manage these kids, we will want to apply that to any child with this kind of brain damage. And arguing endlessly about whether it is alcohol and whether it is unique is missing the human point that we do a perfectly lousy job of managing this form of brain damage, no matter who has got it. And that is what we really need to work on.

## ■ Question 4

### *How can FASD be prevented? Pre-conception initiatives*

#### **Pre-conception initiatives**

*Lola Baydala, Associate Professor of Pediatrics, University of Alberta*

The questions I have been asked to address are: How can FASD be prevented? Are there evidence-based pre-conception initiatives? I am going to focus specifically on school-based substance-use prevention programs, using an example to illustrate how we can move research in this area into practice.

In 2008, the Public Health Agency of Canada published a summary of Canadian perspectives on FASD prevention, developed after consultation with Canadian experts in the field. This summary outlines four levels of prevention. The first level is raising general public awareness through broad strategies, including public policies and health-promotion activities that engage people at the community level. Examples of level one strategies would be information sheets, media campaigns, or booklets that are distributed to the general public. Level two strategies focus on women of childbearing age and their support networks. These strategies involve a collaborative discussion of alcohol use and its risks. Examples of level two strategies include programs that train physicians and other healthcare workers in substance-use prevention counseling. Level three prevention strategies include specialized perinatal programs that provide care and treatment for women who are using alcohol during their pregnancy, and level four strategies involve long-term supports to enable new mothers to maintain whatever healthy changes they have already been able to make in their alcohol use during their pregnancy.

School-based substance-use prevention programs are pre-conception FASD initiatives that encompass both level one and level two strategies of prevention. School programs incorporate discussions about substance use and its risks, and provide children and youth with the knowledge and skills they need to resist substance use. The most effective programs incorporate three levels of knowledge: resistance skills training, which helps kids say no when they are in the vulnerable position of being encouraged by their peers to use substances; social and personal self-management skills, which help to support a child's self-esteem; and factual information about the risks of drug and alcohol use. There is strong evidence to support the effectiveness of school-based programs when knowledge in all three of these areas is included.

A review of school-based substance-use prevention programs can be found on the National Registry of Evidence-based Programs and Practices developed by the U.S. Department of Health

and Human Services. This registry is a searchable database of evidence-based interventions for the prevention and treatment of both mental health and substance-use disorders across all ages. The registry regularly updates a report of evidence-based programs, which includes information about each intervention, its targeted outcomes, the research to support its effectiveness, and whether or not that intervention is at an appropriate stage of development for broad dissemination. The National Registry also rates the quality of the research to support the interventions. They use six indicators to do this: the reliability and validity of the measures that were used in the research; intervention fidelity (was the program delivered in the way it was supposed to be delivered?); missing data and attrition (was there missing data or participant dropout that affected the results?); potential confounding factors; and the appropriateness of the analysis used. The registry asks independent reviewers to evaluate the quality of the research using these six indicators for every intervention that is available, and they assign a score between zero and four for each indicator, with the highest possible score being four.

Based on this evidence and on an independent review of school-based substance-use prevention programs completed by a team of researchers at the University of Alberta, the Life Skills Training (LST) program developed by Dr. Botvin at the Institute for Prevention Research at Cornell University has been found to be the most effective school-based substance-use prevention program available. The LST program has been evaluated in more than 30 scientific studies, most of which were randomized trials involving over 330 schools and 26,000 students in urban, suburban, and rural communities. Ratings of the quality of the research to support this intervention have consistently been between 3.9 and 4.0, which is the highest possible rating. Broad dissemination of the program began in 1995, and since then an estimated 50,000 teachers in 10,000 schools involving over 3,000,000 students in 32 countries have participated in the program. The LST program is an evidence-based generic program, and, as mentioned, has been found by a number of different program providers to be highly effective with students from different geographic regions and different socioeconomic, racial and ethnic backgrounds. However, despite the overwhelming success of the program, it has never been evaluated with Canadian Aboriginal children and youth, and its effectiveness in this population is not known.

The Alexis Nakota Sioux Nation is a community of approximately 1,500 people situated about 100 kilometres west of Edmonton. In 2005, the community invited researchers from the University of Alberta to adapt, deliver, and evaluate the effectiveness of the Life Skills Training program in their community. The goals of the community were to review and adapt the program to ensure that it incorporated their language, visual images, and cultural teachings; to evaluate the effectiveness of the modified program; to make sure that the fidelity of the program was maintained after the adaptations were completed; and to restore and preserve their Isga culture. To achieve these goals, the Alexis Working Committee was established. This committee included community members as well as academic members from the University of Alberta. As a first step, terms of reference were developed that described the roles and responsibilities of each committee member. The committee successfully applied for funding to adapt, implement and evaluate the program, and a band council resolution and letters of community support were

obtained. In addition to the working committee, an adaptations committee was established. The adaptations committee includes community members, school personnel, and elders who attend each meeting.

Over a period of two years, the committees met on a regular basis and completed adaptations to the program, which included Alexis Nakota Sioux teachings, such as ceremonies, prayers, storytelling, and personal life stories, the Alexis Isga language, Isga artists' graphics and pictures, as well as drawings submitted by students who attend the Alexis Nakota Sioux Nation School.

Previous research has shown that cultural adaptations can significantly improve engagement and acceptability of a prevention intervention. Furthermore, I believe that there is an ethical imperative to ensure that interventions developed by one culture do not negatively impact the cultural values, competence, or language of another culture where the program will be delivered. Research has also shown that those who participate in culturally adaptive programs are able to relate more closely to the curricula and engage in the program. We know that culturally adaptive programs aid in the development of a stronger identity and cultural pride, which in turn function as protective factors against substance use. And a community that is involved in the adaptation and implementation of a prevention program is more likely to feel a sense of ownership and empowerment, both of which are critical first steps in creating social change.

The Alexis Nakota Sioux Nation School is attended by children from kindergarten to grade nine. During the 2008 school year, the first level of the three-year adapted program was successfully delivered to students at the school by a community program provider. After the first year of the program, pre- and post-program questionnaires showed positive changes in students' knowledge and attitudes towards drug and alcohol use and significant growth in their social skills. Talking circles, or focus groups, also showed ownership of and investment in the program, teaching approaches that correspond with the learning context, world views, and relationships of the community, and participation of the community elders.

We were also able to document substantial growth in community capacity, using the Public Health Agency of Canada's Community Capacity Building tool. This tool measures nine areas of community capacity: community participation and leadership; the acquisition of community structures; external supports; asking why, which is getting to the root causes of why substance use occurs in the community in the first place; obtaining resources; community skills knowledge and learning; academic skills, knowledge, and learning — there is definitely an academic component of capacity building that occurred; and linking with others in sense of community.

My summary and recommendations are as follows. Highly effective evidence-based substance-use prevention programs for school-aged children and youth exist. These programs should be made available to all school-aged children, both Aboriginal and non-Aboriginal, as part of their regular curriculum. Where appropriate, the programs should be adapted to incorporate the cultural beliefs, values, language, and visual images of the community where the program will be

delivered. And, to ensure community ownership of and investment in the program, adaptations and implementations should involve a community-based participatory approach.

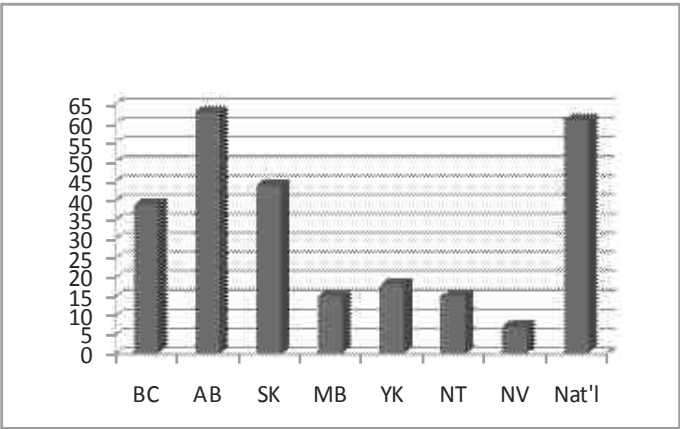
## Inventory of primary prevention campaigns

*Robin Thurmeier, FASD Resources Researcher, Saskatchewan Prevention Institute*

We developed an inventory of FASD primary prevention resources across northwestern Canada in order to discover the scope of primary prevention activities and to explore the outcomes of those that have been evaluated. We completed an environmental scan to create an inventory of existing projects and to identify gaps and successes. For the purposes of our project, we used the primary prevention definition provided by the Canadian Centre of Substance Abuse, which defines primary prevention as community efforts to protect health by increasing knowledge and awareness of a particular health problem.

We included resources in our inventory if they had a focus on primary prevention, if they provided information about FASD, and if they were developed for use within northwestern Canada. The resources could be part of a larger awareness campaign strategy, or they could be produced independently of a strategy (for example, a one-off resource that organizations produced specifically for their communities). FASD stakeholders across northwestern Canada were contacted and asked to provide any resources they had developed and any evaluations done on those resources. We also searched the websites of relevant organizations across Canada to find their current materials. In total, 262 resources were collected. Figure 11 shows the distribution across the provinces (Ontario resources are shown separately, but also included in the national bar).

**Figure 11: Resources Collected by Region**



We decided to include one campaign from Ontario in our inventory, the *Be Safe* campaign developed by Best Start. It included an evaluation component and was similar to many of the



campaigns developed across northwestern Canada, such as *This is Our Baby* from the Yukon, and *Alcohol and Pregnancy* from British Columbia.

The inventory includes print resources, such as posters and brochures; multimedia resources, such as public service announcements, videos, and DVDs; and novelties, such as pins, coasters, and bookmarks. The resources are used to inform their intended audience about FASD.

Women's centre messages provided specific messages to women about how they can avoid alcohol abuse during pregnancy. Community and family support centre messages provide family and friends and community members with information about how to help prevent FASD. The key message across all of these resources is that alcohol consumption during pregnancy can harm the fetus. Targeted audiences included women, youth, friends, Aboriginal cultures, professionals, and the general public.

We found only four campaign evaluations. These were evaluations of the *Born Free* campaign from Alberta Children's Services, the *Mother Kangaroo* campaign from the Saskatchewan Prevention Institute, the *With Child, Without Alcohol* campaign from the Manitoba Liquor Control Commission, and the *Be Safe* campaign that I mentioned earlier. All of the evaluations showed an increase in awareness and knowledge about what FASD is, what causes FASD, and the ways FASD can be prevented. General awareness post-campaign was at least 90% across each of the campaigns that were evaluated. While print resources were the most numerous, multimedia resources were most often recalled by the public. The evaluations show that each campaign was successful in increasing awareness and knowledge of FASD; however, little is known about actual behavioural change. For example, the post-campaign evaluation of the Saskatchewan campaign showed that only 44% of respondents indicated that they had supported a woman's choice not to drink. There were just two questions in the entire survey asking if the respondent had supported past attempts to decrease drinking alcohol during pregnancy. While awareness campaigns generally do not contain a behavioural change component, this change is obviously a desired outcome of these campaigns. Many women continue to drink during pregnancy, and half of the pregnancies in Canada are still unplanned.

We are now looking at social marketing to address these behaviours. Social marketing may offer a tool for creating behavioural change, particularly in identifying and targeting groups at risk. Basford et al. in 2005 identified five target groups that could benefit from social marketing strategies being developed for them. These include women who may drink during pregnancy, women who might be pregnant but do not realize it, youth, partners and friends, and healthcare professionals. This framework also incorporates theory to help understand behaviour, provides strategies for adopting new behaviours, and reduces barriers to the desirable behaviour, while providing opportunity for new behaviours and promoting the new behaviours as attractive alternatives.

Providing a framework to explore the reasons why people engage in harmful behaviours is key to creating effective campaigns. A behavioural change model needs to be employed to guide the creation of materials and interventions that will bring about the desired behavioural change, and

to develop evaluation tools to better understand whether the intended outcomes are occurring. One model that we found to be effective, and which we recommend for future FASD campaigns, is the Protection Motivation Theory. This model suggests that motivation to select positive behaviour is maximized when the threat is viewed as particularly severe. The social, monetary, and physical costs of making the change must be relatively small, and the people need to feel confident in their abilities to make the change.

Here are some recommendations on prevention and awareness campaigns:

1. An effective evaluation strategy is crucial, as it provides the tools for measuring outcomes, regular feedback to keep objectives on track, and a clear plan for future campaign development. It also provides other organizations with information helpful in developing and improving their campaigns. The evaluation process takes time to develop and implement, so it is advisable to begin before even developing the campaign.
2. A behavioural change model should be incorporated into campaign design to guide the preventative strategies and to measure and explain any behavioural change that occurs. Each intended audience needs a targeted message with images and types of media that will engage them. A behavioural change model will help you understand what behavioural change is occurring, what specific groups need to know, how they can learn this information, and how they will move forward with a change. It also helps create a strong research-based precedent to assist in obtaining future funding and to ensure successful outcomes of future primary prevention campaigns.
3. Community engagement is important, and community partners and stakeholders can assist with campaign development and evaluation. Ensuring that you have representation from each of your target groups will create a sense of ownership in the campaign and will improve its chances of success, as they can help develop messages that are meaningful and delivered by the most effective modes of communication for their groups.

## **Primary care physician perspective**

*June Bergman, Associate Professor, Department of Family Medicine, Faculty of Medicine and Dentistry, University of Calgary*

Primary health care is the provision by clinicians of integrated, accessible healthcare services that address a large majority of personal healthcare needs and develop partnerships with patients within the context of family and community. Primary health care also has another dimension, one of looking at the determinants of health and the creation of community capacity. We know from the work of Barbara Starfield and others that a good, strong primary care system improves the health of the community and is highly cost effective. Ninety per cent of all contacts with the healthcare system are in primary care, which means that primary care is the opportune setting in which to provide interventions to patients. However, we do not always take advantage of this opportunity.

Since the 1950s, primary care has been based on the following principles of family medicine: it is relationship-based, resourced in the community, and strong focused on clinical excellence. One way to describe it is that primary care cares for the whole person as situated in the family and the community over time. Primary care is concerned about prevention, identification of disease or risk factors, treating acute disease, supporting people, and opening doors to secondary and tertiary care.

Many organizations in Canada have created guidelines to identify and treat individuals who have FASD or are at risk of drinking during pregnancy. All agree that prevention is the area in which we should focus our efforts. The Canadian Task Force on the Periodic Health Exam has recommended that case finding, counseling, and follow-up are effective. This is not a Level A recommendation because the evidence to support it is not available; but as clinicians, we believe this to be a good recommendation. Other experts agree. A joint statement by the Canadian Pediatric Society and 17 co-signatories recommends prevention efforts that target women before and during childbearing years, along with their partners, families, and communities. The College of Family Physicians recommends that primary care physicians be involved in screening for alcohol use during pregnancy, referral for diagnosis, follow-up, and linking patients to community resources. In Alberta, a group called Towards Optimized Practice (TOP) has developed a clinical practice guideline on the prevention of FASD, last revised in 2005. This guideline divides prevention into three areas: primary prevention, which advocates abstinence from alcohol during pregnancy in order to prevent FASD; secondary prevention, which tries to help women who drink during pregnancy, in order to reduce harm to the fetus; and tertiary prevention, which looks at mitigating the harm to an affected individual.

What barriers do we face in providing effective screening for FASD? Little research has been done on barriers to screening specifically for FASD, but literature on prevention and screening in general divides the issues into provider issues, system issues, and patient issues. The provider issues are likely obvious. A lack of training is a common one, although the TOP program tries to address this by helping primary care offices to implement quality-improvement activities. But training and knowledge is very often the least of the problems. Providers also face a lack of time, often due to business models of patient care that leave little time for screening. Clinicians know what they could do, but do not have the ability to do it at that particular time. Another provider issue is uncertainty about where to get help if screening is done and a problem is found. Clinicians need to have contacts, to be able to draw upon a broad range of health professionals and skills. Providers also face personal discomfort in bringing this issue up with their patients or in their ability to provide services in this area. System issues are shortages of resources, such as qualified, publicly-funded counselors, or a lack of access to such resources. Patient issues include feeling stigmatized by the diagnosis and failing to comply with treatment because they lack understanding or are not convinced that it is the correct treatment.

Primary care reform is underway across Canada, and in recent years every province and territory has shifted the manner in which primary care is provided. Three provinces — Alberta, Ontario,

and Quebec — have moved into partnership with physician networks. The other provinces are in varying stages of the process. They have been more focused on a primary healthcare model looking at determinants of health and community development. All jurisdictions are looking at shifting their focus from responsibility for caring for individuals to responsibility for populations. They are looking more closely at who is receiving care and who is not. They are also thinking more about preventative screening (for example, a patient may have come in for her cold, but it may be an opportune time to get a cervical screen or mammogram as well). There is also a move to multidisciplinary teams that vary with the needs of the communities they serve. These can include nurses, occupational therapists, physiotherapists, dietitians, and others. An important underpinning of each model is information management and technology that provides a means of sharing information and improving the continuity of patient support. Underlying choice for people is another focus and improved access is a strong indicator in all. Primarily, we are looking at ways of providing 24/7 access to care and of addressing the unattached element, that is, the many people in Canada who do not have a family doctor at present.

The new models take many different forms. There is shared care, where primary care physicians partner with specialists, other healthcare professionals, or other programs already in existence. There is team-based care with improved access to mental health professionals. This approach can play an important role in FASD prevention, because a large part of the prevention we can do in primary care is to recognize families and individuals of chaos (that is, people who have high-risk behaviours). In my own primary care office, I have a behavioural therapist and I can get people in to see this person within a week. Some of models emphasize co-location of teams, which is also helpful because we can learn so much from each other. Primary care offices are also now able to partner inside and outside of the health system in ways we never could before. For example, the primary care network that I am a part of is partnering directly with pediatricians in the Kids in Care program in Calgary. Kids are accepted into care in one of our chronic disease clinics, where they have access to pediatricians and ongoing care, but with the intention of moving them eventually to a primary care provider.

The role of primary care in FASD has several facets. First, our role is very much about prevention. New primary care models are giving us the ability to do more anticipatory counseling and early identification with primary, secondary, and tertiary prevention. In the area of treatment, we see people at a young age when they can be referred to specialists for early interventions. Our longitudinal relationships with patients enable us to support both individuals and families within the community. When an individual has a problem, other family members often have their own issues and need support and coping techniques. Primary care also enables individuals to remain in their communities, as we are able to monitor patients over the long term.

These are some of the strengths of primary care that can lead to successful partnerships in addressing any complex condition, but particularly FASD. First, primary care is good at maintaining continuous relationships with patients. This is a key benefit that primary care providers offer to the healthcare system. Primary care maintains a community focus and keeps

people in the communities in which they have lived all their lives, rather than institutionalizing them. Team-based primary care provides a wider range of skills and supports, and the multidisciplinary partnerships for which we now have the organizational structure will provide some of the best intersectoral care in complex issues like FASD.

## **Jury questions and answers**

*(Lola Baydala, June Bergman, Robin Thurmeier)*

**Marguerite Trussler** – Are any of you involved in or knowledgeable about the development of the national alcohol policy, and, if so, are you aware of whether or not they are going to tackle the issue of preventing FASD?

**Nancy Reynolds** – I hear many “no’s.” It seems that there is not an awareness of that and how that is being dealt with.

**David Butler-Jones** – Lola Baydala, you gave us an excellent overview of the program that you have put in place in the Aboriginal community, but you did not tell us what the results were in terms of behavioural change. I presume it was successful in creating knowledge and awareness, but what about behavioural change?

**Lola Baydala** – We are now in the second year of delivering the program. We have some initial results from the first year that show changes in children’s attitude, knowledge, and self-esteem. We do not have any markers yet of changes in substance use, as it is actually a six-year program. Three years of the program are delivered in elementary school, in grades three, four, and five; and then another three years are delivered in grades six, seven, and eight, or grades seven, eight, and nine. Each year builds on the previous year. We know that the program is effective, so the question is, Can we adapt the program and maintain the effectiveness? We will not know that until the end of the six years, but the preliminary results show us that we can. The community is very engaged, there is growth in community capacity, and the findings after the first year were consistent with the literature on first-year findings in the full programs.

**David Butler-Jones** – My real interest would be well beyond when they are in grade nine. What happens to them when they are in their late teens and early twenties?

**Lola Baydala** – The research on the program shows that the effects found at the end of the six years were maintained up to six years after the program was delivered. So there is evidence to support that, and there is no other program available that shows that. Interestingly, in Alberta, one of the programs most widely used in schools is the D.A.R.E program. Every child that I see in my office, as a pediatrician, gets this program in their school. And there is no evidence to support its effectiveness. Not only that, but there is evidence to show that the program is not effective; as a result, funding for that program has been pulled in many schools in the United States. I think this is a very good example of evidence not being translated into practice. That is why these conferences are so great, because we bring together the evidence and the policy-makers.

**David Butler-Jones** – This question is for Robin Thurmeier. Of all of the studies that you looked at, did any provide for longitudinal research, that is, research that would look at how behaviour had changed? Was there funding in those studies to do the longitudinal research? And a corollary to that, what would be the appropriate amount of funding to allocate towards longitudinal research as differentiated from short-term attitudinal research?

**Robin Thurmeier** – There was no longitudinal research. I think most of the post surveys were completed six months after the campaign development, so those were, in effect, six months after. In the Prevention Institute, we have been evaluating our FASD program and awareness campaigns for the last five years. As a result, we have more evidence, and awareness is high; but the evaluation of behavioural change has not been completed yet. As for funding, I am not sure. One would have to contact a social marketing firm, or whoever is brought in to complete the evaluation, to determine what needs they would have financially.

**Rebecca Martell** – Dr. Baydala, I appreciate your example of Alexis Nakota Sioux Nation, your profiling of it as a unique community, and your proposal that the integrity of each community must be honoured in the development of culturally adaptive programs. Do you see this being done for all of the reserves in Alberta — where each reserve would be viewed as unique funds would be made available to develop individual programs?

**Lola Baydala** – That would be ideal. As a result of this project at Alexis, we have received funding to do a similar project at the Muskogee, Bear Hills, Cree Four Nations, and Hobbema. We will be working with them to adapt the program into Cree. That will be four communities, as well as the school at Pigeon Lake, which is an Aboriginal community. Projects in First Nations communities, I have learned — and I think it is very wise — start very small and very organically. You start with one thing and then there are two, and then there are four, and then there are eight. Success comes from working that way, rather than from the top down, and from allowing yourself to be led into the next step. These four communities will be the next step, and then we hope there will be other communities. It will be a long-term process, but it will be worth it.

**Raisa Deber** – Is there any evidence that these programs work differently in at-risk populations than in a general population? Does the program rely on receptive language processing? And is there any need to tailor it to the most vulnerable populations?

**Lola Baydala** – We have observed that the needs of the children in the community are different from those of children in other communities. That is why it is so important that a community program provider be trained to deliver the program — someone who knows the community and knows the kids and the parents, and is able to relate to those children through kinship identification, ceremony, or some other way besides just verbal communication.

**Raisa Deber** – I am wondering whether there is a difference in evaluation and prevention in different subpopulations, because something that would work in one population might not work in another.

**Lola Baydala** – There is a parent component of this program. The community had a discussion about adapting it so that parents could support what the children are learning in school. But that particular parent program assumes that the parents of these children are healthy, and not all the parents in that community are healthy. We are going to have to look at another way of addressing that. So, no, it is not always adaptable, and that has to be considered.

**Lee Ann Weaver-Tyrrell** – This is a question for Robin Thurmeier. In your identification of the 262 resources, were you able to obtain data on the cost of creating those resources?

**Robin Thurmeier** – No, I was not.

**Lee Ann Weaver-Tyrrell** – Are there plans in place for the next phase of a changing-behaviour program to share in the development of resources, or a provincial or interprovincial strategy to work together on that?

**Robin Thurmeier** – Our research team is currently completing focus groups with professional women who are over 30 and drink socially. This is one of the groups considered to be at risk of having a child with FASD. We have been finding a little bit of resistance in this subpopulation. These women look into the research themselves and they find current prevention strategies too simplistic. Our research team is developing a survey to implement this winter, and we are applying for funding to test a social marketing strategy with this group to see what type of behavioural change we can create.

**Christine Looek** – My question is for June Bergman. I am very excited to hear you talk about primary healthcare reform and opening the doors to more relationship-centred care and to collaboration across the health and education sectors. We have universal health care founded on the principles of accessibility, portability, and accountability, but there are inequities in access. In our province, we are seeing a great deal of difficulty accessing care. We have walk-in clinics, but we do not have continuity networks for primary care. What strategies are being created to augment these walk-in clinics? It is difficult to have a frank discussion about drinking during pregnancy or about your child's developmental difference or relationship violence in the absence of a continuity relationship. How will primary health reform address this issue of drop-in walk-in clinics?

**June Bergman** – It is an interesting question. Walk-in clinics are business propositions. If you change the environment and the business proposition is no longer viable, it will not continue to exist in that form. We are already seeing that in most places across Canada. Chronic disease and time-based care are becoming more important. As a result, we are seeing a shift away from walk-in clinics because the care provided there is no longer much of a business proposition. That is where policy and theory come into play. It is a question of what you value in a primary care environment and how you choose to resource that primary care environment. The various provinces are now doing such things as shifting fee schedules, providing money for multidisciplinary teams, providing a different kind of incentive for outcome-based medicine. You get the right outcomes only if you do the right things ahead of that, and the rewards system

is tied into that. That is being done right now in about 12 different ways across Canada. I believe we will end up in a similar place, but the comparative evaluation has been limited by slowness in the infrastructure of looking at primary care.

**Anne McLellan** – This question is for June Bergman. In reading some of the research, I was surprised by the fact that family physicians do not appear to have a protocol for discussing the risks of drinking during the pregnancy with pregnant women. I read that doctors in some cases are even resistant to asking whether the woman in front of them, who is pregnant, does in fact drink. I would have thought that was pretty standard for any doctor. How do family physicians approach the young woman who comes to their office, who is of a certain age, maybe seeking contraception, maybe not. Do they have a discussion at some point about the risks of drinking and pregnancy, whether planned or accidental?

**June Bergman** – The prenatal forms in most provinces include a little check box for “Have you discussed alcohol with this patient?” Whether individual physicians do it or just check it off, I do not know. It is there as a reminder, and I assume that people do it in a very logical way. The other question is a bit more difficult. As primary care physicians, we are right now shifting away from doing annual medicals and moving into periodic health assessment. It is a different thing. When we do a periodic health assessment, we look at people in the context of their lives, their age and stage, and we apply a little algorithm to that so that we can say, “These are the risks for you at this age and stage.” We may not listen to the heart all the time, but we address those things. Are we doing it very well? Probably not as well as we could. That is why I am excited about primary care networks. I think as we move into teams, as we get out of our isolation, those kinds of things will be introduced more as the way you do business. Primary care networks shift us from being independent, private practitioners running a business only — and doing the best job that we can in that context — and bring us into a place where it becomes easier to do the thing we should do than to not do it.

**Gail Andrew** – Physicians and their team members need to be able to work with that woman who says, “Yes, I drink.” I think that is the barrier. You do not want to hear the “yes,” because what is next? But if you have in your team the resources to give her the help she needs, whether it is a brief intervention, motivational interviewing or connecting her with a higher level of treatment, if that is at your fingertips, you will go there.

## **Audience questions and answers**

**Audience, John Sproule** – I am wondering about prevention strategies in the area of communicating to a woman’s partner or other family members the actions they might take if she is drinking and therefore exposing the fetus to alcohol. What are the responsibilities in that kind of communication? I know there are issues around the rights of a woman to have control over her body, but other people might also have some participating rights. And a second question: I have heard that there is some bias in reporting in FASD because of stigma — that a condition that would be diagnosed as FASD in an Aboriginal population might be diagnosed as something else



in a non-Aboriginal population. I am wondering if that is true and feeds into prevention efforts in a primary care physician's office.

**June Bergman** – One of the major benefits we have in a primary care environment is that we are not an alcohol clinic, we are not a sexually transmitted disease clinic, we are not a whole lot of things that have stigma attached to them. We are a primary care clinic. Everybody goes to them. The second benefit is that we look at people in the context of their family and community, so it is very easy to ask questions about what kind of supports they have. Oftentimes, we have already identified women who are in chaotic relationships, and if we have the ability to provide counseling, they often have already been there. In primary care networks, with an increased skill set behind you, you can more easily ask the questions that get you to the place to say, “Okay, we can easily do a small intervention here. We do not even have to go outside this clinic; all of those services are here, no stigma attached.” The gender issue I find interesting. I am the mother of three sons and the difference in relationship between them and their children, and my husband and our children, and my father and his children, is phenomenal. This new generation of men is wonderful. They are part of the family in ways that I have not seen for a long time. So I think those questions are becoming easier and easier to ask.

**Robin Thurmeier** – In regard to community action and prevention, any actions that are suggested to the community must be carried out in a respectful, non-shaming way. Our efforts at community engagement need to educate the community on FASD, as well as on what supports are available if they want to bring up an issue with their partner, or with a friend, so that if they choose to take action, they know what to do.

**Lola Baydala** – With regard to the diagnosis of FASD being higher in Aboriginal populations, I know that FASD crosses socioeconomic boundaries. However, when you control for poverty, the rate of diagnosis of FASD in Aboriginal populations is exactly the same as for the general population. There is a huge confounding variable which is poverty, and that is the issue.

**Gail Andrew** – And on the other side, are physicians asking women from the higher socioeconomic group the question, did you drink during pregnancy? We are not sure. In my clinical experience, I see children from across the spectrum of socioeconomic groups. In several cases, the birth mother has admitted to alcohol use, but has said, “I do not wish to have this written any place but this will help you to understand my child.” I am therefore unable to make a diagnosis. My part is to counsel her to get help for her child and, over time, I have had some of those women come back and say, “Okay, I am ready to move on, to get the help we need to have my child better understood and supported.”

**June Bergman** – From a primary care perspective, I would add we are not looking for a fetal alcohol diagnosis so much as we are looking for a child who is struggling, who is not developing the way we would like. Our part is to identify the not normal, or the not average. From there, we need resources behind us to help with identifying very clearly what is going on. Is there brain damage? Is it mental illness? What is going on?

**Audience, Nancy Poole** – I would like to answer the jury question about the national alcohol policy. The prevention of FASD is not at all adequately integrated into the national alcohol policy work, and it would be most welcome if the jury saw fit to make note of that. I have just had the great pleasure of being a visiting scholar for two months in Australia, where I visited a number of communities in which alcohol policies, including restrictions on alcohol availability, have been put in place. This has had a tremendous impact on their capacity to reach women and prevent FAS. I think there is much to be done to link up our work in FAS prevention with those larger alcohol policies, and it is very important to achieve this integration. On that note, a number of us are presenting on this issue to the Issues of Substance conference in Halifax, a conference sponsored every two years by the Canadian Centre on Substance Abuse. We are hoping to open up dialogue on this point with the designers of the national alcohol policy. I do not think it can be over-emphasized how critical it is to link these two things.

## **Mentoring programs for at-risk mothers**

*Nancy Whitney, Clinical Director, King County Parent-Child Assistance Program, University of Washington*

I am here to talk about mentoring programs for mothers at risk and, specifically, the Parent-Child Assistance Program (PCAP), which originated at the University of Washington in 1991. We talked yesterday about risky behaviours and the populations that are at most risk of having children with FAS. These are the mothers that we work with. The problem is maternal alcohol and drug use during pregnancy. It puts those children at risk for health effects that will last for the rest of their lives and it puts them at risk for compromised home environments. Poverty, domestic violence, and untreated mental health problems are all factors that create a less than desirable home environment for children to grow up in. Without intervention, there is a very real possibility that these mothers will continue to have drug- and alcohol-affected children. These problems are very expensive to our society, both in actual dollars and, for lack of a better phrase, in injury to the soul. These families are hurting, and these problems are completely preventable.

PCAP started in 1991 as a federally-funded research program in Seattle. It has since acquired state funding for expansion into nine Washington counties and has been replicated all over the United States. Many sites here in Canada are based on the PCAP model, one of them being the First Steps program here in Edmonton. This program is evidence-based. I will talk about outcomes and how we measure whether or not we are doing a good job.

The primary goal of the program is to prevent the future births of children that are affected by drugs and alcohol. Simple to state, not so easily done. This is an intensive three-year home visitation program. The staff who do this work are what we would call paraprofessionals. That is, we do not hire licensed social workers, we do not hire chemical-dependency professionals, and we do not hire nurses. We hire women who have some life experience that puts them a little closer to these clients and allows them to come to work with a little extra compassion for what these women face in their daily lives. We call it a home-visitation program. That is a bit of a

misnomer, because in the very beginning of our work many of the clients do not have homes. The more accurate way to express it would be to say that we go where they are. If that is a street corner, if that is a shelter, if that is a treatment centre, that's where we go. I tell my clients, "We're going to stalk you for three years." And they believe that, eventually.

The enrollment criteria are very simple. A woman is eligible if she is pregnant or up to six months postpartum, has heavily used drugs or alcohol during the pregnancy, and is not successfully engaged with community service providers. This is a little subjective, so the way I explain it to social workers and people who recommend the program is that if you can give this woman a to-do list and she will do it, or an appointment card and she will keep the appointment, she is not a PCAP mom. A PCAP mom is the one who loses the card in the next five minutes, calls you several times to get the information again, and still does not show up.

Some basic characteristics of our clients are as follows. The average age is 26; most are not married; by the time we meet them, most have two children and are likely not caring for either of them. They have not completed high school; they are likely to be homeless; they are unemployed; they are on welfare as their main source of income; and they have been to jail at least once. As my boss, Dr. Grant, is very fond of saying, these women are the children we are trying to prevent. For 90% of them, one or both parents were substance abusers. So a significant number of the moms that I work with are probably fetal alcohol affected and have probably gone their entire lives without diagnosis or help. The majority have reported physical or sexual abuse, or both, during childhood. Many of them have been in foster care. What is rather scary to me is that although almost 90% of them were raised in substance-abusing households, only 25% were likely to have been removed. This means that a significant number of them stayed in those substance-abusing households for the duration of their childhood. Not surprisingly, 67% of them ran away from that household as a child.

At least half of them report at least some alcohol use during pregnancy. At least 25% of them report binge alcohol use, which we know is the most dangerous drinking pattern for FAS. They are also poly-substance abusers (methamphetamine 58%, cocaine 34%, heroin 12%, marijuana 52%, tobacco 79%).

The PCAP intervention is a two-pronged approach. I have talked about the experience that the advocates bring to the job. The other important aspect of the advocate is that she is very well trained and closely supervised. We do not just throw these mentors out into the field. To do this work they need a great deal of help and support, and we make sure that they get that.

The advocates have two jobs. The first one is to work with the client and her family, which includes whoever is in the woman's circle. It may be her children; it may be her mother; it may be her boyfriend. We try to engage everyone in her circle in the process of her recovery, even if that means offering them services or connecting them to services in the community. The second job is to work with the community providers. You saw our earlier slide saying, "When case management isn't enough." That was the title of the original article. The reason it was called that is that these women had case managers, they had CPS [Child Protective Services] workers, they

had welfare workers, they had probation officers, they had public health nurses, and still the problematic behaviour continued. They were slipping through the cracks. So our job at PCAP is to work with those providers to keep an eye on what they are doing with her and asking her to do. If the chemical dependency counselor tells her to go to group three times a week and the social worker says to do visitation three times a week and they happen to be at the same time, these moms are not very good at advocating for themselves and saying, “I can’t be at two places at once” or “How do I do this?” or “Can somebody try to switch the schedule?” So they pick one and they fail at the other. Our job is to keep an eye on those things and keep her on track. This is a comment from one of our advocates, demonstrating where they come from:

“I know what it’s like to be a single parent, homeless, and on welfare. I share a common ground with my clients as far as those things go. The difference is that I saw what the obstacles were and overcame them. I just kept moving ahead and learned that where there’s a will, there’s a way.”

PCAP is a model of effective case management. We tailor the program to the individual. There is no curriculum that says that on visit one you do this and on visit two you do that. It is based on the individual woman’s situation and needs. We promote competency in the individual. It is very much strength-based. We believe that the relationship between the advocate and client is the key to effective change. We actually believe, although we will never be able to measure it, that it might be that relationship — the first positive, unconditional relationship that they may have had in their lives — that is more crucial in change than any service that we may connect them to. Somebody standing behind them and saying, “You can do this, and I’m going to help you,” is what we really think will make the biggest difference. It is very family-centred, community-based, and multidisciplinary.

This is how we try to envision what we do. Mom is in the middle, and the inner circle is everyone who is important to her and who we are going to try to engage in the process. An important part of this is what we do with the kids. PCAP moms are not the greatest parents, because they did not have the greatest parents. So when we are doing our home visitation, we are modeling parenting. We are sitting on the floor and talking to the kids, we are doing tummy time, we are encouraging bonding and attachment just by role modeling. We are also keeping an eye on those children. Is this child fetal alcohol exposed? What are the developmental milestones we are going to look for and how are we going to get that child into early assessment and early intervention if it appropriate to do so? And then there are all the community providers on the outside.

PCAP does have a theoretical framework. The first of the three theories on which we base our model is Relational Theory, the idea that women must have a positive relationship in order to effect change. The second is Stages of Change: where is she in making those changes in her life? She may be at several different stages, depending on the problems. She may be in contemplation or action for chemical dependency, but she may be in pre-contemplation for domestic violence and family planning. And, finally, Harm Reduction. She is not going to get to the exact place we

want her to be today, but we are going to keep working with her to make incremental changes and keep using motivational interviewing to move her along. These three theoretical foundations and our identified core components (which I did not bring today) are the basis and defining features of PCAP. If you want to call your organization PCAP, these are the things that you must base your model on. On the other hand, PCAP tries to be very responsive to the unique needs of its community. Within the state of Washington, we have 11 sites. They are in urban areas, in rural areas, and on Native American reservations. And each team approaches their work as they need to in order to engage in that community.

Our formula for preventing alcohol- and drug-exposed births is to motivate women to stop drinking before and during pregnancy and to help women who cannot stop drinking to avoid becoming pregnant by using family planning.

We have a great deal of data on the outcomes of the program and have published three studies. Beyond that, we do ongoing program evaluation every six months and report that to our funder. Here are some of our three-year outcomes. Ninety-six per cent of our clients in the state of Washington have completed in-patient or out-patient treatment, or are in progress of treatment. Forty-nine per cent have been clean at least six months, many of them more than six months at graduation. And 84% of them have been clean and sober at least six months during the program. We have numbers for people who go through the whole three years clean and sober, and for people who have two years clean and sober. They are excellent recovery rates.

One of the other outcomes that we keep an eye on is the family planning. Seven percent of our clients are using family planning when they enroll in our program and 68% are using it on exit. And 61% are choosing a reliable method, such as the pill or the patch. Only 12% of our clients have a subsequent substance-exposed birth. Reduced risks for subsequent alcohol and drug exposed births is 76%. That represents the women who are not going to have another exposed child, because they are either using reliable family planning or are clean and sober, or both.

Some other recovery-related outcomes are in employment, housing, and education. At graduation, 37% of clients have employment as their main source of income; and whereas 72% were on welfare when they started, only 37% are on welfare at the end. Seventy-four percent are in permanent housing and 72% have attended or are enrolled in a training or education program. I won't read them all, but these are very good outcomes. They show that over the three years these women really do start turning their lives around, from chaos to stability.

Outcomes translate to cost effectiveness. We can look at cost effectiveness on an individual basis or we can look at it across a program. Here is an individual example. This mom had a warrant out that she forgot about, and she got picked up. The offence was something like cheque forgery and they wanted to send her to prison for a year and a half. She was clean and sober, she had custody of her child, and she had housing. If they had sent her to prison, it would have undone all of that and it would have cost us \$18,000 to place her child in foster care for that time and \$50,000 just for prison itself. We convinced the court to put her on home electronic monitoring instead, which would allow her to continue her treatment and continue to parent her child. The

cost of electronic monitoring was \$6,500 per year. We saved the state of Washington over \$62,000 by helping with that change.

A study by the Washington State Institute for Public Policy looked at more long-term cost savings for the kids down the road. They specifically looked at several evidence-based home visitation programs, including PCAP. They found that for every dollar spent on PCAP or similar programs, \$2.27 was saved in the long run by keeping kids out of incarceration and other specialized services.

The big outcome, however, is in preventing future alcohol-exposed births. Without PCAP, 78 of the moms in a particular cohort were heavy drinkers and about 23 of them could have gone on to have another exposed pregnancy. By helping these women to stop drinking or to use family planning, or both, we reduced that by 66%, preventing about 15 alcohol-exposed births. Based on the estimated 4.7% to 21% incidence of FAS births among heavy drinkers, we think that PCAP prevented 1 to 3 cases of FAS. We talked before about the average lifetime cost of one kid with FAS being 1.5 million dollars. If we prevent just one mother from having another alcohol-exposed pregnancy, then we have funded PCAP for 102 women.

PCAP does not achieve good outcomes because we do all the work ourselves. We have good policies and we have good support systems in our community. One thing that has been key for us is that Washington State has continually supported treatment for women. We have 153 beds in Washington where women can go to treatment for six months and take their children with them. Not having their children with them is the number one reason why women will say they cannot go to treatment. We took that excuse away and that is why we have a 96% success rate engaging women in treatment.

At every three-year interview, we ask clients what they think about the program. Here are some quotes:

“There were times when I felt like I was going to relapse and my advocate would be there for me and she would keep checking on me and I’d get through it. I learned so much about myself and how to be responsible again and a good mother. It was all what she taught me and she changed my life.”

“I never thought about goals. They showed me the right direction. They showed me that I am responsible. That no matter who I am or what I do, I am somebody. It’s never too late.”

My recommendations are to support intensive case-management programs with the highest-risk mothers in the community and to support specialized treatment centres for women where they can go and take their children with them.

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### **Strength and support: A women's perspective**

*Amy Salmon, Managing Director, Canada Northwest FASD Research Network; Clinical Assistant Professor, School of Population and Public Health, Faculty of Medicine, University of British Columbia*

My presentation is going to encourage us to shift our focus from FASD prevention as a children's health issue — and a health issue that extends for those children across their lives — to consider what it means to address FASD prevention from a women's health perspective. I by no means want to suggest that we look only at children's health or only at women's health in order to do good FASD-prevention work. Rather, I want to try to balance our conversation a little by noting that we talk a great deal about mothers' drinking behaviour when we talk about FASD, but women's health often slips away from the conversation. I am going to focus on some of the structural factors that sometimes frustrate our ability to address FASD prevention more broadly as a women's health issue. Nancy Poole will then present some of the solutions to these frustrating challenges that have been put in place across Canada. Specifically, we will focus on some of the work of the Canada Northwest FASD Research Network.

In Canada, our approach to FASD prevention is largely centred on children's health. When we look more broadly at care for women during pregnancy, which is of course crucial to FASD-prevention work, we tend to think about such care from a social determinants of health framework. We do that because it is an evidence-based approach, and alcohol does seem to have greater teratogenic potential in the presence of what are sometimes called "permissive" or "provocative" cofactors. Most broadly, we talk about low socioeconomic status as one of those indications.

We think about the health of women in pregnancy because we assume that healthy women have healthy babies. But what produces health for women? In addition to biological factors and genetic endowment, we look at social determinants of health. In the report "What Determines Health?," which many of us use to guide our work, the Public Health Agency of Canada has enumerated social determinants of health to include income and social status, social support

networks, education, employment and working conditions, social environments, personal health practices, healthy child development, culture, and gender. All of these factors are important when we think about FASD prevention. However, it is important to note that social determinants of health have been very unevenly supported by governments across Canada in the development of policy and programs. In one study that looked at this very closely, Jim Frankish and colleagues at the University of British Columbia surveyed all of the health regions in Canada to examine how non-medical (or social) determinants of health are being addressed. They found that we have invested a great deal in child development and personal health practices, and by personal health practices, we mean specific actions people take to make themselves healthier. The majority of health regions report making those investments both within their systems and through intersectoral activities that include partners outside of the healthcare system. However, culture, gender, employment, and working conditions, which are of course closely linked to income and social status, received the least attention in most regions. This is a problem for us in FASD prevention, because we recognize very clearly that culture, gender, income, social status, and the potential for engaging meaningfully in employment are very important in supporting women's health, and the health of their children and families, across the life course.

We know that women who give birth to children with FASD are the ones most likely to have their own health and well-being compromised by addictions and mental health problems, including diagnosable psychiatric disorders, very high stress levels, depression and anxiety, and extensive experiences of trauma, grief, and loss. We know that these women's lives are impacted by violence, by isolation, by poverty, and by lack of social support and care before, during, and after their pregnancy. The complexity of these issues demands a coordinated response and approach to care. The Parent-Child Assistance Program (PCAP) models give us an example of how we can do that when we have strong infrastructure to make it possible.

Unfortunately, women who require such care are often bounced around programs and systems, and many of the services that respond to these issues remain siloed. We see a great deal of this with women who are at risk for having a child with FASD. A woman goes to an addictions treatment centre to try to address her substance use and the addictions treatment centre says, "Sorry, we also note that you have a bipolar one diagnosis, so you're going to have to go over to mental health services before we can treat you for addiction." Mental health services says, "Sorry you have to be clean and sober before you can come to mental health services." In the meantime, she is getting beaten up daily by her partner at home and she needs somewhere safe to go. When she goes to the transition house, the transition house says, "We'll be glad to take you if you're not using substances and you get some treatment for your bipolar disorder." Eventually, these women are bounced out of the systems entirely and we lose many opportunities to provide them with the care they need.

We have talked a great deal about shame and blame and acknowledged that the lives of birth mothers and children with FASD are imbued with shame and blame at a fundamental level. Shame comes from many places, including women's knowing that they should not drink when



they are pregnant and yet lacking the supports they need to keep from doing what we often refer to as “hurting your baby” — as though this is something they do on purpose. Blame often comes from a woman’s acknowledgment that her children have disabilities or are experiencing problems at school or in the community that are attributable to her substance use. When we think about what this means for prevention, we have to think about the fact that most of our prevention approaches have remained grounded in blame and shame, not just on an interpersonal level in interactions between women and individual service providers, but also at a societal level. These approaches to FASD prevention have been shown repeatedly to be ineffective at reducing drinking among the highest-risk groups and result in many missed opportunities for providing supportive care.

I have the tremendous honour of being able to do my research in Vancouver’s Downtown Eastside, where I work with women who are teaching me a great deal about what it means to do good FASD-prevention work at the primary, secondary, and tertiary levels. One of the things that I have learned is that FASD as a diagnosis is different from other kinds of diagnoses because it is rooted very much in shame and blame.

Here is an example from one study. Super Woman is a young woman who is raising her child. This child is about seven years old. The mother managed to keep her child with her, largely as a result of her engagement in a mentoring program. She had exited the sex trade, she had good housing, she made sure that the daughter had the supports that she needed, and that she as a mom had the supports she needed. Now, her daughter, who had a diagnosis of fetal alcohol syndrome, was having problems at school. So this mother went to the school, as we are all supposed to do as parents of children with disability, to do advocacy work. She talked to me about how frustrated she felt after this experience. She said:

“I was the one advocating to get my daughter all of these supports. I’m the one who put her on all the wait lists and signed her up and filled out all the paper work and advocated for myself. And now she’s having problems and [because those problems are attributed to a very specific diagnosis that is connected to her behaviour] the principal at the school is telling me that the problems are stemming from home. And I told him, ‘No, there’s stuff going on at school, too. I’ll take my blame or my responsibility for part of it, but there’s stuff going on at school.’ And he said, ‘No, I don’t think that is the case.’”

We do not blame the mothers of children with other disabilities in the same way that we are still very keen to blame mothers of children with FASD, and we do that in many different ways. Here are a few examples of shame and blame being directed to substance-using mothers at a societal level. On the right is an anti-smoking ad in which Britney Spears is coming out of a bar. She is very heavily pregnant and she has just lit a cigarette. She is told, “You’re not just eating for two... you’re breathing for two.” Even the breath sustaining her life is not her own. These images encourage us to think that women who are drinking, smoking, and using other drugs when they are pregnant are selfish and irresponsible, as opposed to being women who are really struggling. On the other side is an example from an FASD-prevention campaign, which tells us

that “Every year thousands of babies are poisoned in homes just like this one. Please don’t drink, smoke, or use drugs during your pregnancy.” Again, this underscores the belief, which still operates at a societal level, that women who use substances when they are pregnant are doing so because they intend to hurt their babies. Yet the evidence that we have speaks very clearly to us that this is not the case.

These messages not only reinforce the shame, blame, stigma, and discrimination toward substance-using pregnant women, but often operate to exclude women from exactly the kinds of care they need. Social isolation and marginalization decrease timely access to supportive care, as we have seen documented across a wide range of sites. In the context of my research, one woman described her interaction with service providers in trying to get this supportive care: “It’s like I have to beg and, if it’s not begging for things that I or my kids need, I have to fall on my face before they recognize that I have problems that I need to face. That’s the frustrating thing. It makes life a lot harder.”

We have systems for responding to crisis, but we do not have systems that are able to work with women in a preventive way to keep them from falling on their face or that tell women they do not have to demean themselves or beg in order to get help that they need. We see this not only in social services, but also in primary care settings. In a recent study that we did on access to primary care for women who use drugs in the Downtown Eastside, one participant explained, “When you don’t get health care, you don’t get a sense of belonging, you don’t get a sense of your importance.”

If women are coping with feelings of marginalization and exclusion by using substances, we can see the implications for FASD prevention. Mothers also see it. Again and again through research, mothers have shown us that social support is critical to having a healthy pregnancy; and interventions that increase social support, like the ones in the PCAP model, reduce the likelihood of future substance-exposed pregnancy. We also see this documented in evaluations that Nancy Poole has done of the Sheway program, and in evaluations of the Breaking the Cycle program in Toronto. In a study at Sheway looking at the importance of social support, women were asked, “Why did you get help from Sheway, and what was meaningful to you about it?” One woman responded, “Because they took me for who I was and they didn’t care that I used and they didn’t care that I used when I was pregnant. They just wanted to make sure that I was fed and had somewhere to go. I honestly think that if it wasn’t for this place, my children wouldn’t have survived my pregnancy.” A very clear articulation of the need for a sense of belonging and importance.

Unfortunately, we continue to find that while we have very good examples of standalone programs that can work with women on an individual level, that work is more often than not made impossible, or at least very frustrating, by a lack of system coordination and cohesion. This further increases isolation and frustrates our efforts to provide care to women when they need it. I’ll show you a couple of examples of what this looks like in British Columbia, which is a relatively well-resourced province. These images come from a mapping study that we did with

the Canada Northwest FASD Research Network. The study looked at the availability of specific types of services that could be engaged in FASD-prevention work and are a part of that coordinated system of care that women require. On this map of British Columbia, the white dots represent places in the province that are densely enough populated that we would expect to find services there. The blue dots are the locations of addiction treatment services that are prepared to enroll women in treatment during pregnancy. You will see that many of the white dots do not have blue dots. What this means in the life of an individual woman is that if she is thinking about going for treatment, and that is what we all tell her she should do, going for treatment means going hundreds of kilometres away from her community — if there's a bed — and always leaving her children behind, unless she ends up in one of the fewer than 20 beds in the Peardonville House treatment centre in Abbotsford.

These purple dots are locations of anti-violence services at the community level in British Columbia. Again, we see a lot of white dots with no purple dots on them. These are transition houses that are prepared to accept pregnant women. If we were to map solely those transition houses prepared to admit pregnant women who are using substances, most of those purple dots would disappear. Here are the locations of pregnancy outreach programs that are prepared to serve pregnant substance-using women and work with them on their substance use as part of a healthier pregnancy. Again, you will see that there are many communities that do not have pregnancy outreach programs and do not have addictions treatment services and do not have anti-violence services for women. While we are very keen to blame and shame women for not getting the care that they need when they need it, we also must think about the fact that we have not built systems that are ready for women.

### ***Recommendations***

Evidence tells us that, within services, the most important aspects of service provision are to take a welcoming, supportive, nonjudgmental approach that addresses the fear, shame, blame, stigma, misinformation, and discrimination that substance-using pregnant women encounter on a daily basis; to meet women where they are; and to help women with related harms. Between services, intersectoral collaboration is critical, and note that in order to have intersectoral collaboration within our communities we need multiple sectors at work. This requires collaborative efforts — not simply knowing where the other services are, but cross-training, development of program mandates and policies for working with women in a positive way, and providing support to enable staff to collaborate with other agencies in the manner that is required. The evidence tells us that collaboration is especially important between primary care, maternity care, addictions treatment, mental health services, child welfare authorities, anti-violence services, and income and employment supports.

Increasing system capacity for FASD prevention requires recognition that FASD is not only a children's health issue but also a women's health issue. It requires responses to maternal substance use that are meaningful, effective, compassionate, and which, in particular, recognize the root causes of women's substance use and are willing to work on those with women, when

they need it and in a way that works. This requires increased systems capacity for interagency cooperation that is wrapped around the mother, child, and family unit.

## **Prevention of FASD: A broader strategy in women's health**

*Nancy Poole, Research Associate, British Columbia Centre of Excellence for Women's Health; Research Consultant, Women and Substance Use Issues, British Columbia Women's Hospital*

I am going to begin by touching on six foundational issues that prompt us to employ a women's health approach to FASD prevention.

1. There are barriers to discussing substance use with women: women report that guilt, shame, and fear of losing their children to child welfare authorities prevent them from getting the help they need, and physicians report that they do not feel fully prepared to discuss substance use with women.
2. This situation is exacerbated by highly negative media portrayals of mothers who use substances. "A Motherhood Issue: Discourses on Mothering Under Duress," a study of Canadian print media over a one-year period, found that women were often portrayed as deliberately using substances and harming their babies and that the system was represented as having no responsibility for improving care to them.
3. We need to hear women's voices on the impact of stigma and for women to participate in designing services. The following quote from "A Motherhood Issue: Discourses on Mothering Under Duress" shows that mothers are concerned about the systemic bias against them and see a need for change: "We're slipping through the cracks and everything else, and when you push and shove and take away the children and stuff, I mean, we're losing mothers in droves here, you know, so there's a flaw in the system."
4. We need to attend to women's health and link the interests of the mother-child unit. Mary Berube spoke of the messaging on substance use. Often in the past we have separated the interests of mothers and children as if they were not inextricably linked and in so doing often demeaned mothers. This 1980s ad ("If you won't think of yourself, think of your children.") illustrates how we disparaged women as not caring about their children's health.
5. The problem is not only alcohol. We need to attend to the determinants of women's alcohol use in pregnancy, both the more distal ones (determinants of health) and the proximal ones (nutrition, use of other drugs, access to prenatal care, mother's stress level and overall health).
6. We need to improve access to high-quality treatment and care for Aboriginal women. This is a critical issue in FASD prevention.

In summary, we recognize that we need preventative interventions that:

- address gender-specific barriers to care;

- reduce stigma;
- are women-centred, and link and enhance the mother–child connection;
- address the needs of diverse women and are culturally relevant;
- are oriented toward harm reduction;
- integrate social and vocational issues; and
- involve women in the design of services.

Next, I will speak about promising practices in four interlocking and mutually reinforcing levels of FASD prevention. These are: 1) broad awareness building and health promotion; 2) discussion of alcohol use and related risks with all women of childbearing years; 3) specialized holistic support of pregnant women with alcohol and other health and social problems; and 4) postpartum support for new mothers, assisting them to initiate and maintain changes in their health and social networks and supporting the development of their children

### ***Level 1: Broad awareness building and health promotion***

We do not have all the evidence we need to determine the best strategies for broad awareness building and health promotion, but organizations across Canada are balancing threat and self-efficacy in their messaging about FASD and alcohol use in pregnancy. They are also thinking about how to couple the research on prevention with messages that are sensitive to women and culturally relevant. [Examples of messages on poster from BC Aboriginal Network on Disability Society: “Healthy pregnancy. Healthy baby. Healthy Nations.” “Friends help friends choose a healthy lifestyle. Please don’t drink alcohol during pregnancy.” “Your baby needs you to take care of yourself. Please don’t drink alcohol during pregnancy.”]

We are also finding ways to deliver prevention messaging that is oriented towards harm reduction and does not stigmatize women who are at the highest risk for drinking during pregnancy [poster from Alberta Alcohol and Drug Abuse Commission: “It can be a fight every day not to drink or use. Every step you take to stop drinking, smoking or using other drugs will help you and your baby.”] We have also involved birth mothers in designing materials that take a broader view of women’s alcohol use beyond pregnancy [booklet entitled *Women and Alcohol: A Women’s Health Resource*, published by the British Columbia Centre of Excellence for Women’s Health].

Another aspect of level one prevention is broad community development, as exemplified by a project of the Public Health Agency of Canada that is taking place in the communities of Happy Valley-Goose Bay, Winnipeg, Sioux Lookout, Edmonton, Burns Lake, and Kugluktuk. These community-based programs link FASD prevention and intervention, and in best-case scenarios also link to women’s health services.

## ***Level 2: Discussion of alcohol use and related risks with all women of childbearing years***

Amy Salmon and I were involved in a systematic review of interventions for women in pregnancy and pre-conception (“Double Exposure: A Better Practices Review on Alcohol Interventions during Pregnancy,” published by the BC Centre of Excellence for Women’s Health). We used the National Institute for Health and Clinical Excellence (NICE) guidelines for selecting and appraising studies for methodological rigor and quality. Then we used the Canadian Tobacco Control Research Initiative (CTCRI) Better Practices Model for producing program components, approaches, and recommendations. Finally, we consulted the wider literature on women’s health and substance use in order to frame the results of the systematic review. We looked at three types of interventions: screening (18 studies), brief interventions (11 studies), and intensive interventions (nine studies).

The use of formal screening tools was endorsed in the studies of screening, yet I have three caveats regarding screening: 1) the studies compared screening to practice as usual and not to brief interventions that use a nonjudgmental approach; 2) we found that women’s reporting of alcohol use was increased by assurances of confidentiality, something that we cannot ensure in our modern, high-tech healthcare systems; and 3) evidence was lacking on whether certain screening tools are better with certain subpopulations of women.

All but two of the studies on brief interventions showed that women were helped to reduce their alcohol use during pregnancy, the two exceptions being cases in which the reduction was achieved through the screening process itself. Many of the successful brief interventions were based on motivational interviewing (MI), an approach that has a strong influence on drinking and other health-related behaviours beyond pregnancy as well. I want to acknowledge the work of our American colleagues, particularly Dr. Louise Floyd and Dr. Karen Ingersoll, who have helped to bring together the evidence for using MI in different contexts, including before, during, and after pregnancy (e.g., Project BALANCE, Project CHOICES). In Canada, we have advocated linking motivational interviewing with mother-centred harm-reduction strategies as part of a compassionate and caring approach to discussing substance use in pregnancy with all women of childbearing years.

To summarize the level two prevention recommendations, it is very important to:

- establish safety and trust in conversations with women and link the identification of women who use alcohol to supportive action;
- tailor education for subpopulations of women with different drinking patterns;
- acknowledge the impact of multiple stressors on women’s alcohol use; and
- acknowledge women’s family roles as mothers and partners and how these affect their ability to focus on their own needs.

### ***Level 3: Specialized holistic support of pregnant women with alcohol and other health and social problems***

In the “Double Exposure” systematic review, all nine studies on intensive interventions found, among other significant outcomes, that intensive programming helped women to reduce their alcohol use in pregnancy. All program models specifically addressed barriers that prevent women from engaging in services, and it is notable that the values of staff appeared critical to success. An example of a level three service is the Sheway program in Vancouver, which meets all the criteria identified in level three prevention. Sheway principles are to provide services in a flexible, welcoming, nonjudgmental, nurturing, and supportive way; to support women’s self-determination, choices, and empowerment; to offer respect and understanding of First Nations culture, history, and tradition; to take a harm-reduction approach to substance use; and to link women and their families into a network of health-related social, emotional, cultural, and practical support. The many services that Sheway offers as specialized holistic support are all grounded in this idea of reducing barriers to care.

I want to emphasize one aspect of Sheway’s work, which is supporting women in reducing their exposure to violence and in building supportive relationships. We in Canada are doing a great deal to link work on violence, substance abuse, and mental health issues, given the study by Dr. Astley and Dr. Clarrén showing the significant correlation between substance abuse and a history of violence and mental health problems. At the British Columbia Centre of Excellence for Women’s Health, we have studied the positive role of transition houses in supporting change in women’s substance use, even when they provide minimal support that is specific to alcohol use. The US SAMHSA-funded study on Women’s Co-occurring Disorders and Violence has also shown the benefits to women of working on violence, mental health, and substance use issues in an integrated way. And in fact, we are finding more and more evidence for doing “trauma-informed” services and systems as well as providing “trauma-specific” interventions such as the Seeking Safety program.

To summarize the promising practices in level three prevention (from the “Double Exposure” systematic review), we need to:

- provide support to reduce harms related directly and indirectly to substance use;
- work with women to identify their own goals for change;
- appreciate that violence against women is common in relationships;
- address women’s multiple substance use, including use of tobacco; and
- increase accessibility of care through trans-disciplinary care integrated in multiple settings.

***Level 4: Postpartum support for new mothers, assisting them to maintain/initiate changes in their health and social networks and to support the development of their children***

Level four work links postpartum support to the prevention that is done before, during, and after pregnancy. There are many great examples of this in Canada. The Breaking the Cycle Program in Toronto is an exemplary program doing this level four work. What we do not have enough of in Canada is something that the Breaking the Cycle program does have, which is the Jean Tweed Centre, a women's treatment centre that accepts mothers and children and provides treatment to both.

***Foundations of this work***

Finally, let's look at the foundations of these four levels of FASD prevention. In implementing prevention and intervention programs, working from principles is extremely important. Here are the five principles we have established in British Columbia, from our FASD Strategic Plan:

1. respect, compassion and cultural sensitivity
2. comprehensiveness
3. collaboration, inclusion, and capacity building
4. balance (efforts are directed equally to FASD prevention through provision of support to women, and to intervention through provision of support to people with FASD and their families)
5. evidence-based

Six areas that we are attempting to link in our work in British Columbia are public awareness; early identification and support for women; focused intervention with women; timely diagnosis, assessment and planning for those with FASD and their families; comprehensive and lifelong intervention and support; and leadership and coordination. I think that if we in Canada are leaders in FASD prevention and intervention, it is because we got this part right: working from principles and linking our work in a comprehensive plan.

My recommendations are as follows:

1. Bring a women's health lens to the prevention of FASD and apply this lens when we are doing research, evidence reviews, health promotion, brief and intensive support, treatment, knowledge translation, and policy work.
2. Recognize the inextricable linkage of women's health and children's well-being and demonstrate respect for women as mothers.
3. Continue to expand the practice and evidencing of these four complex and interlocking levels of FASD prevention that exemplify women-centred care.
4. Ground FASD prevention in inclusive community processes and strategic plans that link prevention and intervention initiatives.



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## **Jury questions and answers**

*(Nancy Poole, Amy Salmon, Nancy Whitney)*

**Raisa Deber** – We hear a great deal about women. Is there a role for men?

**Nancy Poole** – There absolutely is a role for men. We have not done very much of that work yet, but the implication of taking a gendered approach is that we balance work that is gender-specific to men with work that is specific to women. Because women are the ones that get pregnant, we started with women, but we are increasingly aware of the role of men. I am on a number of research teams that are looking at the role of fathers in helping women to stop using tobacco in pregnancy. We have found that it is important to do interventions with men, but to de-link those interventions in some way, so that they are parallel but not necessarily integrated with the interventions with women. Because of the issue of violence against women, it is important not to force a woman into an intervention that includes her partner, but to do interventions that honour the needs of both for recognition and action.

**Nancy Whitney** – There is an ongoing bias in our society that men are not important to the parenting process. This is often reflected in child welfare: we hear that a woman has a child taken away, but we very seldom hear that a child has been taken away from a father. When court orders are handed out, it is the women who are required to do services; only now are we starting to see them saying to fathers, here are the services we want you to do, and we're going to help connect you to those services. Very often in my program, women are put in a position of having to choose between their partners and their children. They do not always choose wisely, and the children get left behind in that process. One thing that I love about our program is that if a father wants to be involved, and the mother says she wants him to be involved, the advocates will offer connection and referral services for him so that he can step up and do the right thing and be clean and sober as well. Too many times, however, the men in our women's lives are violent, they are prostituting them, they are the ones who give them their drugs, and they are the ones that drag

them down. It's very hard to separate the women from those guys. It's an ongoing struggle for us.

**Amy Salmon** – It is important to note that while the better-practice programs, such as Sheway, are built around the mother–child unit, both Sheway and Breaking the Cycle are community-based drop-in programs that welcome women to include whomever they define as their support system. Sometimes that is the male partner, who may or not be the father of the target child. Sometimes the men who are included are the woman's father, brother, uncle, or other men within her circle that she defines as being supportive. Part of the good practice at Sheway is to support women in making those choices about who is supporting them and their children. Further to the cautions that my colleagues mentioned on the issue of violence, there is some evidence — often insufficiently attended to in policy— that when we provide addictions treatment to men who are violent, their rate of violence toward their female partners actually increases. This is counterintuitive. We build policy responses that assume that men are violent toward women because they drink or use drugs and that when we remove the drinking or the drugging from the context of their lives the violence decreases. The evidence shows that that is often not the case. Therefore, it is very important when we are building systems that include support for men that we continue to check in with the women, recognizing that their need for support around safety and violence issues may increase, at least in the period immediately following their partner's treatment.

**Christine Looek** – This is a question for Nancy Whitney. Nancy Poole has talked about the inextricable link between women's health and children's well-being. In the absence of universal daycare in both of our countries, and in the absence of access to universal programs, how does your program help women connect with programs when their kids need support for early developmental concerns?

**Nancy Whitney** – We are rather spoiled in Seattle, and not all of the programs in the state of Washington have access to the same services. If a woman is on welfare in Washington and if she is staying in her program, going to group sessions, getting mental health treatment, those are considered getting-ready-for-work activities, and daycare is paid for while she does those things. We will try to guide her in picking a daycare that will support the goals of the child's development. Beyond that, in King County, we are very lucky to have Childhaven, which is a therapeutic childcare program providing stimulation and smaller classrooms. Dr. Perry is a consultant for them. In all of our communities, we have what are called Birth to Three Centers, to which we can refer children for developmental assessment and interventions if necessary. At the University of Washington, one step down from the Fetal Alcohol and Diagnostic Clinic, we have the High Risk Clinic, which provides specific and sensitive assessments of development, as well as hearing and vision, at a very early age. We try to use whatever the community has available to us.

**Mark Hattori** – This question is for Nancy Whitney. We are hearing the words collaboration, integration, multidisciplinary. Easy to say; harder to do. Apparently, you have the privilege of

having some of those things happening in your area. What are some of the key elements and what is the information that you are passing on to policy-makers in order to sustain that or to make that happen?

**Nancy Whitney** – We do a kind of back-door collaboration, which is one worker at a time, one program at a time, one client at a time. That is very hard to do, but as these mentoring programs become part of the community, our expertise and efforts pay off and systems start to make changes. It is difficult to answer the question about policy, because we do it rather backwards. We do the work on the front line and the people upstairs notice and make changes. This is why we have been able to increase the number of inpatient treatment beds, why we have therapeutic child care that gets paid for, why we have 11 PCAP sites in the state of Washington. What you must do in making policy is pay attention to what is working on the front line and support those programs to the best of your ability.

**Nancy Poole** – When we started work on FASD strategic planning in British Columbia, we included politicians right from the first day as a part of the network of people who needed to be involved. I think this made a difference in getting the funding for the Canada Northwest FASD Research Network, which the policy-makers in western Canada support. One of the ways that the Jean Tweed Centre in Toronto brought trauma and children's programming into women's treatment programs was by including policy-makers in the early discussions and even in learning together what needed to happen next. It is not only collaboration between services that is important, but collaboration between sectors. We have this discussion with policy-makers, with researchers, with service providers, and with women themselves. And with those four sources of evidence, we begin to make decisions.

**Gail Andrew** – In Alberta, we have the FASD Cross-Ministry Committee to bring together all the key sectors to set our strategic plan. Sometimes we collaborate at that level, but the plan does not get out the door. I think what is much more important is operationalizing it, getting it into the community. We need to make sure that happens.

**Nancy Poole** – Sometimes it is dialogue that makes a difference in policy work, including at conferences like this. I see some of the folks from the Public Health Agency of Canada's FASD Policy Unit here today. It was at one of the conferences on FAS that PHAC representatives in conversation with prevention experts came up with the idea of publishing our perspective on the four levels of prevention, to help policy-makers and service providers develop a better system of care.

**Lee Ann Weaver-Tyrrell** – This question is for Nancy Poole. Could you comment briefly on any national strategies or strategic plans and interprovincial strategies, and what your recommendations would be in those areas?

**Nancy Poole** – We do not at this moment have a national prevention strategy in place, although processes like this allow us to think about it. For instance, there were 26 of us from across Canada who put together that idea of what a national prevention plan might include. Your

comment yesterday about using the national alcohol policy as a way of doing that has great promise as well, of integrating prevention into our broader thinking about alcohol availability and community-wide issues related to alcohol.

**Amy Salmon** – We have a very good example of a current and active interprovincial collaboration in the Canadian Northwest FASD Partnership. This is an alliance of seven jurisdictions — British Columbia, Alberta, Saskatchewan, Manitoba, and the three northern territories — that have been working together for nearly a decade in all three areas of FASD: diagnosis, prevention, and intervention. We have representatives from the steering committee of that partnership here, and one of their functions is to fund the Canada Northwest FASD Research Network. There are other programs that are benefiting from interprovincial collaborations as well.

## **Audience questions and answers**

**Audience** – When we started long ago with child protection — and we have a long history of child protection in Canada — one of the unfortunate consequences was that we often pitted the rights of children against the rights of the parents, or we pitted the interests of children against those of their parents and families. There is an inextricable link between what happens in the child protection system and these mothers that we want to wrap services around. A high percentage of the mothers we work with in our programs have children in care, and, conversely, there are many children in care whose mothers might fit this profile but for whom there are no services. And, intriguingly enough, often it is the child protection or child welfare system that funds programs for women who need the kinds of services we have been talking about; and when there are financial challenges, choices have to be made. To separate in any way the needs of children from the needs of mothers, particularly women who are under duress and are attempting to parent, and to try to choose one or the other to support probably leaves us in far more trouble than we want to admit. I would ask the jury, when they are considering their recommendations, to please think about the mothers and children in the child protection system as inextricably linked. They are not two separate groups.

**Audience** – In Washington State, we are now in our 42nd year of doing FASD prevention; and as a professor in public health, I work with an interagency group that produced a document that shares the 40-year chronology of everything that Washington has done since 1968 in public health campaigns, education, the beginning of the FASD clinic and the PCAP program, and links it with the Centers for Disease Control's Pregnancy Risk Assessment Monitoring System (CDC PRAMS) data. As other provinces and states are moving forward with prevention, you may be able to learn from Washington State's experiences. The document is posted on the "Prevention" page of our website at <[www.fasdwa.org](http://www.fasdwa.org)>. [See Fetal Alcohol Syndrome Interagency Work Group, "Fetal Alcohol Spectrum Disorder: Washington State History, 1968 through 2004."]

**Audience, Marilyn Van Bibber** – I would like to speak to the members of the jury about the question of the national agenda. You asked for advice on that. I am speaking from the

perspective of an Aboriginal person. Fetal alcohol syndrome is a legacy of the history of Canada. I have heard some fabulous intervention and prevention strategies here, but what I have not heard is that the root causes, those things that cause the men to be violent and the women to drink, stem from the colonization that took place in our history, in particular the residential schools and their impacts and continuing impacts in present-day Canada. I think that in order to develop any kind of strategy that is really serious about addressing fetal alcohol syndrome, you have to go a step back. We have come a long way: first we looked at the child that was affected, and then we looked at the child's mother, and then the family and community supports. We need to look also at the nation and what the state has done and continues to do. We need to look at the broad policies and not look at this as just a health issue. It is much broader than that. I would also like to say that we have an urgency in our Aboriginal communities. We have something good to offer both the country and the world in terms of our perspective on how we live on this earth. If we can take a much more holistic perspective on this issue, then I think we can have some good benefits.

**Audience** – In discussing FASD prevention, we have talked about a few subpopulations. I'm concerned that we may be missing some of those. Nancy, you mentioned middle class women and women who are over 35 years of age. A recent study in Alberta showed that women who are over 35 and pregnant were very unlikely to stop drinking. Another study showed motor delays in the children born to women who were older and continuing to drink. This goes back to the incidence and prevalence. We need a better understanding of that, so that we can plan universal and targeted strategies for addressing all subpopulations that are potentially drinking during pregnancy.

**Audience** – This question is for Nancy Whitney. You mentioned supervision briefly. How important are training and ongoing supervision of the advocates and mentors to the success of a program like yours? And, second, do you see a difference in the needs of women who themselves have FASD and those who don't have FASD?

**Nancy Whitney** – Relational theory is a key piece in the success of our program model, and that means that we need to retain our staff. To be able to do that means giving them very good training and very good supervision, because this is very hard work. Working with these women day after day wears on the soul. Supervision, for us, is not just "Come and tell me what's going on with your clients." It's "What are you struggling with? Tell me what's going on. How can I help? What training do you need? What are your clients doing that you don't feel you are prepared to deal with, and how do we increase your skills?" Supervision is absolutely key, and I don't think that anyone who goes down this road and does not provide enough supervision for staff is going to be successful.

To reply to the second question, about 25% of the clients I work with are probably fetal alcohol affected. They also have cumulative traumatic brain injury because of neglect and physical abuse, car accidents, and domestic violence. The challenges for them are very different; we have to learn to set smaller goals. We have staff who become easily frustrated because these women

do not make the kind of progress in the linear fashion that we wish and hope they would. There is a great deal of supervision of staff when we are working with clients with brain injury. We have to ask pretty hard questions, such as, “Can this person parent, and will she be able to parent with the support systems that are available to her?” For each person, that’s a different support system and a different answer, but we do have to ask that question. While we have heard repeatedly that people with FASD need lifetime supports, my program is only three years. If I am not very careful, I make that mother look good when she is parenting for three years, and then the day after I leave everything falls apart. We have to be very careful about what support systems we put into place for her, for the rest of those children’s lives.

## ■ Question 5

***What policy options could more effectively support individuals with FASD and their families across the lifespan?***

### **Educational system, parental, and community support**

***Frank Oberklaid***, Director, Centre for Community Child Health, Royal Children’s Hospital; Professor, Pediatrics, University of Melbourne

For several decades now we have struggled to formulate public policy and service responses to issues and conditions, such as FASD, that interfere with children’s reaching their full potential. As someone who is not an expert in FASD, I have asked myself a number of questions. FASD is a condition that seems to be well described, and its etiology seems very clear. Why, then, does it continue to be a public health and clinical issue? Is it due to a lack of information or a lack of public policy or a lack of resources? Are the programs uneven or of poor quality? Is there a lack of expertise among professionals working with these children and their families? Are there cultural barriers to the introduction of effective programs focused on preventing abuse of alcohol? What does the road map look like for the future? When I looked at what needed to be done, the path forward at first looked quite clear to me: prevention, intervention, and high-quality treatment programs — very straightforward. But as my colleague Don Berwick says, “Nothing hard is ever easy.” Trying over the last decade to formulate policy and service responses for the psychosocial and environmental factors that prevent children from reaching their full potential, and FASD is a good example, has been among the most difficult challenges of my academic career.

Let’s review for a moment the core concepts of development and why children are so affected by the environment they grow up in. We know that from birth, or even before birth, all children begin a developmental trajectory that can be either a positive one or a suboptimal one. Children’s development is the end result of a dynamic and continuous dance between biology and experience. This is called the transactional model of development: it is an interplay between genetic and biological factors and the experiences that children have through their life course. FASD very clearly is the result of biological insult. However, the subsequent outcomes, once

that damage has been done in the developing brain, are very much dependent on environmental factors. Therefore, if we want to influence outcomes for these children, we need to focus on prevention in both the biological and the environmental spheres. I am not certain that there is strong evidence for the efficacy of prenatal alcohol-use prevention programs, but there is very strong evidence for the various environmental factors that either promote or hinder good outcomes. This research has been going on for decades. We know that throughout life, but particularly in the early years, there are environmental risk factors that have the effect of pushing what would normally be a good developmental trajectory down to a suboptimal one. There are also, right through life, but particularly important in the early years, environmental protective factors that can alter what would otherwise be an at-risk or suboptimal trajectory to a more favorable one. It is this balance of risk factors and protective factors that largely determines outcome in an individual child.

From a child development point of view, the way to make a difference — and this is not specific to FASD — is to address risk factors and emerging difficulties before they become entrenched problems. The goal is to diminish or remove risk factors, while at the same time strengthening protective factors. This changes the balance between risk and resilience. The earlier we do that, the better. It is never too late, but the research leaves no doubt that if we begin to change that balance early in the life course, the cost is relatively low and the efficacy is relatively high. The longer we wait, the higher the cost and the less effective our intervention. Public policy in most countries has generally been to wait until problems become so prominent and so entrenched that we cannot ignore them anymore, and then we throw money at them. The language of this type of policy is in terms of dollars spent addressing the problem: governments, when challenged, say, “We are doing a good job. We invested ‘x’ number of dollars.” But the dollars have been invested at a time in the child’s developmental trajectory when the cost is high and there is no really good evidence at a population level that those problems can be fixed. These can be viewed as political rather than scientific responses. That is not to say that we should stop helping these children, but at a population level this policy is largely ineffective. If we implement what we know about the factors influencing child development, if we can close the gap between science and policy, we can improve outcomes for children. In the gap between this ideal and our current practice lies developmental opportunity. This is the opportunity that we have as governments and as societies to lift outcomes to an optimal level whereby all children can reach their potential.

Now, how do we do that? I love this quote from H.L. Mencken: “For every complex problem there is an answer that is clear, simple and wrong.” For those of us who are trying to influence public policy, it is very difficult to simplify very complex issues of public policy and service organizations so that they resonate with the media, with politicians, and with society. One often touted simple solution is “more” — if only there were more family support workers, occupational therapists, mental health professionals, and so on. Every professional group says, “If only there were more of us, then we would see marked improvements in outcomes.” Of course, there are shortages in all these professional groups, and of course we need more of all of them; but my assertion is that we will never have sufficient numbers of professionals to deal with

the large numbers of children who need assistance. Another wish is for “better” — if only we could improve practice, provide better training, have better trained staff who devise better interventions, and so on. And, yes, we need to keep on struggling for better, but I am not sure that will make a significant difference either.

In Canada, in the United States, and in all other countries that I am aware of, there are many examples of excellent programs that have been shown to improve early childhood development outcomes. But there are also problems. The studies in the literature are fairly small. There are difficulties in going to scale, such as cost and the question of efficacy versus effectiveness. There are problems with program fidelity. There are competing models in many communities. In many policy responses, there is a notion that one size fits all, despite the fact that every community is different. There is no local ownership; this is a top-down model. There is a lack of data about efficacy. There are issues of sustainability: the published literature is full of three-year pilot programs that resulted in some very good outcomes and then stopped. The early child development programs that we quote all the time, largely from the USA, do not exist anymore, despite 20- or 30-year follow-up studies demonstrating very good outcomes. Finally, we still have an individual rather than a population approach — we focus on individual children with problems rather than take a whole of population preventive approach.

What I suggest, based on our 10 years of struggle with these sorts of issues, is that effective solutions are not about “more” and not about “better.” They are about “different.” If we want to make a sustained improvement in outcomes over a long period of time, we have to start thinking differently. Let’s unpack this notion of “different.” First, we need to take paradigm-shifting approaches rather than tweaking around the edges. We need strategies that move from individuals to populations, thereby shifting the curve. We need to change the service system: why are we still getting poor developmental outcomes when we have a service system that is growing? How can we — and this is an important issue for governments — get better value from existing services? We need to embed treatment and support services into the mainstream service system rather than having them separate. We need to use data effectively: as the saying goes, “No data, no problem, no solution.” We must use evidence wisely and in such a way that it can be accessed by policy-makers and professionals.

In the old approach, the needs of the individual are addressed in isolation and policies are focused on fixing individual deficits. There are strict eligibility requirements and a categorical approach to providing services. Resources are allocated only when problems become severe enough to warrant attention, and the policy criterion is how much money a government throws at a problem. The services tend to be delivered in very narrow departmental and disciplinary silos, although we have heard how important it is to have multidisciplinary approaches.

A new approach calls for:

- a focus on prevention and early intervention, not only in individual services but more broadly across the system;



- holistic interventions and support for children and their families;
- a flexible response to the emerging needs of children and families — acting at the earliest signs of problems rather than waiting until they become established;
- addressing barriers to access (just because we provide services does not mean that everyone can access them, and numerous studies suggest that those who would most benefit from these services are those who are least likely to use them);
- increased participation by community and consumers in local policy and service responses; and
- a focus on outcomes (most service agreements with non-governmental organizations focus on occasions of treatment rather than on outcomes).

Our work in Australia suggests a number of principles to guide effective programs to improve developmental outcomes. Such programs must be built on existing structures. That is, it is not about adding more; it is about doing things differently. Programs must be sustainable; they must encourage partnerships; they must be multidisciplinary, flexible and evidence-based; they must have a quality framework, and so on. None of this is rocket science. It is fairly self-evident, and yet we do not see these principles reflected in our service or policy response to issues such as FASD. Traditionally, we have focused on directing more and more effort toward identifying and then managing the “hard end” — the high-risk group or those with established problems. In our country, we have come to the conclusion that this is too challenging, because there will never be enough resources. We have tried this approach for a long time, and with some success; but if we are going to make a difference to whole populations of children and families, we need something different. What we suggest is a population approach. We understand that many risk factors and conditions operate on a continuum, and we need a service response that reduces the risk among the entire population rather than focusing only on the hard end.

Although most communities in Western countries have a good array of services, there is very little connection between them, so that individual programs that focus on specific conditions such as FASD are separated and isolated from mainstream services. And there are problems with the existing service system: fragmentation, difficulty accessing services, uneven quality, a limited model of care that focuses solely on treatment, and limited local community responsibility and accountability. We would argue for a major effort to improve coordination and integration of services. At present, you almost need a university degree in many communities to find your way around services. People who finally get the courage to go to a service are told, “Sorry, we can’t deal with you because you’ve got these problems and not those.” We need linked services, so that there are no wrong doors. It should be that everywhere in a community that a family and a child make contact with the service system, that is the right door, and they can pass seamlessly from one service to another according to their needs. A seamless one-stop shop, if you like.

Some of the conceptual work that we have been doing is in trying to develop a much more integrated primary, secondary, and tertiary response, and ensuring that this much more integrated service system responds in a flexible way to the emerging needs of children and families. We need to change the way that services connect, one with the other, in order to make the system more accessible. We need to change what we provide: that is, change the services to make them more responsive to families' needs and circumstances. And we need to change the way we deliver services so that we more readily engage with significant at-risk groups. To the traditional school model with its focus on curriculum and governance, we need to make sure there is the additional focus of addressing the various barriers to children's learning, of which FASD is a perfect example. Instead of waiting for these children to enroll in school and then wonder why they do not learn, schools need to engage much more readily with their communities in a comprehensive process to identify and address those barriers to learning that emerge well before children start school.

These are the challenges that I see in addressing FASD. FASD does not exist in isolation. It is associated with many other risk factors at an individual, family, and community level; and interventions need to be broad enough to address those cumulative risk factors. Prenatal alcohol exposure is the important biological risk factor; but once the biological damage is done, intervention subsequently needs to be focused on the environment, where there is evidence that we truly can make a difference. Other challenges are embedding programs in mainstream services, making them sustainable, and, as I have said, gathering reliable data to inform planning and to evaluate interventions.

## **Shifting responsibility from the individual to communities of care**

*Audrey McFarlane, Executive Director, Lakeland Centre for Fetal Alcohol Spectrum Disorder, Cold Lake, Alberta*

I am going to talk about shifting the responsibility from individuals to communities of care, or communities that care. There is a common saying that it takes a community to raise a child. I would add that it takes a community to support a child with FASD. But what does that community look like? The Lakeland Centre for FASD is a good example of communities supporting individuals with FASD. It is a unique, not-for-profit organization based on the principles of interdependence, lifelong support, harm reduction, prevention of problems, and respect. The rural area it serves is in northeast Alberta, about three and a half hours from Edmonton. The travel distance within the area, from tip to tip, is about a three-hour drive. The area has a population of about 100,000 people and consists of one small city, 25 small towns, seven First Nations' communities, four Métis settlements, and one military base.

The Lakeland Centre is the result of the hard work and dedication of a grassroots FAS committee who believed that in order for systems to change, we need to provide good diagnostic services and supports to families. The centre provides mobile, multidisciplinary diagnostic and assessment services for children and adults, and functions as a bridge to local community

services. Every person diagnosed in the clinic is linked to a lifelong outreach worker and to a local system that follows through on the diagnostic team's recommendations and deals with any other issues that might come about. Mothers who are in a cycle of drinking and having babies are supported with a mentor in the Parent-Child Assistance Program (PCAP), who works long-term and intensively in an outreach capacity to support women to be alcohol- or pregnancy-free. In addition, the centre provides training and education, organizes numerous awareness campaigns and information-sharing activities, and has participated in community development in FASD around the country.

In 2010, the Lakeland Centre for FASD will celebrate 10 years of FASD diagnostic services. This agency is a wonderful example of community involvement in supporting individuals and their families in a meaningful way. The community takes pride and ownership in these services. The mobile diagnostic teams, which work a few days each month, are made up of professionals from various government agencies and departments within the Lakeland district who provide these services on an in-kind basis. Diagnostic team members may also provide front-line services for individuals with an FASD diagnosis. Inviting community partners to build the diagnostic team ensures that these agencies and departments are invested in providing better service to individuals with FASD. It means that they have an FASD specialist within their organization and that diagnostic services are accessible in their location. Canada is made up mostly of rural communities, and this model allows rural residents access to services. I'm pretty sure that there is not going to be a specialized hospital built in my community soon.

As for building capacity within organizations in communities, in the beginning it was not always easy to engage the partners that we needed to have at the table. It takes time and continuous effort to keep them there. My first policy recommendation is therefore that payment models for professionals reward the work that is needed to serve those with FASD. Helping individuals with FASD to remain stable takes a great deal of time and support. Professionals such as doctors and psychologists are not supported to take this time. Diagnosis, too, requires significant professional time that is rarely compensated for. Consideration should also be given to rewarding organizations that provide in-kind time to participate in these collaborative efforts, such as children's services and local community agencies.

Our community involvement has not stopped with diagnostic services, but has extended to mentorship of substance-using women who are pregnant or post-delivery. In each community, we maintain informal partnerships with primary care services to better identify women at risk, with children's services to access supports to women post-delivery, and with community addiction services. None of this would be possible if the communities we serve were not prepared. General and targeted awareness campaigns have been extremely important in preparing the communities to receive these services. The training of professionals to build awareness and a desire to have services has been an important readiness tool. In community development work, this is called building social capacity by using personal and professional networks to move a particular issue forward. A second policy recommendation would be to allow communities the

time they need to do this awareness and community-readiness work while they develop service models. Many times, we have seen community services and projects fail because they have no foundation or community support in which to grow.

I will give you an example of how the Lakeland Centre for FASD service works. A mother sought diagnostic services for her teenaged daughter, who was experiencing extreme behavioural problems. With the encouragement of Children and Youth Services, we were able to provide diagnostic and assessment services. When the outreach services of the Lakeland Centre for FASD became involved, it was discovered that the mother was in her 26th pregnancy and in a cycle of binge drinking. She was offered the mentorship program, to which she readily agreed. Since having the baby, she has had permanent birth control. The baby, who is now five years of age, is waiting to be seen by the diagnostic team. After the birth of this child, we diagnosed the mother with alcohol-related neurodevelopmental disorder (ARND). The teenaged daughter found herself in an unstable relationship and became pregnant, but she did not use substances and she had a healthy baby. However, she still receives extensive supports from the centre, as she has developed some mental health issues and needs a strong advocate to help her access services. The daughter has stable birth control. The mother's other five living children are not in her care and have been referred for diagnostic and support services. The mother, who continues to struggle with binge drinking, has been hired by the FASD centre to be the centre's cleaner. A whole family has been supported by this wraparound service. It is great when we are able to catch the whole family when the mother is on her first or second pregnancy, rather than her 26th.

Why did this situation work? There were multiple entry points and consistent ongoing supports that this family could trust. It is also our experience that women having children with FASD may also be FAS themselves. Not all situations work out this well, and the more work we do, the more inadequacies we discover.

I would like to share some real situations in which adults with FASD find themselves that highlight some of the policies that are needed and others that need to be changed. We diagnosed a young man at the age of 10. At that time, he had a stable and loving foster parent in his First Nations community. The centre had minimal involvement because the skills of the foster parent were meeting his needs. Then, just before his 18th birthday, the foster mother died. The centre was called in to meet with Children and Youth Services and provide extensive information on what services they might consider applying for. It should be noted that this young man's IQ is 51. After about a year, he came to our new satellite office and asked for help. He was homeless and living in an abandoned car. People were looking for him to beat him up. He was using alcohol and drugs when they were available. He had no money and his extended family had told him that he was not welcome. What do you do? On reserve, Children and Youth Services said that he was over 18 and not their responsibility, that he had not signed an extended agreement. Provincial Children and Youth Services said that it was an on-reserve responsibility. On-reserve financial services said that they had given him funds earlier in the month and he could get no more, as he was now off reserve and did not qualify for further services. Provincial employment

insurance would support him once he had an address; however, there are no shelters or homeless centers in rural Canada for men and the extended family was unwilling to help. Provincial Persons with Developmental Disability said that they could not open a file as he was considered on reserve, but could not provide a date when he would be considered off reserve. Now this situation is frustrating and downright maddening for our staff. How is a young man with an IQ of 51 expected to maneuver this system?

Too often, social services system abuse comes from well-intentioned agencies and government departments, and it should be noted that as a centre we have very good working relationships with these agencies. Here are a few policy recommendations for your consideration: The on/off-reserve definitions are inadequate and need to be addressed. It cannot simply be on or off status. People move about, they are homeless or couch surfing. It is virtually impossible to find supports when they are in this in-between state. We need clear definitions and options to support people who have neither status. Understanding the First Nations' situation is important. It is not that they do not want to serve individuals, but the funding they receive is inadequate to serve all the adults in their community. The province simply says that it is a federal responsibility, and vice versa. This situation is crazy making and needs to be addressed for all Canadians. There are simply not enough resources for us to build separate systems of care.

We need to plan to serve the most complex of individuals with FASD, such as this young man. If we meet the needs of the most complex, then it will inform systems to meet the needs of those who are less complex. We have a tendency to serve the easiest first and somehow never meet the needs of those with the most complex needs in our society.

Expansion of the Alberta AISH [Assured Income for the Severely Handicapped] Benefits Administration Program has had a huge and positive impact on those with FASD. Individuals who use this benefit can now receive financial guidance. This needs to be expanded to include those who receive Canada Pension Plan benefits and Employment Insurance benefits. When individuals with FASD have financial guidance and stability, their lives can move forward.

I suggest a shift in attitude in government departments, to 'How can we help you?' rather than 'How can we exclude you from service?' Moving away from a focus on saving money will help more people and will actually save real money for governments.

A second tale from the Lakeland Centre for FASD is that of a young man who was diagnosed with ANRD around the age of nine and had the support of his father, with whom he lives. As the young man became older, he began to get into trouble with the law. The first offense was not wearing a helmet when bicycling — not much of a crime, but because he and his father, who we suspect also has FASD, did not understand the legal system, they did not pay the fine, they did not appear in court, and thus a warrant was issued, and the story continues in this fashion. Months later, on probation, the young man got caught stealing a quad [vehicle], and many months later ended up in jail. This took up expensive court time, and this case is only one of many. Do parents learn to provide more supervision in such cases? No, they learn to run when the police come to the door.

Therefore, a further policy recommendation is to reduce the costs to the legal system by redirecting first minor offences. Developing service programs that can help young people with FASD to become more involved in their communities will be more cost-effective and will reduce recidivism rates. I would challenge you to consider the volume of individuals with FASD within the legal system. Instead of screening FASD in, we need to reverse the policy in order to screen it out. Building a system based on this premise would change how we think about the justice delivery system.

Not all situations are negative, although the negative ones tend to be the norm. But I would like to leave you with a positive example. A young woman whom we diagnosed with ARND at the age of 18 when she was finishing high school was struggling to know what to do with her life and started to make some very poor decisions. She had a supportive and loving parent and extended family who wanted to provide good direction for her. She was supported by the family, the Lakeland Centre for FASD, and the community college to attend a program for a year — which she did complete, but she did not like the field she had chosen. So the Lakeland FASD Centre supported her in finding a job in a dog grooming business. Her abilities and limitations were explained to the employer, who then made adaptations for her situation, and the relationship blossomed. When the owner decided to sell the business, she helped the young woman develop strategies to run and own this business. She is now very successful, she lives with a stable partner, she calls her mother and grandmother every day for guidance about various things, and she reaches out to the centre only when she is unsure of the guidance provided by her family. This situation is successful because the family had a support system that was able to navigate the services and obstacles for her — to identify in advance the risks and to take actions to avoid them.

Therefore, here are some further policy considerations: In order for individuals with FASD to enter adult life with stability and thoughtfulness, we need to build systems that can better support families. Many families are unable to cope with their FASD child during the teen years, and this leads to instability and disaster. Effective respites, including long-term out-of-home placements, are important services to build if we want youth with FASD to enter adult life with positive opportunities.

In order to build a skilled work force to serve individuals with FASD and their families, advanced education needs to get into the game with specific programs and information integrated into human service, medical, and legal education programs at all levels, including certificate, diploma, and undergraduate. Consideration also needs to be given to college programs that are designed specifically for this work.

It seems that we need to build residential continuums to serve youth and adults with FASD who can no longer live within a family setting or on their own. In order to do this, we need to gather evidence of what successful residential supports would look like. This requires a major shift to provide capital funding to agencies that are willing and prepared to take on this task.

When we talk about individual responsibility in our society, we mean taking responsibility for our actions. If we make mistakes at work, we are expected to take responsibility; if we mess up as parents, we lose our responsibility as parents. Society expects individuals to follow its rules, and, if we don't, we will be punished. This is based on a belief that we are able to be responsible citizens if we try hard enough. When individuals with undetected cognitive disabilities are held to this standard, it frustrates us as a society that our punishments are not having the desired behavioural changes. Part of this belief in individual responsibility is grounded in the goal of independence. We want people to be independent in their lives. Government makes this a goal for its citizens. We measure success in society by how hard we work, how much money we make, what things we have, how many exotic trips we take, and sometimes by how much we give to others. If we examine our lives, we do not do any of these things alone. Our partners plan the trips we go on, we work only as hard as good administrative supports will allow us to work, we rely on families and friends to help us when we have difficult situations, and we seek out professional supports when we need them. We are not independent people. We are interdependent people, who rely on each other for almost everything.

In reference to people with FASD, we have often hear phrases such as 'If they would just get a job,' 'If they would just stop drinking,' 'They are good until they get their paycheque and then they are gone,' 'We should just lock them up until they get the message,' 'When they are ready they will accept treatment,' and so on. In a shift to recognize the need for an interdependent support environment, wouldn't it be nice to hear individuals with FASD being asked, "How can we support you to stay out of jail?" or "How can I help you ensure that you do not get evicted?" or "I'm sorry you missed your appointment. I've rescheduled you for next week. Can I give you a ride to your next counseling session so that you don't miss it?" That would be refreshing. Making the shift from individual responsibility to communities of care requires both attitudinal and policy changes. The gift that FASD has given us is that it forces us to work in many collaborative ways that we never have before. I challenge you to embrace that gift.

## **Education Policy**

*Elizabeth Bredberg, Education Consultant, Bredberg Research and Consulting in Education, Vancouver, British Columbia*

I am going to talk about directions in education policy rather than refer to any particularly effective program as a basis for recommendation. First, I would like to mention where my ideas come from. I spent seven valuable years as an education consultant on a multidisciplinary FASD diagnostic team in Vancouver, and I thank the people here with whom I had the privilege of working. They were great teachers. But as fine as the clinicians were, even more important was the other half of that experience, which was to travel to 450 schools around British Columbia to see the diagnosed individuals and their families and communities. It was an opportunity to see what those multidisciplinary diagnoses looked like in the real world and to attempt to bring about a synthesis of the diagnostic findings of the clinicians and the capacities and the challenges of

communities, families, children, and teachers. I think that the most recent study on prevalence is going to be very important for education and will finally get people listening.

I want to talk a little bit about a paper by Ryan and Ferguson, which was published by the Council for Exceptional Children in 2006. It is called “On, yet under, the radar.” The following quote from Ryan and Ferguson is a response by an education administrator to a multidisciplinary diagnostic team in Alaska that had informed the school system that the child’s problems were not behavioural, but the result of brain damage.

“The fact that you know something about this person, that they have FASD or their mother abused a drug or used alcohol and this affects them and is going to make a difference — I reject that premise. I don’t think it’s going to make a difference. The fact that you know this is not going to change a thing in the child’s life, unless you get it down to the level of what happens to the child on a day-to-day basis at home, in the community, in the classroom. How does that child learn? How do we have to teach? How do we have to adapt what we are doing, how do we change what we are doing to accommodate his learning needs? That is different for a wide range of people with this diagnosis. What you do for one is not necessarily going to work for another.”

Now there are two issues here. One is that this is represented as the education system not listening to clinicians. The second is that the clinician has heard only one thing, that this person has FASD. He has heard “brain difference.” Yes, there is a brain difference, but the brain is complex. Schools need to hear that, but we are not getting that important message across. We have knowledge transfer problems. How can findings from multidisciplinary diagnoses be integrated into educational programs for students? Where does this fit into education policy? Where does it fit into healthcare policy? How can these two fields hear one another? Not only can education practice be informed by multidisciplinary diagnoses, but it was our observation that diagnostic practice can be informed and enlightened by hearing from education. I think this is critically important and I do not think it is sufficiently addressed.

Current education policy as it affects people with FASD comes under three headings: generic education policy, special education, and explicit FASD policy.

Generic education policy assumes that one size fits all. It assumes homogeneity in the student population in certain salient areas in which FASD populations are affected: eligibility criteria for education; standards of conduct, attendance, achievement, and application; and disciplinary policies, mostly involving suspension or expulsion.

Special education policy assumes that there are some salient differences in the learning characteristics of students. One of the key issues in special education is categorical placement, which is done in all provinces right now. Where are students with FASD placed in the continuum of educational supports? This is not necessarily a physical placement but a notional placement. Are they placed in the learning disability category or the mental handicap category? Are they placed in an emotional/behavioural program? Are they placed with students who have medical



disabilities (what British Columbia calls a “chronic health condition”)? Do they have access to meaningful assessment? This is a critical question, and I will say more about that.

Where does IQ fit in for students with FASD? Does it determine placement? We know that IQ is a poor predictor of function, but it is often used in education policy. It is used primarily because school psychologists are a scarce resource and, as such, they do the quickest thing they can do, which is to administer an IQ test. Does it fit for programming? I don’t think so. A requirement in all special education programs is that identified students have what we call variously an individual education program or an individual program plan or, as I think it is called in Manitoba, a personal program plan. Can programming be based on functional needs rather than on the multidisciplinary diagnosis? If so, who is going to assess and prioritize the needs? There are also capacity issues stemming from lack of professional development. Of the education programs in universities in Canada, and I think this is also true in the United States, none includes a course that is dedicated specifically to FASD — despite the prevalence figures we have heard and despite the kinds of programs that are offered for populations with much lower prevalence. Why? Well, part of it might be therapeutic nihilism. Are we adequately prepared to support students with FASD? Almost certainly not.

Then there is explicit FASD policy. At the provincial ministerial level, there are few policies that directly address FASD. There are exceptions: for example, there is a provincial outreach program in British Columbia and there are some very promising ministerial initiatives in other western provinces. There are school district initiatives that directly target specific populations within the district’s special education policy. Those are the types of programs that I should be talking about as models, but there are some issues with them. Inter-ministerial collaboration requires communicative capacity and action both horizontally across areas of expertise and vertically, and possibility diagonally. It seems to be very hard for tertiary level healthcare professionals to talk to primary level educators, and vice versa. They do not hear each other very well. If you have a Ministry of Education FASD resource program, it is very important that it be staffed by people who are informed about the learning problems posed by FASD and about policies and practices at the district level.

At the division level, what one finds are FASD-specific classrooms. These are often referred to as pilot projects. There is an ethical issue here. Is a pilot the actual support or is it an experimental project? Think of the analogy of medicine: we do not bring people in for an experimental project and tell them that it is going to cure them. I think that we should think of this as parallel. A second issue is determining eligibility for the pilot program. Is it dependent on diagnosis, because, if so, you cannot evaluate that program in a valid way. If eligibility is based on other criteria, such as age, behaviour, or IQ, what are those criteria telling us and what are we actually using? What percentage of students in the district are receiving services in pilot programs, if they exist? What is offered to students who are not included, and is this a typical population of students with FASD, if one even exists? Is the program for the population with FASD, or is it merely separating difficult students from the rest of the student population? As

one of the leading special education specialists in one of the districts that I visited said, “We had to start that program because those students were trashing our behaviour classes.” I don’t think that is a good justification for programming.

What goals should be set for students with FASD? What is our idea of success? What is success for the student? When do students follow an adapted program and when do they follow a modified program? Schools prefer that kids follow an adapted program whenever possible, because, for purposes of accountability, they want them to finish with a proper graduation certificate. But it may not generalize into any sort of adult competence. So is it a good service?

Alberta, like other provinces, has a vision and a mission statement for education. However, neither mentions independence. The terms of reference identify a generic student, but it is my understanding that Alberta is talking about a shift from categorical funding and associated medical assessments to functional assessments and service provision on the basis of strengths and needs. The current state of affairs for FASD in Alberta is comparatively good. The Ministry of Education has published one of the best guides to supporting students with FASD; and through the Cross-Ministry Committee on FASD the groundwork is being laid for a collaborative, interdisciplinary model of support for affected individuals and their families. The Committee has also made available to educators three strong videos on FASD.

What will the future hold? What would be the impact of a non-categorical system for students with FASD? What is a functional/needs assessment, and who is competent to do it? Will it be situated within a multidisciplinary diagnosis? Will regional and cultural diversity be recognized? If the brain domains are not recognized, will the supports be meaningful for the individual student affected by FASD or will they be picked up from a program designed for another condition? Will the supports reflect, as we heard from Dan Dubovsky, that we have an obligation to address co-occurring conditions and that interventions will be different for students with an FASD diagnosis? Is FASD just a medical condition? Advocates of functional, or needs-based, provision of services seem to dismiss the categorical provision services as medicalized; but can FASD be treated as something other than a medical condition?

Policy should mandate some things. All education professionals should receive pre-service and in-service education about FASD, provided by educators who have current qualifications in both FASD and education. We need to build into our FASD policies recognition that age and IQ are misleading and useless as criteria for eligibility or exclusion from service. We have a mandate to recognize that situation-specific learning may require that education move out of the classroom, because the population does not generalize learning reliably. We need to recognize that educational success is not always defined in academic terms. We need programming and placement that is shaped by commitment to build on students’ strengths. It needs to be jointly informed by multidisciplinary assessment and community and school assessments. A hopeful thought: the Alberta review of special education has among its emphases a commitment to respecting difference. This has the potential, I think, to allow students with FASD to play

distinctive, contributing roles in their schools and in the broader community, as has been described in the provincial mission statement.

## **Jury questions and answers**

*(Elizabeth Bredberg, Audrey McFarlane, Frank Oberklaid)*

**Marguerite Trussler** – I am interested in what the budget for the Lakeland Centre is and what your funding sources are.

**Audrey McFarlane** – Currently, our money comes from a number of government departments, but mostly from the new Alberta FASD Network dollars that have been put out by the Cross-Ministry Committee on FASD. Our annual budget is about \$800,000, which is supplemented by the society's own fundraising efforts. Sterling Clarren asked how many kids we see. We see four children and one adult per month. Overall, we have seen almost 500 people now.

**Anne McLellan** – I asked someone outside how many other Lakeland Centres there are in Alberta and I was told none.

**Audrey McFarlane** – As far as I know, the Lakeland Centre is the only one of its kind in North America which through one agency does all these things: diagnosis, support to families and to high-risk mothers, training, education, resource development, summer camp, and so on.

**Anne McLellan** – It seems like a good example of a wraparound service delivery model. Can you tell us why this forward-looking approach to service exists in Lakeland and does not exist anywhere else? Was it your identification of need and likeminded people in Lakeland?

**Audrey McFarlane** – I think it has to do with the fact that we have been working at this since 1994 as a committee of concerned individuals. It started off, as most committees do, with raising awareness, getting the message out, and learning more about the disability, and it progressed to learning that we cannot change systems unless we provide clear diagnostic processes. It is unlikely that education is going to change its practices unless a child has an actual diagnosis, not a suspected diagnosis. We have seen education take tremendous leaps and bounds in the last 10 years as we have been able to provide clear diagnoses and reports. I think, too, that there is a very good sense of community. When the FAS committee started, it was inclusive of anyone who wanted to participate. It was inclusive of First Nations partners and Métis partners. It never occurred to us, when we started to deliver service, to exclude those communities. This was much to the chagrin of some of our funders, but, basically, they have accepted that we are going to serve everyone. Our attitude has always been that we will keep serving everyone and hope that the funding falls into place.

**James Hees** – Audrey, could you talk a little bit more about funding. More specifically, you have professionals who travel the length and breadth of your area to do these assessments, and I wonder if some of their work is done for free because there is not enough money?

**Audrey McFarlane** – Most of the professionals on the diagnostic teams live in the Lakeland area. Yes, someone is always traveling to the various communities for clinic. The health

authority provides the speech pathologist and the occupational therapists for one or two days per month. The only people that are compensated are the psychologists and pediatricians, because we do not have any in our area to do the assessments that we need. They travel in from Edmonton and most have been with us the full 10 years.

**Gail Andrew** – I am going to steal one of Frank Oberklaid’s phrases, that you can develop partnerships built on existing systems. As an example of another diagnostic system, our diagnostic clinic at the Glenrose Rehabilitation Hospital has developed close partnerships with Catholic Social Services in transitioning the families and kids after diagnosis into their wraparound system of care. Fortunately, in a large community, we identified the existing services and did not have to duplicate them. Our funding is through Alberta Health and Wellness; their funding is from a very different source.

**Christine Looek** – We have heard that lack of system cohesion and coordination leads to increased isolation. The challenge is how do we, as Frank Oberklaid said, “embed FASD programs in mainstream services” and still have policy that allows communities to develop their own programs; and how do we develop partnerships so that we do not have isolated programs that separate moms’ and babies’ interests?

**Frank Oberklaid** – I think the cutting edge of policy and service delivery is in what we call broad-banding funding. If you go to any community and map all the resources and services in that geographic area and all the money going into various programs, there is a heap of money. But there is often duplication, overlap, and lack of access. We are starting broad-banding funding in our state now. This is where a community maps the services, finds out what the demographics are, finds out what the needs are, and then develops a plan to improve outcomes. Each community may be slightly different, but if it operates within a state government policy, then ideally that community would be given a single cheque on the basis that the people in the community know far better how to use that money to achieve those outcomes than would a central agency. We call these tight–loose controls: very tight on outcomes, but loose on how the community goes about achieving those outcomes. In our state, government has accepted this in principle and has started discussions with a number of communities with regard to implementation. They will not get a single cheque, of course, but they will begin the process of moving towards broad-banding funding. I am convinced that we need to plan community by community, because every community is different. You are not going to create any sustainability and you are not going to get the outcomes you want from top-down funding. It is very challenging for central governments, because it is about letting go. It is about trusting that a community is going to do it better than you do. The challenges for central government, state government and central agencies are to get the policy leaders behind it and then to develop accountability and responsibility mechanisms and let the community then deliver those outcomes. Difficult work.

**Nancy Reynolds** – How do you find that that kind of funding approach works within the Westminster model of government?

**Frank Oberklaid** – That is a good question. There is a science to this that really should transcend politics. I think that early childhood is a perfect bipartisan issue. The left says we need to invest in prevention and early intervention, because it is the right thing to do. The right has a more economic argument, how to get a better return on investment. At the end of the day, perhaps we should be framing this in economic terms — if we invest early, whether it be in FASD or other developmental or psychosocial issues — we save money down the line. It is not rocket science. It is about persuading government to go beyond ideology and just look at the evidence.

**Sterling Clarren** – I was the founder of the FAS clinic in Washington State. Our program was the grandfather of all the programs that do diagnosis in western Canada. We either trained them, or the people we trained have trained others. From the very beginning, we received funding from the Centers for Disease Control and Prevention (CDC) to demonstrate that the reason for a unique clinic was to link FAS to prevention. It was our suggestion that The Parent-Child Assistance Program (PCAP) begin working with alcohol-using mothers, not just drug-using mothers, and members from their programs have sat at our table weekly from then until today. It is very interesting, and this is the important sociological and structural point, as people came from Canada and embraced the notion of a multidisciplinary clinic and took it back, most of them got funding from provincial governments. However, the government cut the cord with the prevention programs. The only people who have been able to keep prevention and diagnosis together are people like Audrey McFarlane who work independently. This is a good example of governmental interference with a model because of the silos at work. You have wonderful programs like Audrey McFarlane's that are very successful but not the way we usually deliver services in Canada, and these excellent programs are struggling and do not get traction with the government programs. I think that is absolutely fascinating.

## **Audience questions and answers**

**Audience** – Elizabeth Bredberg, I believe you said that, to the best of your knowledge, there are no classes or courses on FASD in North America.

**Elizabeth Bredberg** – I said that there are no classes or courses on FASD at the university level in education programs.

**Audience** – Are there classes or courses offered in other faculties?

**Elizabeth Bredberg** – Yes, but they do not inform educators.

**Audience** – Audrey, I think it would be worthwhile for people to understand how you build community capacity through the multidisciplinary, private money that comes in, as well as the political work that you had to do.

**Audrey McFarlane** – In the work we have been doing since 1994, every activity has been built upon another. It is similar to the concept that if I tell two people, they will each tell two people and so on. That has worked very well. We have used our personal networks, which in rural communities you can do because you know people and you have easy access to politicians and

school board leaders. Those kinds of people we could engage. Our struggle was that we were not always engaging the business population that thought that this disability did not affect them. So we started to hold big fundraising galas and we specifically targeted the business people in the community to come out and give us their money for a good cause. In the process, they learned about FASD. About a year ago, I went to an oilmen's club to ask for money for the summer camp. This was a room full of men who own oil companies and I asked how many knew about FASD and was absolutely thrilled and shocked that about 80 per cent of them raised their hands. I said, "Where did you learn about this?" They said, "Your fundraiser." There are multiple levels of community engagement, and we need to think beyond professional engagement to everyone into the community. I was going to change the name of my session from "shifting responsibility from individuals in care" to "shifting responsibility to individuals that care." This is the work that we have been doing.

**Audience** – I am a parent of a child with FASD. I want to go back to the name of the conference, Across the Lifespan. I want to caution the jury against thinking that putting a lot of money in early and less in later is going to solve problems. FASD is almost unique in that problems do not become less with intervention. In fact, the need for resources later may be even greater. Many of the parents that I talk to get Program Unit Funding, which is great in Alberta, but when the children enter grade one, they get next to nothing, and when they get to grade four they get nothing. A concern for many parents is that when children reach 18 they no longer qualify for medication funding, yet the need for medication does not magically change at 18. Another big concern is supervision. My son is 15 now; he wants to go to the mall after school. He cannot go to the mall, but he does not qualify for daycare anymore. Many of our children get into trouble when they do not qualify for supervision as they get older. I am asking the jury to keep in mind that FASD is across the lifespan.

**Audience** – I work in the central and south central regions and I think it would be fantastic if we could all have Lakeland Centres. I work with individuals from youth to adult. We have adults that are 20 going on 10 and we cannot find homes for them. They are involved in the justice system and we cannot get help for them — not through Persons with Developmental Disabilities (PDD), not from anywhere. I hope the jury will take into account the funding needs; we need help for all of these individuals.

## **Development of life skills: education, parenting, and family mentoring**

*Claire Coles, Professor, Department of Psychiatry and Behavioral Sciences and Pediatrics, Emory University School of Medicine; Director, Fetal Alcohol and Drug Exposure Clinic, Marcus Autism Center, Children's Health Care of Atlanta*

I am going to talk about intervention programs. In the 1970s, it was discovered that alcohol has an effect on the developing fetus. In 2009, we are just starting to evaluate programs that attempt to improve outcomes for affected individuals and families. There are very few evidence-based programs focused on assisting affected individuals. People with FASD have to deal with

significant problems throughout their lives and it is a very complicated process to provide appropriate treatment for them. One of the many problems that make up the background of this condition is that FASD often goes unrecognized. The developmental, educational, and behavioural problems associated with FASD are often attributed to other causes. In many cases, the diagnoses or treatments of FASD (or FASD-associated conditions) are non-specific and may not be what is necessary or sufficient for all individuals with FASD or must be supplemented with additional therapies or diagnoses. For example, individuals may need complex educational programs; however, the school system is not experienced in providing these kinds of programs and often has no idea what is needed.

There is a myth that because these children have brain damage, they are not treatable and there is no known method to provide the services that they need. Individuals with FASD and their families often have no advocate. Usually the advocate will be the parent — if not the birth parent, then the adoptive parent. However, the etiology of this disorder makes advocacy more difficult for the families, and frequently there is neither a family advocate nor a professional acting as an advocate. The treatments available to individuals have generally been dependent on what is available based on local laws and regulations. But what is available may not meet the needs of individuals with FASD. Until recently, there was no support for FAS-specific programs and there were no evidence-based interventions. FASD is a lifelong disability, but there are no long-term programs or plans that have been evaluated.

There are also a number of myths surrounding the treatment of individuals with FASD. Many clinicians believe you cannot identify FASD at infancy; however, it is possible and it is regularly done, and we should stop using this excuse that prevents us from diagnosing people who are being more broadly treated. Another widely used excuse is that FASD occurs only in certain ethnic groups or social classes and it is not possible to work well with those groups because of their various characteristics. I do not believe this either. Another myth is that children with FASD cannot learn and do not respond to therapy. People say that people with FASD cannot generalize — that is, when they are taught a skill they cannot apply that skill elsewhere. This is also not true. Another myth I hear frequently is that behavioural modification or behavioural techniques do not work with these individuals because they have certain types of brain damage. Also, many people wrongly believe that all individuals with FASD have attention-deficit disorder (ADD) or attention-deficit hyperactivity disorder (ADHD).

I am going to talk now about an intervention program that has been evaluated and shown to be effective. At the Marcus Autism Center, we used a number of different funding sources to start a program that would provide services that were not otherwise available in Atlanta. The program includes early diagnosis and certain standard therapeutic interventions used for children: behavioural management, psychotherapy, family therapy, certain medical interventions, and educational interventions. If you are going to start looking at what works, you have to start here because these are the existing treatment modalities. It is essential to make a diagnosis of FASD. Many people still ask, “Why don’t we just diagnose the pieces of FASD and not worry about the

totality of FASD?” There is strong evidence of the neurobehavioural basis for the problems we see, and we believe that a diagnosis of FASD helps to organize observations and govern the expectations of the child and the family. It also focuses the health professionals and educators involved on the multiple risk factors that must be dealt with and provides a guideline for intervention and treatment.

Currently there are no standards of care for FASD and little research on the standard treatments of individuals with FASD. When someone asks me, “My child has FASD. What is the standard treatment?” I have to say that we will have to make it up as we go along. Potential treatment options are changes to the environment, skill-building programs, medication, various kinds of therapeutic interventions, and vocational programs.

Very few programs or clinical trials have published research on the effects of particular interventions for FASD. A few studies, some in South Africa, some in Atlanta, and some in Los Angeles, have looked at specific intervention programs, most of them with school-aged children. A study published in 2009 by Bertrand et al. summarizes a number of evidence-based programs and looks at five studies that the CDC in the United States supported to evaluate the effects of specific interventions on FASD. Very recently, a program from the National Institute on Alcohol Abuse and Alcoholism (NIAAA) has funded programs to study evidence-based treatment. This effectiveness research is still in its infancy.

Because there is little research, we cannot tell the school systems or the funders or the medical programs what actually works. This has been one of our major problems. We are now just beginning to be able to provide an answer that has some evidence behind it, but there are still some unexplored areas. The studies that have been done suggest that targeted interventions improve the specific outcomes they target. Affected individuals will respond to standard treatments if treatments are adapted to the special needs that we find in FASD.

Very few drug treatments for FASD have been tested. A great deal of medication is given to alcohol-affected individuals, but many FASD-affected children do not have a pharmacological response to the medications that is consistent with the response of people who are diagnosed with other conditions. Thus the small amount of empirical research argues against drug treatment because it does not produce a consistent and reliable outcome. A recent review paper by Peadon et al. (2009) from Australia looked at the few interventions that are targeted specifically. They noted that the pattern of hyperactivity in FASD seems to be different from that in ADHD, and that healthcare professionals still have the perception that there are no effective interventions. Streissguth noted earlier (although this was a study without control groups) that a stable environment instituted early in the child’s life leads to much better outcomes (Streissguth et al., 2004). Some might think this is obvious, but it is not well recognized by the system. Early diagnosis, receiving services, and having your basic needs met lead to better outcomes.

Dr. Bertrand (for the FASD Intervention Consortium, 2009) made the following recommendations based on the improved outcomes that they were able to achieve:



1. Existing methodologies can and must be adapted to the special needs of FASD.
2. Intervention treatments can be provided within existing networks.
3. One of the most important factors is caregiver involvement: the parents have to be part of the treatment and intervention.
4. Explicit instructions are effective in helping children learn new skills.

My recommendations for policy are as follows:

1. We must diagnosis early to prevent negative habits. We also need to provide interventions throughout the lifespan, but it is better to start early.
2. We must provide environmental stability and a high quality of care.
3. We must develop and use focused treatments that take into account the characteristics of FASD, the special learning abilities of people with FASD, and the special needs of people with FASD. Caregivers must be central to this process, because without their support and help we cannot do any of it.
4. We must make education and healthcare professionals and policy-makers aware that we have programs that work, that we have demonstrated methodologies that can make a difference. In the United States, and I would assume in Canada as well, we need to change the educational social service regulations to include FASD as a category that qualifies for care. Otherwise, people are prevented from receiving the education that they need.

## Life stages and transitions

**Brenda Bennett**, *Executive Director, FASD Life's Journey Inc., Winnipeg, Manitoba*

Our agency, FASD Life's Journey Inc., is quite an anomaly in this country, as we work solely with adolescents and adults who have FASD. We started our work in 2002 as a community development initiative. In the absence of research or best practice for this age group, we saw the lives of people impacted so adversely by FASD that we were very motivated to find ways to assist them. We have developed a broad range of supports for adults and adolescents, including residential supports, from fully staffed community homes to assistance with interdependent living in the community. We also have professional services that frame our work with this group, including the services of a psychiatrist and a psychologist. A year ago, we began a new initiative in partnership with our provincial government, called the Spectrum Connections Program. The program was designed to assist youth who are in state care to evolve into adulthood. This has been a great venture for us and has taken us back to our beginnings, to the reasons that we started this work. We do not consider the journey to adulthood as a transition to independence for people with FASD; we consider it a transition to interdependence. We do not believe that there are strict time or age markers of life's passages for someone with FASD. What we will do today is look at coming of age in Canada and some of the risks and protective factors related to this

stage of development. We will also look at how the transition to interdependence might look for someone with this disability.

A marker we all look toward in adolescence is that magical coming of age. Typically, it is defined as a chronological age, the age of majority in Canada being 18 or 19 years, as determined by the provinces. It is both directed by the law of our country and entrenched in our societal expectations. Regardless of whether we have a disability, coming of age is a two-sided coin. We think, “Oh, wow, it’s going to be great to be on my own.” But we also look at it with some apprehension: “Am I prepared? Am I going to be able to manage to do this?” The same is true for people affected by FASD, but for them it is further complicated because areas of their brain have been damaged by ethanol exposure.

The law presupposes that by the time we have reached the age of majority, we have the competence to make that magical transition into interdependence; but we are well aware that this is not always the case with the FASD population. The age at which adolescence ends is particularly difficult to define for this group. In most of our services, it is 18 years; and in many federal government programs, it is 29, which is probably much more reasonable. For the people we work with, the transition out of adolescence is a process specific to the individual. We have to forego the expectation that it will begin or conclude at a specific time. In seeking agencies or processes or cultures that manage this well, many are looking to the Aboriginal community, where family members are loved, cared for, and supported throughout their lifespan. Certainly, it is a model that we could all espouse.

Most of us are biologically and psychologically able to acquire the skills needed to manage as functioning adults out in the world. But over the last 20 years, there have been some significant shifts in social trends. Many of us can attest from personal experience that young people are making the transition to interdependence at a later age. They may be affected by economic realities or may require parental support for a longer period of time while gaining an education. For those coming of age with FASD, there are some specific issues that add significant complexity. A person who is younger than the chronological age of majority is considered a minor. For a person with FASD, age 18 is going on age 10 developmentally, and the individual is typically affected by an array of co-morbidities and contextual factors. Therefore, we need to ask when adulthood begins for individuals who are affected by FASD. For them, the developmental trajectory has not yet been identified. We have a great deal of experience and anecdotal evidence, but we do not have life trajectories defined by research. A good question for all of us who are working with FASD individuals is, when does this population emerge into adulthood?

Many of the people we work with are trying to make the transition to adulthood in the context of having a brain that is permanently damaged. But in addition to those issues, a number of other complexities affect them. We have to frame our expectations around their realities. Many of the folks that we see have significant cumulative risks. They have low stress tolerance and are egosyntonic with respect to substance abuse. This may not be something that they want to address. Meanwhile, we have to continue to provide for them while they are actively using

substances. This is the profile of many of the people we work with in Winnipeg. They are not the easy clients. We took those who were on the street, homeless, and chronically unemployed. Many of them did not have a source of revenue when we met them. They had very poor health outcomes: diabetes, sexually transmitted infections, tuberculosis, AIDs, and HIV. Many had profiles of long involvement in the criminal justice system. Many had acquired brain injuries from their youth in care, and over their lifetime had had partners and loved ones who were very abusive.

When we first met this group of people on the street, we acted as a community intake service which had only one door. Referrals would come to us and we would determine which support program in Manitoba they would qualify for. We found that many of them were in the same predicament. They had come out of structured programs and residential supports as youth in the care system — as we know, many of the kids in care are affected by FASD — and were facing the reality of “Oh, my God, *now* what am I going to do?” We call it the “surprise after surprise — welcome to adulthood!” Just a week ago, an individual came to see me one afternoon at about four o’clock. She was going to be 18 at midnight and she wanted to know where it was that I had the house for her, and the telephone, and the new clothing, and the TV set and furniture. That was her expectation of what a transition would look like.

I asked “Cheryl,” my foster daughter, if I could share her story because it was the reason that we were motivated to do something to help people with FASD during this very awful period of change as they emerge into interdependence. Cheryl was a child in care, beginning when she was four. She attempted to kill herself 12 times, and at the age of 13 was removed from her northern reserve and sent to Winnipeg to a specialized secure facility. She met other girls there who had had very difficult early life experiences in which they were sexually exploited and physically harmed. They taught her how to find a pain-free presence, and for her it was using crack cocaine to kill the memories of her horrible and traumatic early life.

I first met Cheryl when I received a call from an emergency ward in one of our hospitals. They said, “Brenda, could you do something for this young girl? She has been beaten up” (she was found hanging off the second-storey balcony of an apartment after being beat up by a ‘john’), “she has some head injuries, but she is refusing care and we cannot do anything to help her.” In the emergency ward, I met this absolutely amazingly resilient, beautiful Aboriginal woman. I got her a pair of pants to wear, stopped at Wal-Mart and got her a pair of shoes, and off we headed to detox. On the journey, I asked her how she ended up where she was. She said that she had been in care, and a month before she was to evolve out of care at the age of 18, her Child and Family Services worker had obtained an apartment for her. The apartment was rented in her name, it was furnished, it was all ready to go with groceries. They waved goodbye after they gave her her birthday cake, and a month later, when she came back to her apartment, her key would not work. So she talked to the landlord, and he said, “Well, no one has paid the rent, Cheryl.” She asked, “What about all my stuff?” He said, “That will have to pay for this month’s rent that no one has

paid.” Between that time and the day we found her in the emergency ward, three years had passed and she was then 21. Her story since then has been much better, as she has had support.

That story is typical, certainly not an isolated case. As we know, many of the kids with FASD are permanent wards and are evolved out of care early, with less support than any of us had at that stage. Deborah Rutman has done some great research on the condition of some of those kids who have lived in care. We can add the information she has acquired to what we know about the situation of individuals with FASD who are evolving into interdependence. It is not a pretty sight in light of their disabilities. They are expected to do more, sooner, and within the context of a permanent brain-based disability that is often invisible. They may look like you or me out in the community, and many times people have no awareness that they have permanent brain damage until, for example, they forget to pay their rent.

The magic wand discriminates against FASD. I have one that hangs in my office and it has never worked, no matter how much we have willed it to. Many people do not appreciate that the social vulnerability of these individuals does not diminish at age 18. It does not go away. I was in court a week ago with one of the young ladies I work with. The judge said, after hearing from her, “If she was a youth, I’d know exactly what to do with her.” He had the impression that at the age of 18 something magical must happen. That truly is a fallacy. Many of them are socially isolated and excluded due to their social illiteracy; many of them have significant social adaptive deficits; they struggle with poverty. Many individuals who are affected by FASD are homeless, living on the streets. They are lonely. They do not have that emotional support that they had when they were in care. They are incredibly anxious and fearful. Imagine living on the streets in the core area of Winnipeg. It is similar to living in a war zone, and in many cases they are out there with the adaptive ability and developmental level of someone who is age 10 or 11. It is not hard to figure out why such horrible things happen to them in such a hurry. This is the transition-by-default destination. It is the black hole in rural and urban settings, and it is typically where the kids in care transition to.

To review the risk factors, many individuals with FASD are not equipped for independence and there are all kinds of deleterious outcomes for these folks: homelessness, poverty, unemployment, criminal activity, and incarceration. Many of them are unprepared for employment. If we could start helping them to develop skills at a much younger age, when they are four and five, they would be a little better prepared when they are adults. Criminalization due to disability is another risk factor. We see it all the time, in the absence of a diagnosis. In many cases they look like you or me, and the criminal justice system therefore treats them as if they are typical individuals. But the codified principles of sentencing require that courts impose sentences that take into consideration any mitigating circumstances relating to offenders. The Charter of Rights and Freedoms further requires that the accused be given equal benefit and protection of the law without discrimination on the basis of disability. This is certainly something that we struggle with in Winnipeg. We have some very innovative projects, such as our youth justice diagnostic project which has had a significant impact in this area. However, there are no

diagnostic services for adults in our province, so they largely go unidentified and invisible. There are also very few adult services directly related to FASD. As I said, our agency is quite an anomaly in that we are one of the only agencies in the country that provide support to this specific population.

Our recommendations are as follows:

- Make FASD diagnostic services available to all Canadians, regardless of age, so that service providers can focus interventions on areas of known disability. Do not forget about adults.
- Develop a range of specialized supports and services, including access to mentors, to provide adolescents with assistance and guidance when they need it.
- Provide individualized strengths-focused and disability-sensitive services. Neurobehavioural service systems are often driven by ethical principles that are very counterproductive to specialists in this disability, particularly in the corrections system. We need to shift our focus from intelligence as the purpose of the brain to functionality and individual uniqueness, so that we can normalize the people we work with and alleviate that huge stigma of not being intelligent.
- Base our services on the level of support needed right now. Harm reduction is incredibly important. Housing is greatly important as well. It must be structured housing that is interdependent and sustainable. It is not as if we are planning for these folks to move out on their own one day. They will always need a certain level of support.
- Consider lifelong apprenticeship or non-traditional supports so that adults with FASD can sustain jobs.
- Extend the period of transition to interdependence. Much of the work that we do for youth in care can be extended to age 21. We may need to look at a gradual and extended transition period of interdependence for all FASD-affected youth.
- Recognize that for people with FASD, adulthood cannot be framed by traditional life trajectories. Establish life trajectories and analyze the costs and benefits of extending care.
- Learn from cultures in which there is lifelong inclusion and support.
- Let's put an end to the black holes in our communities!

## **Social services and corrections**

*Sharon Brintnell, Professor, Department of Occupational Therapy, and Director, Occupational Performance Analysis Unit, Faculty of Rehabilitation Medicine, University of Alberta*

The title of this presentation should be “Health, social services, and corrections in adults with FASD.” However, the evidence in this area is limited. I did not find anything of an empirical

nature that specifically addressed adults with FAS/FASD in the correctional system. Instead, we are limited to evidence from descriptive studies of offenders and the environment of corrections. I will be presenting recommendations from those studies, but it is essential to note that more research is needed in this area.

My argument is that social services are essential supports to people with FASD within the correctional system and immediately upon release. When we speak about community integration for people with FASD, we are talking about crossing domains in service delivery in a way that we have not done before. Here are some statistics on the size of the challenge of FASD in the correctional system. I think that many people are familiar with these numbers and it is one of the reasons for the interest in using corrections as an environment in which to deliver services to individuals with FASD. FASD affects 2% to 5% of the population in North America and Europe (Malbin, 2004; May et al., 2009; Fast and Conroy, 2004), and there is an estimated 10 times greater incidence of FASD in the correctional population than in the general population (MacPherson and Chudley, 2007). This means that approximately 20% of incarcerated people may have FASD. Some of the statistics are not quite complete and are difficult to substantiate currently, but you can see that there is good reason to look at corrections as a place where we can meet some of the responsibilities that we have failed to meet at an earlier time in affected people's lives.

The following are my key discussion points on this topic:

- FASD and recidivism: At a recent planning meeting for the integration of health services into corrections, we were told that 14% of chronic offenders account for 43% to 47% of the corrections admissions. These are individuals who we suspect have FASD or serious compromising mental illnesses.
- Social determinants of health: I applaud Amy Salmon and Nancy Poole who gave you the details on the social determinants of health. I do a great deal of international work, using the World Health Organization (WHO) documents as a framework. I think that some of the comments about the neurobehavioural and societal issues associated with FASD can be reframed within the social determinants of health as elements to be addressed in tertiary prevention efforts.
- The legal rights of persons with disabilities, not just people with FASD: It took the international Year of Disabled Persons, which was way back in 1981, for wheelchair ramps to be installed in buildings. We need a similar focus for people with significant developmental disorders, including brain dysfunction or impairment. The adults with FASD are not improving. In fact, there was even anecdotal evidence given in Vancouver that some people with FASD were showing declines in some of their test scores. These were people who had been tested multiple times and were in their early 20s. What are the functional implications of that? We do not know. But if the declines are in executive

functioning, that has major ramifications for our transitioning, for our supportive environments, and our long-term care.

- We need to look at how people with disabilities, including FASD, fit into the larger framework of services needed to ensure equality for all citizens. Currently, adults with FAS/FASD face challenges, such as being cut off from programs and services at a particular age or not being provided with services at all because of the lack of a medical diagnosis (even though from a functional viewpoint they are obviously in desperate need).
- Physical co-morbidities: Most people with FAS/FASD have co-morbidities, both mental and physical. I want to highlight the physical issues, as we have not had much discussion about this aspect of FASD. Myles Himmelreich told us this morning, “I get up in the morning and I am tired. I have sensory problems, my muscles ache, and I do not move as well.” All of those problems have implications for somebody who wants to live and work in the community. Physical co-morbidities may also include those common in substance abusers or addicts, such as HIV and Hepatitis C. We must remember that the brain is connected to a body, and the body has needs as well.
- System integration: Health systems, correctional systems, and social systems must be integrated. Right now, coordination often happens informally rather than as a built-in characteristic of the systems. Coordinated programs will ensure that mental health needs are being met, not only while adults are in corrections but as they are released into the community.
- Life skills training: An effort must be made to improve the skill sets of adults with FAS/FASD. In order to perform the activities of daily life, people need to be taught systems and skills that will help them function. Myles Himmelreich referred to his habits and routines as important factors in his success. Correctional settings provide an opportunity to rehearse tasks and start beneficial routines that can be continued in the community on release.
- A menu of programs: There is a debate between those who favour individualized programs and those who advocate generalizeable programs. I believe we need a menu of programs to meet the diverse needs of individuals with FAS/FASD. No two people are alike and their needs differ in intensity and change over time. A menu of programs that cross disciplines would allow us to select the appropriate programs as they are needed and in the intensity that is warranted.
- Transition support: Undoubtedly, there are problems with recidivism in the population of offenders with FASD. We see people being re-arrested 24 hours after they leave, because of the company they keep and the environments that they go to. Housing is a critical factor in transitioning to the community.

- Screening and diagnosis: Within corrections, we have the opportunity to screen and diagnose adults with FAS/FASD. We know there is a cohort of individuals in the corrections system who have never been diagnosed or whose diagnoses are not in their files, and consequently they are not being properly managed. These individuals often appear to be non-compliant and belligerent. There is a need for special units within the correctional system to better meet the needs of offenders with FAS/FASD.

Where does this lead us? What does it mean? What can be done to intervene? Here are some recommendations that I have extracted.

- Adults in the justice system should be screened for FAS/FASD and assessed for the life skills needed to sustain community tenure upon release.
- We need to respond to organic brain disabilities by providing appropriate environments and instructional strategies.
- We must integrate health and social services into corrections. People with FAS/FASD need a thorough physical examination.
- An individualized pre-release and post-release program should be established before the individual leaves the correctional system. I have had experience with two programs directly. One is for women, called Corrections to Community (C2C), done in collaboration with the Bissell Centre, for incarcerated Aboriginal women with FAS or suspected FAS. We are in the planning stages of a program called Corrections and Connections to the Community (3C) that targets male offenders with FASD.
- FASD programs must be evaluated for their integration with other programs. We cannot look at functional outcomes without considering how much opportunity people had to participate.
- This comment relates to rural and urban splits of resources. I am a believer in community development. We have to work with what is there in the community; we have to enhance it and support it. We cannot continue to put programs in. Instead, we have to do things differently.
- Training should be provided to corrections, justice, and parole personnel in order to help them understand the special circumstances of people with FASD. A larger effort should be made to ensure that teachers, health professionals, lay workers, experts, and the general public know more about FASD.
- Formal community support in transitioning from the correctional system to the community should be provided to adults with FAS/FASD by case managers who are assigned to them while they are still in corrections.
- Health literacy programs are very popular and we need to be sure that FASD is one of the topics covered.



My key argument is that services may begin within corrections and be offered immediately upon release, but they need to continue as the adult transitions into the community. The factors that reduce recidivism are more in the social domain, in my opinion, than they are in the health domain.

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### **Jury questions and answers**

***(Sharon Brintnell, Claire Coles)***

***Lee Ann Weaver-Tyrrell*** – Dr. Coles, I wonder if you could give a brief description of how you are diagnosing at infancy.

***Claire Coles*** – Depending on the age of the infant, we look at the birth records and maternal history. We look at the infant's physical characteristics and behaviour, just as we would look at an older child, and if they meet the criteria for fetal alcohol effects, we diagnosis them. It is just a matter of experience to know what we are looking at.

***James Hees*** – I wonder if each of you could talk a little bit about the research that needs to be done. I think Dr. Coles talked about drug research, Brenda Bennett about transition to adulthood, and Dr. Britnell about research within corrections to determine FASD rates and how to reduce recidivism.

***Claire Coles*** – We need more clinical trials of treatment methodologies in order to determine whether or not the standard treatments are in fact effective. That applies also to medications of all kinds. We see children coming into the clinic who are five years old and on eight medications, which is insane. Therefore, more appropriate evaluation needs to be done of effectiveness, and then more reasonable guidelines need to be developed. The same applies to any other treatment.

**Sharon Brintnell** – The identification process and the research is underway with guidelines and the use of screening tools in FAS diagnostic clinics. What we need to do, then, is to follow up on those strategies. I think the missing part, and a part that we are going to focus on, is the functional assessment. The diagnosis in itself and the general characteristics do not tell us how people will deal with day-to-day activities. In the 3C project, we are not only looking at functioning, like crossing the street and managing money, but also doing a fitness test. We know that exercise has an impact on the brain, so we are going to offer that. Ours is a demonstration project, not technically a research project.

**Gail Andrew** – I like the word ‘function,’ and I think that is something we need to keep in mind in research when we evaluate whether an intervention is getting the right outcome. What is the right outcome? The outcomes need to be functional for the individuals and their situation in life. If intervention provides a discrete skill that is learned in a particular well-prescribed place and time, and at a specific age, will that be generalizable? Is this going to carry over across time and across settings? It comes back to the International Classification of Function (ICF). We have to move beyond the biological; we have to move into the biopsychosocial. We have to look at the activity and participation of the person across life. Those should be the guiding principles as we go forward in evaluation of our interventions and programs.

## **Treatment for FASD**

**John McLennan**, *Assistant Professor and Child Psychiatry Consultant, Departments of Community Health Sciences, Psychiatry and Pediatrics, University of Calgary*

I am practicing child psychiatrist and I see children with mental health problems, with and without prenatal alcohol exposure. My research interests are in examining the attempts to improve the delivery of evidence-based services to at-risk children. I will start with my policy recommendations and will follow with a series of rationales to back up these policy recommendations.

1. There is no compelling scientific evidence to support the creation of separate services and treatment tracks for children with FASD and their families at this time.
2. Treatment and services required by children with FASD and their families should be delivered within a needs-based service system, not one driven by a diagnostic category.
3. Emphasis should be placed on strengthening the existing service system to better deliver evidence-based interventions to all children with service needs, including those with FASD.

Rationale #1. Many of the difficulties seen in children identified as having FASD in referred clinic populations (that is, kids who come in for treatment or assessment) are similar to difficulties seen in other children with developmental and/or mental health difficulties. The overlap far exceeds any unique difficulties. This is not suggesting that there are not unique difficulties, but many of the characteristics and problems are seen in other clinical populations.

Rationale #2. The diagnosis of FASD, in and of itself, provides little or no information about the specific needs of individual children and hence it does not inform treatment planning. I will give you two examples. The first is a child who is referred to me with an FASD diagnosis. Using the 4-Digit Diagnostic Code, the child comes in with 3-4-3-4, that is, demonstrating growth retardation, facial features consistent with FAS, a ranking of three for central nervous system damage, and high-risk prenatal alcohol exposure. This diagnosis and pattern provide little information to inform treatment planning. In contrast, the following profile can be informative for developing a treatment plan. Mary meets criteria for a learning disorder in math and demonstrates severe attention deficits. Her mother suffers from a major depressive disorder. This clearly leads to provisional plans for treatment. What is important, though, is that whether or not Mary has FASD does not necessarily alter what we recommend for treating this group of characteristics.

Critics will presumably raise the issue of alcohol exposure in this case and inquire about the treatment implications of the alcohol use or abuse by the mother. I would make two points here. First, if our aim is to identify and aid mothers with alcohol-abuse problems, we should develop an approach to identify this need and not rely on the manifestation of FASD in offspring as the primary indicator of maternal need. There are mothers with substance-abuse problems who do not have an FASD child, so you would not want to use FASD as your only indicator of maternal alcohol abuse. Second, why would you focus on a single maternal risk behaviour, in this case alcohol use, in order to flag potential need for more services or supports? What about flagging or prioritizing maternal mental illness, domestic violence, and so on to inform treatment planning? Certainly, when we plan treatment and assessments we consider this. What I am questioning is why we would flag or prioritize only one single risk factor when developing and planning a treatment service system.

Rationale #3. The needs of different children identified as having FASD are so heterogeneous that grouping them together for specific services or treatments is likely to be misguided or, at a minimum, inefficient.

Rationale #4. The needs and difficulties manifested by a child with FASD are not all due to prenatal alcohol exposure alone. Each child is influenced by many genetic and environmental factors and their interactions. This is true of FASD kids, as it is for all other kids. This has very important treatment and service implications. One example of the importance of looking at other risk factors is illustrated in an important paper written by Sood et al. and published in *Pediatrics* in 2001. The study looked at a number of risk factors and whether these factors predicted behavioural difficulties in a birth cohort of six- and seven-year-olds. The researchers had information on prenatal alcohol exposure, nicotine exposure, and many other risk factors. They did demonstrate that prenatal alcohol exposure is related to child behavioural difficulties, but it explained only 0.6% to 1.7% of the variance in child behavioural difficulties. In contrast, measures of maternal psychopathology in the prenatal period explained between 13% and 29% of child behavioural difficulties.

Here is another simple example that illustrates some points. Johnny has FASD because mom drank during pregnancy. On further inquiry, we find that Johnny also has an attention deficit. We make the assumption that his attention deficit is either a manifestation or a component piece of the FASD and perhaps directly related to the alcohol exposure as well. But on further inquiry, we find that mom has attention-deficit hyperactivity disorder (ADHD). ADHD is one of the most heritable disorders in child psychiatry, and if mom has ADHD there is a high risk that Johnny will have attention deficits, whether or not he has FASD. We must now ask whether our initial attribution of attention deficit to the alcohol exposure or the FASD may have been a misattribution. There is some support for this. Some recent, sophisticated studies have tried to tease the genetic role in ADHD out from the influence of such things as substance abuse and prenatal alcohol exposure. One was a twin study (Knopik et al., 2006), and one controlled for maternal alcohol use in a quasi-experimental way using a large US data set that was able to tease out some of these factors (D'Onofrio et al., 2007). When they controlled for some of these other factors, the relationship between attention deficit and alcohol exposure decreased or disappeared. Therefore, we know these other factors are quite important. We also know that ADHD kids are at risk for substance abuse. Mom in this case had ADHD before she was pregnant and before she was drinking alcohol, given that ADHD is a childhood-onset disorder. On further inquiry, we might find that dad has ADHD, and, of course, there is a genetic link between a father's ADHD and attention deficits in kids.

I now need to raise the issue of referral bias. Much of our clinical experience with FASD, and a number of FASD studies, are based on children who have been referred to specialty clinics. What we need to take into account in studies of clinical populations is the high risk of referral bias, or what is also known as Berksonian bias. Kids come to services for a reason, not necessarily just for assessment. Referral bias can lead to spurious or exaggerated associations between conditions, such as between FASD and behavioural problems. A child may come into services because of the severity of the behavioural problem, not just because of the alcohol exposure.

Within the population of prenatally alcohol exposed children in the community, some kids have behavioural problems, but not all; some have learning problems, but not all; and some are in foster care placements, but not all. The kids we are likely to see in the FASD clinic have some or perhaps all of these factors. They are not representative of the larger population of children exposed prenatally to alcohol. We study this clinical population and often make assumptions that it is representative of the whole sample, which is unlikely to be the case.

Continuing with the ADHD example, often FASD kids seen in clinics have attention deficits. Some debate whether that is ADHD, but let's go with that assumption for a second. Burd et al. (2007) recently did a summary of co-morbid mental disorders, primarily looking at clinic-based studies, and estimated that ADHD diagnosis occurred in about 48% of kids with FASD. There are many methodological problems with the studies contributing to that review, but I think if you talk to the people working in FASD clinics, they will say that they frequently see attention

deficits in this population and perhaps even higher rates than reported overall in the summary paper by Burd et al. (2007). Again, these clinic-based studies are at high risk for referral bias. What we need are population-based studies, and we have some of those now. For example, the Italian study that Philip May presented earlier (Aragón et al., 2008) avoided referral bias by using population-based sampling that included collecting information about the rates of ADHD in these populations.

Teachers' ratings of ADHD symptoms reveal an excess of the inattentive subtype of ADHD in the FASD population (17%) compared to a comparison sample (0%), but a lower rate of hyperactive-impulsive behaviour among FASD children (0%) than in the comparison group (4%). Nine per cent of the FASD group and 5% of the comparison group exhibited both inattentiveness and hyperactive impulsivity. These values are much lower than what we see in the clinics, likely because clinical rates reflect the referral bias mentioned earlier. I would argue that much of the ADHD that we then see in children with FASD in the clinic-referred groups is likely *not* a function of alcohol exposure or FASD but is rather the same as for other children with ADHD. Some of these kids have generic ADHD. Not necessarily all of them, but some certainly do. This does not contradict the scientific evidence that there may be unique attention problems in some children with FASD, as demonstrated in some of Dr. Claire Coles' work, or that there may be overall higher levels of attention problems in this population. What I am saying is that the clinic population comes in with many different problems. Some are related to the alcohol exposure, but many are not, and this has treatment implications.

One of the treatment implications is that children in FASD clinics who present with ADHD ought to be offered evidence-based interventions that have been demonstrated to be effective for ADHD. We have quite a robust literature on evidence-based interventions for ADHD. Certainly, medication and certain behavioural modifications are the only two robust evidence-based strategies for short- and medium-term effects in ADHD. My concern is that the current approach to carving out FASD services actually may impede access to evidence-based interventions. As was raised earlier, some people seem to believe that behavioural modification strategies do not work with FASD, even though there is no scientific evidence to support this belief. I have never seen a single reputable paper that demonstrates that these strategies are not effective for children with FASD. It is a very important treatment option that has been beneficial to many children with a range of difficulties, and if you create a structure that separates out these children based on beliefs associated with them that are not necessarily accurate, this may impede access to treatment. There may be a benefit to linking children with FASD and their families to evidence-based mental health or developmental services aimed at addressing a given child's individual problems or challenges, that is, based on a pattern of need, as opposed to creating a separate service infrastructure driven by a diagnostic category. The same rationalization may be argued for other difficulties, and this is not specific to ADHD.

**Rationale #5.** Findings from the very limited number of treatment intervention studies of children with FASD indicate that treatments can lead to improvement. That was presented by Dr. Claire

Coles, and there was also a good review paper recently published. However, I would argue that these promising treatment approaches work, or are likely to work, with non-FASD populations that share the difficulty targeted by the treatment. Thus a math intervention may benefit other kids with math disorders that do not have FASD. In fact, the social skills study actually borrowed the social skills intervention that has been demonstrated to be effective in other populations.

**Rationale #6.** The scientific evidence that would challenge the policy recommendations that I am making would be findings identifying treatment approaches that are uniquely or preferentially beneficial to FASD children and their families and not to other children and their families with overlapping needs. That would argue for consideration of creating separate service pathways. To the best of my understanding, there is no evidence of this type for FASD at this time.

I will conclude with three points:

1. There is a substantial need in Alberta for improvement in services for all children with developmental, social, academic, and mental difficulties. There are huge gaps in our service system.
2. Children with FASD represent one group within this larger population and should be served within an expanded evidence-based service system for all at-risk children.
3. Emphasis should be placed on improvement of the overall service system and, where appropriate, unique components built in for particular subgroups where there is compelling evidence that these components are uniquely or preferentially affected for the designated subgroups.

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## Justice issues

*Mary Kate Harvie, Associate Chief Judge, Provincial Court of Manitoba*

The criminal justice system is very much the repository of society's problems and it is ironic that, despite the fact that society expects us to address these issues, we are often given very few tools with which to do that. One of my colleagues once described it as like being asked to treat cancer with a band-aid. FASD is no exception to that particular challenge.

The criminal justice system presupposes a couple of things. It presupposes, first, that individuals have the capacity to learn from their mistakes. This is something that we refer to as specific deterrence, when the court metes out a sentence that seeks to address the individual offender. The criminal justice system also presupposes that members of society as a whole have the capacity to learn from the mistakes of others. We refer to that as general deterrence in the criminal code. The Youth Criminal Justice Act modifies that a little bit by focusing more on rehabilitation and what we call meaningful consequences. It is very unnerving when one considers the possibility that for some members of our society our criminal justice system is based on false premises. If we ask ourselves what we do about those individuals who cannot learn from their own mistakes and cannot learn from the mistakes of others, we are left with a daunting and in some respects scary proposition: that while the people involved in the criminal justice system want to do the right thing, we have perhaps been doing it wrong for a number of years.

I will begin by making some general comments based in part on the Manitoba experience. I am fortunate to work with some judges who are very advanced in their knowledge of FASD and of education and community issues generally. There have been a number of educational programs about it. However, while the issue is known of, it is still not well-known by people in the justice system. I think there is suspicion, or has been until recently, that a significant number of offenders are affected by FASD, but very few solid assessments have been available to the court. The court system relies on the information that is provided to it by counsel and it is difficult for counsel to get access to such information. The criminal justice system is very poorly designed to deal with challenging and often complicated issues like FASD. We seem to have mastered the sausage-factory approach to dealing with offenders — the system is able to process people on a mass basis, but when you ask us to step outside the box and deal with specific issues, we are quite challenged.

In an effort to break that pattern, we established the Manitoba Youth Justice Program. We did this in the youth system because the Youth Criminal Justice Act allows us to consider rehabilitation and, more importantly, has provisions under section 34 which allow the court to order assessments. The program began in September 2004 with federal funding and has carried on with provincial funding since October 2006. We are very grateful to both the federal and provincial governments for their support, and to Dr. Longstaff and Dr. Chudley for the support

that they have given us through the Clinic for Alcohol and Drug Exposed Children, which is now the Manitoba FASD Centre.

The goals of the Manitoba Youth Justice Program are to:

- assess youth involved with the criminal justice system that may have FASD;
- provide recommendations to the courts for appropriate dispositions consistent with the Youth Criminal Justice Act;
- build capacity within the youth's family and community while enhancing government and non-government FASD supports and services; and
- implement multidisciplinary interventions and reintegration plans with supports for youth affected by FASD and their families.

We focus largely on youth who have come before the court system and have never been diagnosed. It is not about getting them off, and it is not a diversion program. There are diversion programs within the community that try to steer youth out of the criminal justice system before they get involved, but we deal with youth who are within the system. Most of the youth that we deal with are in custody because of their difficulty in following court orders and complying with the general expectations of the justice system.

I will not describe the process in detail, but will emphasize a few things that contribute to the success of the program. Once a youth is identified and an assessment is ordered, the youth is paired with a coordinator. The coordinator works with both the family and the youth to prepare the young person for the assessment, and continues to advocate for and assist them throughout the case and after the disposition in court. About 50 of the youth we see are in care, and a significant number of those continue to have a relationship with their birth mother. The coordinators work with anyone and everyone who is involved with the youth. As you can imagine, this is very time consuming, but it is one of the successes of the project. The coordinators provide the kind of continuity that is often unavailable within the criminal justice system. Linda Burnside spoke about how challenging it is for youth to see different social workers, different probation officers, and different intensive support and supervision officers. For an FASD-affected youth, this can be an even bigger challenge.

To date we have received 332 referrals, which I think speaks to the lack of availability of assessments within the community. That is improving in Manitoba, but we have a long way to go. There have been 94 assessments completed and all assessment reports were forwarded to the court, including those for youth who did not receive a diagnosis of FASD. Sixty-six of those youth received a diagnosis of FASD of one type or another, and 55 of those diagnoses were alcohol-related neurodevelopmental disorders (ARND).

I want to pause for a moment and emphasize to the members of the jury that these numbers reflect the invisibility of FASD. I have had exposure to some of these youth through the sentencing process. Some are highly affected and very low functioning; yet when they come into



the courtroom one cannot guess that there is anything wrong with them. They have the appropriate social responses readily available. I spend time with all youth, questioning them to ensure that they understand the system and what is happening. These kids are giving the right answers, but they are sometimes leaving the courtroom with no understanding of what has gone on. They present with a wide range of disabilities. You have seen the brain domains that are affected by FASD. Among these youth we have seen virtually every one of those brain domains affected in different ways and in different groupings. The average age is 15.5 years. This is very interesting, because it points to the group that is falling through the cracks.

Some of the recommendations that I want to make are related to the fact that, to date, we have limited this project to youth who come under the Youth Criminal Justice Act. The Criminal Code of Canada does not have the provisions to allow the kind of broad-based orders for assessment that are available under the Youth Criminal Justice Act — and it is not only FAS assessment that can be ordered under the Youth Criminal Justice Act, but assessment for a broad range of disabilities. If the Criminal Code were amended to allow us to do with adults what we have been doing with youth, that amendment would need to be coupled with the availability of diagnosis and supports in the community.

One of the questions that I am frequently asked is, “What is the point of a diagnosis? FASD is a health issue and not a justice issue.” I think that the extent of involvement in the justice system of youth and adults with FASD does make it a justice issue. Once we have a diagnosis and know what the deficits are, we can use a sentence-conferencing provision in the Youth Criminal Justice Act that allows us to get everyone together to talk about what we are going to do to support this youth. What kind of orders can the court make that are appropriate? These are not necessarily in exchange for a custodial disposition. Often it is planning for when the youth returns to the community. It has been very interesting for me to hear how difficult it is for the mothers to navigate the many different systems that exist in support of families, many of which are very well-meaning but operate independently of one another. When we are dealing with families who are disadvantaged already and who are challenged and perhaps intimidated, and further, with families in which the mother may be affected by FASD herself, we are setting up an impossible task. Sentence conferencing brings everyone in a room to work together.

We have put a great deal of time and effort into high-risk groups because they are just that: they are high risk. It is important to remember that some of these youth are involved in very dangerous activities — dangerous to themselves and to the community. We had one young man with an IQ of 55 who cannot read, cannot write, and cannot tell time, but he can beat the immobilizer on a Chevy Avalanche in under 60 seconds. When he is out driving around in the community, it is a very dangerous situation. Let’s talk a little bit about the characteristics of this group. They are involved in gangs and substance abuse. Thirty-five of the 322 youths are not attending school, and 44 of them have an IQ under 70. This is a very disadvantaged, vulnerable group.

As for outcomes after diagnosis and intervention, we are seeing a significant decrease in the severity of the charges, a significant drop in admissions, and a decrease in the rate of charges, particularly after six months. It seems that if we can keep the youth out of the criminal justice system for six months, we can have some significant success.

We need to recognize that a diagnosis is not enough. We need to increase support for people in the community who are involved in the justice system. For example, we need to review the role of probation officers and parole officers. What is our expectation of them? If our expectation is changing, they need to be supported so that their caseloads can reflect the work that we expect them to do. You have already heard that those affected with FASD are challenged in accessing community support and housing. We need to re-evaluate the use of an IQ of 70 as a determining factor in assessing whether or not individuals can access support and housing. That absolutely has to change, because it is not relevant to FAS youth.

I have looked at some of the crime statistics in Winnipeg. The Winnipeg police service posts crime maps on the Internet so that you can see the crimes in your community. This is a picture of the crimes committed in one of the high-risk areas in Winnipeg during the last six months of 2007. The houses on the map represent house break-ins (589), the other buildings are commercial and other break-ins (640), the S's are sexual assaults (14), the cars are stolen cars (931), and the dead bodies are homicides (10). This is the environment that we are asking people to live in. We are sending them back there without supports, and that is a huge problem. Therefore, one of my recommendations is that we establish halfway houses or community homes for adults and youth so that as they reintegrate themselves into the community they have some support and some ability to follow court orders.

Finally, we focus a great deal on the accused and often forget about the victim. Crime victims with FAS present in court as poor witnesses because they tend to be fidgety and easily distracted. There is a fear from counsel's point of view about bringing forward the fact that their witnesses have FAS because the court may not accept them. We have to try to educate people within the court system so that we remove some of that stigma, some of that fear of the FASD victim. We also need somehow to include victims of crimes committed by FASD-affected offenders. Every time I have victims come to court, which is not very often, it is a positive experience, because they learn a little bit about the person who committed the crime. It demystifies and helps to explain it a little bit. I think that reviewing the present sentencing process to allow for greater victim participation and therefore greater community awareness is something that we need to take a long hard look at.

## **Policy development in FASD**

*Dorothy Badry, Assistant Professor, Faculty of Social Work, University of Calgary*

FASD presents a number of complex, multi-dimensional issues that have implications for policy development in the areas of health (including mental health), social welfare, education, and justice. The delivery of human services to individuals and families living with FASD should be

considered from a human rights perspective that appreciates the complexity of FASD. Children with FASD have a predisposition and vulnerability to psychiatric disorders and are at risk for abuse and neglect over their lifespan. The invisible disabilities and biohealth fragilities that are endemic in FASD lead to cascading vulnerabilities in the social world. (In electrical systems, cascading vulnerabilities mean that if one part of the system goes out, the rest follows.)

It appears that for policy purposes, FASD service delivery falls into the realm of disability supports. However, the current policy framework that uses IQ scores as a determinant of eligibility cannot fully respond to the unique needs of persons with FASD. We need a new paradigm for treating individuals and families living with FASD, one that applies scientific medical research to the development of social service responses. Social science research in FASD has not kept pace with biomedical research. Traditional practice, which is structurally related to economic rationalism, managerialism, rationality, and generic competency frameworks, does not work in the case of FASD. We must look through a new lens that acknowledges the similarity of FASD to other disabilities while appreciating novel differences, such as multi-layer problems and complex intergenerational social histories.

In the past, the Canadian response to disability was to encourage parents to institutionalize their children and forget about them. While the focus is now on community living, individuals with FASD require lifelong supports in order to succeed. Without these supports, history threatens to repeat itself for individuals with FASD, who are vulnerable to institutionalization by the child welfare, mental health, and justice systems. A lifespan-management policy model must be developed. Those who intervene in early childhood must consider the implications of those decisions in later life. A multilateral, cross-disciplinary, collaborative approach that offers 24/7 treatment models is required. Such intensive and life-enhancing supports can mediate against the vulnerabilities of FASD. In response to FASD, individualized service plans that extend beyond current policy allowances and case-management practice standards, particularly those standards that limit time per case because of economic considerations, require examination. The FASD Cross-Ministry Committee of the Government of Alberta has representation from all the ministries listed in Figure 12 and is under the jurisdiction of Alberta Children and Youth Services. This Cross-Ministry Committee is an outstanding example of collaboration in the development of policy and practice that recognizes that individuals with FASD need program support in all areas of their lives and that intervention models need to expand in scope in order to meet these needs effectively.

Policy must also be developed regarding post-secondary education of professionals with a focus on practice-based strategies and case management that recognizes FASD as distinct from other developmental disabilities. The role of case management is an area requiring greater attention by policy-makers, as is a much needed increase in case work hours. We are currently doing a study of FASD child welfare practice standards in Alberta. This study's pilot was carried out between 2003 and 2005. The current study, with \$100,000 in funding over the next two years from the Alberta Centre for Child, Family and Community Research, includes five regions of Alberta

Child and Family youth services. Approximately 240 children with FASD or suspected FASD are involved in this study. We are realizing benefits very early in the research, as we did in the pilot, from case management standards that dictate more contact with children and foster homes.

The provision of care for those with FASD should focus on health promotion and not on blaming women. It is important that we intervene prior to the birth of children with FASD. We cannot develop social policy regarding the morality of alcohol use during pregnancy, but neither can we reasonably and ethically ignore the right of the fetus to develop in a healthy way. The Network Research Action Team on Women's Health has developed a mothering policy framework, but there is no corresponding fathering policy. This is a huge gap. It is time to start talking about the fathers in relation to alcohol treatment programs such as Alcoholics Anonymous, and it is time to begin a dialogue on how to involve fathers.

Although FASD conferences and training courses are venues for practitioners to inform service delivery, various constraints limit attendance. There is no consistent educational framework across disciplines, and this contributes to uneven service delivery.

Alcohol education policy is very important, considering the role that alcohol plays not only in FASD but in domestic violence, crime, and health. Since alcohol use is normalized and legal, educational policy must be instituted and curriculum developed to teach children about the risks associated with alcohol use. These education programs should be introduced in grades five or six, with follow-up in junior high and high school. This is one tangible way that we can contribute to teaching future potential parents about FASD. The severity of the impact of FASD is often not realized until substance-abuse problems develop in an individual. Children with FASD are having children with FASD.

Child welfare policy plays a crucial role in our response to FASD. Many children with FASD go into the child welfare system, but care of a child with FASD is not considered a lifelong mandate in child welfare. If we examine the long-term picture of children's lives, including their multiple placements and the wounds and trauma related to their families of origin, perhaps a more compassionate understanding of these children will emerge. It is not their fault that they have a disability that is complex, difficult to manage, and encompasses the physiological, physical, emotional, and spiritual dimensions of their lives. Blaming children for the problems of their alcoholic parents, who also had their own problems, is not just.

A very important point that I believe has not been addressed in this conference is the need to develop Aboriginal policy in relation to FASD. There is an over-representation of Aboriginal children in care. FASD is not a racial issue. However, we should develop policy that is culturally relevant and specifically addresses the needs of any community where FASD is found. To date, policy and programs that are culturally relevant are limited. Aboriginal children who have FASD and are in the care of the child welfare system reflect a history of intergenerational trauma related to the residential schools. Groups developing policy and responding to FASD within Aboriginal communities should reflect on this history and on other issues such as poverty.

That mental health is often a reflection of social health is an important consideration in policy development. Mental health policy (and social policy in relation to mental health services) for persons with FASD requires ongoing development. The mental health system has a key role to play in helping individuals who are struggling with the social problems associated with FASD. Professional practice models generically demand client-driven responses, yet expectations of independence permeate social practice and there is little appreciation of the explicit need for managed care of FASD. Although independence is desirable, this response inevitably fails individuals with FASD.

We have no national framework for FASD, and no federal minister has yet championed this cause in relation to developing federal policy. I recommend that we appoint a minister with such a portfolio. Further, it is important that there be advocates for children with FASD in every province in this country.

These are some key policy recommendations that I would like to make:

- Develop discipline-specific standards of practice (e.g., in psychology, social work, and related disciplines) in response to FASD.
- Develop alcohol-education modules starting in elementary school and continuing in high school and post-secondary education.
- Inform young people at all ages of the risks of alcohol use. Develop a framework on how various programs offer education on FASD, from those on the front line to those in program administration.
- Engage a new model of lifespan planning for children in care: life-trajectory planning that recognizes that these children need support in the community.
- Develop policy that maximizes support and improves quality of life for children with FASD, who live with challenges all their lives while professionals move on to new cases.
- Open a channel of informational research (at the federal level) that encourages the development of best practice.
- Develop a unilateral model of understanding FASD from a social paradigm that is consistent and easily applied with respect to specific geographical needs.
- Develop child welfare policy and practice that support longitudinal case studies. We do not currently have the infrastructure in our research policy frameworks that give funding for such research.
- Reduce differences in youth transition experiences across provinces and territories. We need greater cooperation between federal and provincial governments, between urban and rural communities, and between social services, education and health authorities in order to reduce duplication of program development spending.

## **Figure 12**

### ***The Alberta FASD Cross-Ministry Committee (FASD-CMC)***

The FASD-CMC is made up of:

- Alberta Children and Youth Services (Co-Chair/Administrative Lead)
- Alberta Health and Wellness (Co-chair)
- Alberta Aboriginal Relations
- Alberta Advanced Education and Technology
- Alberta Seniors and Community Supports
- Alberta Education
- Alberta Employment and Immigration
- Alberta Justice and Attorney General
- Alberta Solicitor General and Public Security, including Alberta Gaming and Liquor Commission
- Alberta Gaming and Liquor Commission
- Alberta Housing and Urban Affairs

The FASD-CMC also has adhoc agency involvement from the Public Health Agency of Canada, First Nations and Inuit Health, Alberta Health Services, and Safe Communities Secretariat.

## **Jury questions and answers**

***(Dorothy Badry, Mary Kate Harvie, John McLennan)***

**Edward Riley** – Dr. McLennan, would your rationale for policy recommendations hold true for many other developmental disabilities besides fetal alcohol syndrome?

**John McLennan** – It certainly could. Partly, we have to look at what evidence-based tools and interventions we have and track kids that will benefit from those services. Unfortunately, diagnostic categories do not line up particularly well with our treatment options, and we see a great deal of co-morbidity across different developmental and mental health difficulties. Yes, I would make the same argument for other populations.

**Edward Riley** – Thank you for raising one of the big issues we have in the diagnosis of alcohol-related neurodevelopmental disorder (ARND), which is trying to separate genetic factors from teratogenic factors. There are heritable genetic factors, such as in attention-deficit hyperactivity disorder (ADHD), that may influence drinking and be passed on to the child as well. I would like to know if you have any ideas about how we might better inform the medical–psychiatric community that there is a great deal of data showing that even non-dysmorphic individuals with heavy prenatal alcohol exposure have brain damage, and that the animal models, where one can

control for environmental stresses, show similar types of behavioural problems as well as similar brain damage? It seems that much of the medical community attributes these behavioural problems to ADHD genetic factors or to parenting. How do we make them aware of the potential that these problems are due to underlying brain damage?

**John McLennan** – I do not think the medical–psychiatric community necessarily ignores that. I think that the notion of multiple risks is broadly recognized: certainly, alcohol is one exposure, and certainly there is accumulating evidence of the impact of nicotine exposure in utero. Ideally, one would look at multiple factors. But when it comes to treatment services, what strategies can we use to address those things? My argument was around separate treatment services. I am not at all questioning the brain injury impact of alcohol, but the issue is whether that has treatment and service implications. I do agree that there is a lack of understanding of the effect of alcohol exposure. I would say there is a lack of understanding of many other exposures as well. There is lack of understanding of the impacts of nicotine and cocaine, as well as a lack of appreciation of the role of genes, in particular for mental illness, despite a substantial evidence base.

**Christine Looek** – Dorothy Badry, you mentioned in one of your recommendations the need for a specific policy for standards of practice. I assume that this would also involve training in the mental health, social services, and health professions, which would include child psychiatry, pediatrics, developmental medicine, and so on. I am challenged by Mary Kate Harvie’s remarks that the majority of kids that come before her in court have never had a diagnosis. Our experience is that children born in the 1990’s, before we knew what FASD was, did not do well without a diagnosis. My question is to John McLennan. What policy would you recommend towards training child health professionals, including child psychologists and pediatricians, to deal with maternal psychopathology — or, as Nancy Poole put it, mothering under duress — and adverse childhood experiences? How can we constitute child development clinics to deal with complex intergenerational histories in the context of delivering services to kids without incorporating such complex social determinants? What should we do in our training to prepare us to do that?

**John McLennan** – In my training, we learned to be fairly comprehensive and to look at all risk factors, such as domestic violence and multiple exposures. We continue to do that in training. It is not clear to me that we have a training gap. There is certainly a service and treatment gap. I see many kids each day, and I know what questions I am supposed to ask, and I ask them. I can identify many problems — a need for parenting, housing, income support, and so on — but I do not have those services to offer them. The biggest problem is the absence of services. I am not saying that we do not need any more education, but lack of services is a much bigger problem than lack of education. I hear every day that we are struggling in our child mental health and child developmental clinics due to lack of services. We can identify the needs, and we can make recommendations, but the services are not there.

**Gail Andrew** – When training my residents, I go back to the 4-Digit Diagnostic Code. We look at the rankings for growth, the brain, the face, and the alcohol exposure. But there are two boxes

that I highlight and make sure my residents work through. I tell them to look carefully at all the other prenatal factors and to rank them. How many of them are influencing the child's presentation? Then we go through the same exercise in the postnatal box. How many of them do you think are there? That needs to be considered in both your differential diagnosis and your treatment plan.

**Christine Loock** – My follow-up question is about the capacity of working in shared-care models. It is my experience that we do not do well at training in a multidisciplinary or a multi-sectoral way. We need to recognize that we cannot do this as single practitioners or in a single model, and that the proper clinic for kids with such complex histories would be one having those resources in a program. That is an argument in favour of having multidisciplinary clinics that are able to address complex multi-generational histories such as present with FASD but may also present in some other developmental disorders.

**Anne McLellan** – I have a question for Mary Kate Harvie. The judicial system, like the healthcare system and the social welfare system, are stretched for resources. While you talked about support from the federal and provincial governments, you did not put a price tag on the program that you have in place. What are the actual costs, and is your project viewed as a pilot project or has it been integrated into the justice system in such a way that you do not need to worry about losing funding for it?

**Mary Kate Harvie** – We costed it out on a pilot basis. I do not have up-to-date numbers on the cost, one reason being that we expanded to The Pas [Manitoba]. Second, part of the challenge in costing is that we have so much in-kind funding. The doctors, for example, provide services for which they do not bill us, including the preparation of reports. It is very much a team collaborative effort in that respect.

When we try to cost it out, certain costs are often challenged. Out of interest, we costed out one of our high-risk youths who had been in custody for virtually his entire youth, from age 12 to age 17, before he became involved in the project. Over a 50-month period, he was in custody for 32 months. During that period, he was convicted of 31 auto thefts along with a variety of other charges. We thought it would be interesting to find out how much that cost, even though it is only one case and does not provide the cross-section needed for statistical support. Our friends at Manitoba Public Insurance tell us that when a car is stolen there is an average of \$3,500 in damage. If you do some basic math, 31 times \$3,500 is \$108,000 of damage to vehicles. He spent 973 days in custody. If you average the cost of the custody, depending on the institution, it cost the system upwards of \$251,000 for the period of time that he was in custody. For the period that he was on community supervision, we estimated the cost to be approximately \$53,000. He was arrested 22 times, and if you estimate 8 hours per police team per arrest at \$150 an hour, that is \$26,000. If he had gone into community care after that, the community care cost during that period of time would have been \$74,000. We did not include medical costs, judge costs, lawyer costs, court costs, or other costs of that nature. I raise this as an issue that everyone needs to give some thought to, because I was challenged on some of these numbers. The response I received



was, well, we are running an institution anyway, so you do not save us any money by keeping him out of custody; and they said, well, we have a police force, so you are not saving us any money if he's not arrested. The best response I could come up with is that that is very stupid. I couldn't think of anything else to say other than that only in government would you say that it is free to have someone arrested or kept in jail or put into community services.

It would be very helpful if we had some recognized cost factors so that we could say, yes, it is acceptable to factor in the costs of having a kid arrested 22 times by the police, who are crying for more police officers; and it is acceptable to factor in the cost of having him in custody when all of our jails are overcrowded. Our project, when we last costed it out before expansion to The Pas, and not including some of the in-kind funding, was about \$423,000 annually. We figure that one youth was costing over \$10,000 a month. I think we need to know what is acceptable to include in the costing amounts.

**Anne McLellan** – Is your program under any threat, or have the evaluations shown outcomes that the system sees as positive and therefore you will continue this program indefinitely?

**Mary Kate Harvie** – We are embedded in the system now, and the provincial government is very supportive. That does not mean that we will never be at risk, and we find that there are not enough resources available provincially for statistical analysis and evaluation. We started doing that ourselves, because we need to be able defend the program if it is ever challenged. Manitoba is very positive and proactive in addressing FAS, but one of the challenges and one of the legitimate criticisms of the project is that we focus on diagnosing and supporting youth who come into a system without a diagnosis. We have a huge community of youth who come before the court with a previous diagnosis who are not eligible for our program simply because we are not sufficiently resourced to include them. Their lawyers come to us and say that their clients are not eligible because they have a diagnosis already, but they need as much support as some of the other kids. One of the things that I and people in corrections have been advocating for is an expansion to allow support for some of those youth. That is where I think we need to expand next. There and into some of the regional areas.

**Lee Ann Weaver-Tyrrell** – I am assuming that individuals who have developmental disabilities other than FAS are also eligible for this program.

**Mary Kate Harvie** – For our program, no. We focus on FASD youth. We receive a great deal of information about youth apart from this, such as in pre-sentence reports that come to the court. We target FASD because we saw a gap in services in the community and had concerns that we did not know what was going on with some of the youth appearing before the court. We needed to get some answers.

## **Audience questions and answers**

**Audience** – I am a consultant pediatrician in Iqaluit, Nunavut. I have a comment and a point to make to the jury. If we are talking about creating policy that is truly universal, then we should not forget the Inuit in Nunavut. It is a small population of about 31,000 people, but it is a

population that struggles with alcohol and with behavioural and developmental problems. I very much appreciated Dorothy Badry's comment about making policy that is culturally relevant. This is very important. I hope that one day we will be able to provide diagnosis, assessment, and management plans locally, but we will not be able to do this until we have more professionals up north. In the meantime, we rely heavily on expertise and specialized diagnostic and management teams in the south. One of the frustrations I have is that we have trouble accessing these centres. As an example, for the past year I have been managing a little eight-year-old boy who has been an unbelievably difficult diagnostic dilemma for me. He had encephalitis as a child and has neuropsychological problems as a result. He is in foster care, likely was exposed to alcohol in utero, and has significant attachment and psychological issues. I think I have asked every single diagnostic centre across the country to accept a referral for this child, and I have been refused every single time. The reason that I have been given is that, I am sorry, but you do not fall into our catchment area. This is a serious problem. I think that when we talk about developing policy we have to keep in mind that it does need to be universal so that all Canadians across the country have access to appropriate services.

**Audience** – I am from the Bigstone Cree Nation. I am a survivor of an Indian residential school. Surely, the victimization that has been done to our people can be recognized as part of the outcome we are facing today in our communities. Family is the most important factor in a child's ability to thrive. Is it any wonder that foster children go searching for their biological parents to find that connection that is missing in their lives? Our reserves continue to have high rates of suicide, substance abuse, and criminal activity. It is obvious that the system has failed our people when we see four to six per cent of Aboriginal children in care and a very high percentage of people of Aboriginal descent in our jails. It is a heavy weight on our society. As Aboriginals, we have our own unique culture, traditions, and values. We have accepted the apology from the Canadian government, and healing has begun, but we also need a voice to deliver our own services and policies within our own communities.

**Audience** – I want the jury to consider Dr. McLennan's comments. The system of care was changed because of a need. The system of care that we had for FASD kids led to no diagnosis and many of these children fell through the cracks. They were given behavioural diagnoses, but the possibility of an etiologic diagnosis of brain injury was ignored. My son was diagnosed by a child psychiatrist as having ADHD and he is now is an owner of a very successful business. He does not have FASD; he has ADHD. Kids with attention-regulation problems, functional memory problems, and executive function and social adaptation problems, who constitute the majority of FASD kids, do not often experience that kind of success. The diagnosis requires considering the possibility of FASD, and the previous system ignored those children. A recent survey done through the Public Health Agency of Canada showed that physicians are uncomfortable about diagnosing FASD. This is a special, unique situation that requires special care and a multidisciplinary approach. I want the jury to consider that Dr. McLennan's views are not isolated, and not new. Our approach now to diagnostic clinics and assessments and treatment programs is a result of doing things differently.

**Myles Himmelreich** – John McLennan, thank you for your presentation. My question has been touched on by the jury and in this last audience comment. I am wondering if you are saying that someone with ADHD would not have the same behaviours as somebody who has FASD?

**John McLennan** – Presently, most people are using the Diagnostic and Statistical Manual (DSM) for ADHD diagnosis. The approach in the DSM has been described as a phenomenological approach — a description of signs and symptoms. It is not a system that determines the cause, or etiology. We make the diagnosis and then speculate whether the etiology was alcohol exposure, genetic influences, low birth weight, exposure to nicotine, and so on. The diagnosis is somewhat separate from the determination of etiology in the way we have set up our diagnostic system. When we diagnose FASD and see attention problems, some of that may be a function of the alcohol exposure or intrinsic to the FAS, but some of it is ADHD that is not alcohol-related. It is very hard to see a distinction at a clinical level. Under research paradigms, some differences have been demonstrated, but within the clinical population it is not clear how one separates those things or what the treatment implications are. I am not saying that an attention problem is all parental genetics, but a component of it is; and sometimes the attention problem is all attributed to alcohol or FASD, and that is probably inaccurate.

**Gail Andrew** – I think there is uniqueness in FASD. I am a strong believer in universal access to early intervention programs for all children and, in fact, young children with FASD benefit from being with their typically developing peers. They learn visually; they copy good behaviours; they learn from their peers. Peers are the greatest teachers. But in many of the early intervention programs, there is a strong parent component through which parents learn strategies so that they can follow through in the home environment. I question, with the FASD population, who brings the kids to the program? Who works with them within the program? Who is going to follow through at home? We have different levels of caregivers. Many of the foster mothers that I see have six or more children with FASD in their care. How much time do they have to come to the FASD intervention program and how much time will they have for the follow-through? What about a birth mother who has FASD herself but has not been diagnosed or, even if she has been diagnosed, is not connected with the support services? Will she be able to learn the strategies in the program and carry them over to home, or will she just be failing one more thing? I think that is one aspect of the uniqueness of FASD: it is not only who they are, but who they come with.

## ■ Question 6

*What further research into FASD is needed?*

### Health and social policy

**Sterling Clarren**, CEO and Scientific Director, Canada Northwest FASD Research Network;  
Clinical Professor, Pediatrics, School of Medicine, University of Washington, Clinical  
Professor, Pediatrics, Faculty of Medicine, University of British Columbia

I would like to start by taking us back to the beginning of the day. I hope that Myles Himmelreich will forgive me if I use his excellent description of a day in his life as a case study for what FASD is all about. What many people have attempted to do is put a human face on what we are trying to grapple with; but at the end of the day, what we are trying to grapple with is mystery. Fetal alcohol spectrum disorders have been, for me and many of my colleagues, an endless mystery.

Think about what Myles talked about this morning and imagine that we are observing a day in his life through a two-way mirror. What do we see? We see a fellow who is tall, thin, strong, probably athletic, good looking, has great presence, can walk up onto a stage and give a coherent talk, and tell a good story. And he's funny. Not only is he funny, but he uses irony. We see a very well put-together guy and what do we assume? We assume that his brain function is normal. Now, when he gets to work and sits idly for an hour and a half, what do we see? Do we see somebody who is depressed, hung over, drugged, despondent, lazy? All of those words and 10 more are going to come to our minds before we think of brain damage. How does he get through his day? Does he walk up to everyone and tell them, "I have FASD. Be nice to me." Absolutely not. Myles is doing the best he can. I am guessing that the people in his office know something about him, so that when he sits there for an hour and a half, they cut him some slack. And when he needs help sending a fax, they help him. If he asks them again, they help him again, because they understand. They have looked through the invisibility and mystery of this disability and they understand it to some extent. Myles goes home at the end of a horrible, awful, miserable day, and he makes himself some supper and plans to go play volleyball. Even though he has had a miserable, awful day, he knows how to do some self-nurturing and get on with his life; and, in part, he can do this because of what he has learned. It is not a question of etiology; it is a question of understanding and of appropriate intervention for a population that is persistently mysterious.

I will give a brief outline of what we have attempted to do in western Canada over the last three or four years. Ministers of child services and health from the four western provinces and the three northern territories started meeting about 10 years ago and realized that they needed more data to inform public policy on FASD. The Canada Northwest FASD Research Network was our response to their request. It is a potential model for bringing data to the subjects of FASD diagnosis, prevention, and intervention.

What came out of our initial consultation work in 2004 was recognition that over 170 demonstration, implementation, and research projects on various aspects of FASD were underway in western Canada. Virtually none of them was being assessed and few of the groups were talking to or learning from one another. We brought them together into what we call Network Action Teams (NATs). These are five teams responsible for data gathering and research in diagnostics, intervention, and three prevention topics. Why three prevention topics? Because in 2004 the people in prevention did not want to work together. Group one were people who wanted to do universal prevention, ad campaigns, and teaching. Group two were people who

wanted to work with high-risk mothers. Group three were people who wanted to do FASD work through the determinants of women's health. All of those people are now working together because they realize they have a great deal to offer one another and that this work has to be integrated.

We then organized Network Implementation Teams (NITs). These are smaller groups that work across the Network Action Teams to provide everyone with key information on First Nations sensitivity, knowledge transfer, data management, and ethics and methodologies. The network is administered through our central office and led by a board of directors and, ultimately, our ministers.

I am confused about the difference between the terms 'clinical research' and 'quality improvement.' I have been very persuaded by the work of Don Berwick, and my favorite quote from him is, "Every system is perfectly constructed to give the result that is achieved." If we do not like the result, we have to try to understand what we are doing to produce that result. That is what clinical research is. That is what quality improvement is. This is what we need to do. We need to evaluate what we are doing, to evaluate how it might be done better, and then to implement and disseminate change.

Clinical inquiry on FASD has four aspects that inform one another and need to be advanced synchronously: prevention, diagnosis, intervention, and surveillance. Accurate diagnosis has to drive prevention and intervention; and if you are not doing surveillance to understand what it is that you are doing, you are not going to make progress. Diagnosis depends on diagnostic capacity. If we assume, as a simple estimate, that the prevalence of FASD in Canada is one in 100 people, then the incidence of new cases of FAS is approximately 3,200 per year, the number of cases of FAS is 32,000, and the number of cases of FASD is 340,000. Yet the number of evaluations that we can do annually in all of Canada right now is 1,500.

How are we going to increase that diagnostic capacity, and what should we increase it to? My way of thinking about it, and the way that most of the clinics think about it, is as follows. Normally adaptive people are those who have normal temperament and mood that directs their conduct, normal cognition and information processing, normal environments, and normal ability to learn. What we see, on the other hand, are people with psychiatric conditions, with cognitive processing difficulties, with medical issues, and with adverse environments, all of which suggest maladaptation. Does every one of those 340,000 need to come to an FAS clinic? Of course not. If their disease is mild and focal, they will go to a doctor, psychologist, or psychiatrist and get treatment, and they will be fine. If their IQ is 40 from fetal alcohol exposure, they do not need an FAS diagnosis. With that IQ score and their general level of disability, they will get the interventions they need. But what we see in our clinic are the people who need more, and we are not sure how many of them there are.

Not all maladaptation is approached in the same way. If we think that a maladaptation is due to a health or environmental issue, our societal judgment is that it is a disease, and our intervention goal is to treat it or cure it. If we believe that maladaptation is due to temperament or mood —

that it is psychiatric — we may still think it is a disease and intervene with treatment or cure. However, that same maladaptation of temperament might be called disobedience in the court, and the intervention might be punishment or separation. If the issue is cognition or performance, our societal judgment then, and only then, is that it is a disability that we have to accept or treat.

What is mysterious about the FASD population is that they have all of those maladaptations at once. That is why we need a multidisciplinary group who can assess them at the same time, and preferably over time, to see what percentage of the maladaptation is actually brain damage. People may go to genetics clinics, or to developmental disability clinics, or to psychiatry clinics or neurology clinics. The problem is that those programs in Canada are already oversubscribed and they operate as silos. Developmental programs focus on functional deficits rather than etiology. Genetics clinics try to determine etiology, but are not equipped to provide the interdisciplinary assessment needed to establish brain dysfunction. Most people work in only one area. The integration simply is not there, and that is why these clinics have been built. What we are trying to do with the Canada Northwest FASD Research Network is to operationalize this by bringing everyone together in action teams to ask and address questions that will inform policy. We believe that the data, when brought together, can inform policy. We have very little funding, and it is very expensive. We are persisting nonetheless. Most of the people on our teams work for us as volunteers.

The type of questions that we think need to be asked right now are as follows. How much should we increase capacity? Where should new programs be located? Who should staff them? How do we monitor them? Answers to those questions come by analyzing the clinics themselves. Who is on the staff? How much time do they spend? Do they need more time? Could they do it in less time? What is the experience in different places? Are urban clinics different from rural clinics? These data is being gathered as we speak.

Clinics should not be isolated, but rather linked to prevention programs. We need to be able to integrate services, as Audrey McFarlane has done in the Lakeland Centre for Fetal Alcohol Spectrum Disorder. But how do we link clinics to prevention programs when, as Amy Salmon has told us, prevention programs are not necessarily available where the clinics are? We can start by using common forms so that we can all understand the functional diagnoses of patients. We know that there is a laundry list of functional problems, but which ones are the common ones? What are the common treatment recommendations? Are people successful in getting these? Are they available? What do they cost? Those are questions that we could answer now if we had a chance to do so.

What about surveillance? We know that passive surveillance is not working. It did not work 10 years ago, it is not working now, and it is not going to work in 10 years. We can do active surveillance, but there are legal, ethical, and fiscal issues in doing that. Somebody has to be brave enough to sit down in government and say, let's work through this, we need to count this. We do not know what works in intervention, and that information is not going to be available any time soon if we do not evaluate the success of the work that is currently being done. It is a

golden opportunity, but no one funds the demonstration and implementation projects to evaluate themselves in a way that allows us to understand how they are like other similar programs.

As for prevention, again what is missing is the understanding that every aspect of prevention is a piece of a whole. I beg you not to be overly concerned about what the right public health message is and whether people should be told whether they can drink or not drink. That is a small piece of the pie. It is cautioning the low-risk people to be no-risk people. Creating public awareness is extremely important, but we have been listening to people telling us about very difficult populations that need to be reached in effective ways, and that has to be coordinated and counted. We can do that too. This is not beyond us. We just need a chance to get people of good will together to talk about what they are doing and understand it.

In summary, we do not know how to do this work effectively, but we can learn from our shared experience. If we are doing the same things in six months that we are doing today, we have failed. If our practices differ more from each other in six months than they do today, we have not learned from each other's experience. Persistent and sustained effort will make a difference in this field.

## **Clinical**

*Sara Jo Nixon, Professor, Department of Psychiatry, and Director, Biobehavioral Core, Clinical and Translational Science Institute, University of Florida*

I was asked to talk about the kind of research that we need to be doing to inform our next phase of clinical development. As I reviewed the literature, one of the key points that stood out is the challenge of dealing with the hallmark of fetal alcohol exposure, which is heterogeneity of outcome. That heterogeneity is reflected, first, in structure and function dissociation — that is, when a part of the brain is not functioning well, how is that reflected in the neurocognitive behaviour, IQ score, and functional adaptation? I hope that with the development of more sophisticated imaging and related measures, including behavioural measures, we will become better at determining that. Perhaps more fundamental is the dissociation between alcohol exposure and outcome. This is a problem for us, because it interferes with our messaging to pregnant women. In the literature on both animal and human studies, a great deal of attention is given to the quantity, frequency, and timing of alcohol exposure and to the idea of critical periods of fetal development — that if alcohol exposure occurs during this period, the face will be affected, and if it occurs later, the face may not be affected but there will be neurobehavioural outcomes. But no one can say exactly how much alcohol and when. That uncertainty leads us to recommend that no alcohol be consumed during pregnancy, but we all know that there are women who drink at some point during their pregnancy and do not have an affected child. What are we going to do about that? How do we deal with an uncertain dose-response curve?

We see in the literature increasing attention to co-morbid substance use and co-morbid psychiatric disorders. Certainly, we now know that the interaction of tobacco and alcohol is not merely additive, but synergistic, and its outcome for babies is negative. Smoking does not cause

FASD, but it increases the opportunity for a negative outcome; and it does so in a way that may affect placental integrity, child growth and a variety of factors that play to that. If we look at the women least likely to be able to quit drinking while pregnant, a number of them smoke or are exposed to second-hand smoke. We also know that domestic violence may lead to hypoxic episodes that are related to various negative outcomes. These are co-morbid issues that play into the neurobehavioural outcomes that we see. There is growing attention, particularly in animal studies, to the protective effects of dietary supplements. Is it relevant to the human condition that facial dysmorphology is not observed in alcohol-exposed mice when zinc is administered? What does that say about the opportunity for early intervention, even after exposure? We can ask the same questions about choline.

All of this comes down to the issue of fetal risk. For reasons that we do not understand, not all fetuses have the same probability of a negative outcome when exposed to what we know are neurotoxic effects of alcohol. We must indeed come to a better understanding of what fetal risk conditions are. This is particularly true if our desire is to remove the stigma and the blame and to focus on maximizing outcomes for children who may have been exposed to alcohol prenatally.

The second area for research is the development of models. At present, we do not have a particularly good model of neurobehavioural deficits. One thing that always amazes me is that we talk about emotional behaviours, such as mood and temperament, as though they are not behaviours. We look at an individual's neurobehavioural functioning, and here we are talking about math and reading, and we look at adaptation to the world as reflected in mood regulation. Those are all behaviours and they are all moderated and mediated through the brain. All of the actions, outcomes, and areas of deficit or dysregulation are linked to brain damage. None of what we observe says that the disease is not in the brain. Rather, it says that many things are mediated through the brain; and when the brain is exposed to alcohol, there are effects, and those may or may not be the direct effect of alcohol.

We heard in Joanne Weinberg's talk about the need for a systems approach — looking at the stress-diathesis model, for instance, and the implications of that for temperament and other aspects of behaviour. If we are going to model neurobehavioural deficits effectively, we have to ensure that we have the appropriate control groups. If we are interested in the effects of alcohol on the brain, and if we want to examine that separately from attention-deficit hyperactivity disorder (ADHD) and mood disorders, then we need control groups that allow us to dissociate those things. These are expensive studies, but they are the only way to isolate the effects of alcohol from other factors that affect the brain and behaviour.

Another area that we need to look at is our approach to analysis. We very often do endpoint analyses, looking at the IQ and achievement scores; but a more subtle and sensitive measure would be to look at process orientations. Claire Coles has done that in some of her studies, where, for example, the aim is not simply to say that there is a memory problem, but to identify more specifically that the problem lies in the encoding or in some other process. Then, when we narrow it to encoding, we can look further at very specific areas, such as attention. Is it really an



inability to attend to what is relevant, or is it an inability to ignore what is irrelevant? This is not a matter of semantics. It is a matter of differential brain damage and it calls for different interventions.

Next, we need to look at compensatory mechanisms. Instead of skill building — the idea that the individual is bad at math, so we have to do more math — we need to focus on skill substitution. What can help this child to achieve the goal, if, for example, the goal is to go grocery shopping and have enough money but the child cannot add? How do we substitute appropriate skills for those that are not working right? We do not have enough research to help us direct those interventions, and so we go by the seat of our pants.

We need also to identify the links between what we call neurobehavioural deficits and social and emotional skills. We know that they are related. We know that sometimes deficits in particular aspects of cognitive and emotional processing are associated with general areas of the brain. Knowing this, we can move backwards. That is, teachers and others who see these deficits can say, “I need to know if this is related to a brain issue.”

And, finally, we need to look at opportunities for intervention. When we talk about prevention, we talk about prevention through abstinence. If we are going to focus on maximum outcome in these babies, we also need to consider the neurobiology of later intervention. We have to understand that the nervous system is highly plastic and that there are many opportunities to intervene in its development, even after birth. We have often stayed away from that. We have identified the alcohol exposure and looked at the deficits, but we have not done a particularly good job of looking at interventions that would have a direct effect on brain development.

We have an inadequate interface with the growing sciences that could help us address this. The behavioural, developmental, molecular, and cognitive neurosciences have direct impact on the questions we are asking, but people who are doing molecular work or basic behavioural work are often not very interested in FASD. They do not see it as a way to increase their understanding or their contribution to brain research. They think FASD is a clinical question, and yet the two are inextricably intertwined.

So what do we need to do? What kinds of research do we need? We have pointed out that maternal health interventions are essential. Healthy moms have healthier babies. However, we need to be willing to consider the possibility of post-exposure intervention, both in utero and after birth. For instance, we might consider direct fetal intervention if we came to understand that a particular dose of choline could offset alcohol effects and we knew how to administer that choline. Is it reasonable to consider that, or would it give a mixed message about drinking during pregnancy? Following birth, we need to look at neonatal, infant, childhood, and adolescent interventions. It is not over when they are born; in a way, it has only just begun. Considering that the frontal lobes and the connections, the white matter tracks, continue to develop until the 20s, surely we can make better use of that time. We can do that through specific kinds of behavioural interventions; for example, we know that enriched environments help and we know that stability helps. We could also look at specific pharmacological interventions that are known to have

neurotropic effects. This is not particularly popular, and it places the emphasis on the baby rather than on the mother; but if we are serious about not blaming, we have to focus on maximizing the outcome, and our research efforts should do that. It does raise questions of how much, when, and who gets what. There are limited resources, and people are not always in a position to receive those resources. How do we go about making resources that we know work available to a larger or universal population?

In regard to personality and temperament, a question has come up repeatedly about the role of inheritance of related disorders that result in behavioural dysfunction and can arise from either parent. In studies of children of alcoholics who are not themselves alcoholic, we have found that children of alcoholics are prone to having a number of externalizing and internalizing behaviours that are not dissimilar to the problems we have seen in children that have had exposure to alcohol in utero. We must therefore ask, is it the fetal alcohol exposure, or is it the fact that the woman who gave birth to this child is involved with an alcoholic, or she herself is alcohol dependent? It is a tricky question, but one that we need to address. It does not downplay the significance of fetal alcohol exposure; it just says that it is more complex than that. We see similar issues in neuropsychological assessments of impulsivity, behavioural inhibition, frontal lobe functioning, executive function, and even abstraction and planning. We see it neurophysiologically in differential brain activation and, in particular, in brain changes known to be affected in working memory and attentional processes.

The bottom line is that we need a clinical research agenda that integrates the progress we make in animal models with the opportunity to address these questions through clinical trials with humans.

## **Child health and well-being**

*Bruce Perry, Senior Fellow, Child Trauma Academy, Houston, Texas*

I believe that we are well intended, but the concept that we can take this incredibly complex set of problems and, in three days, summarize and come up with consensus recommendations is, with all due respect, a bit arrogant, not that I don't want to be part of that process. What I want to do is share a few things that should be taken into consideration in this process.

The first one is best summarized by this: that the problems of fetal alcohol spectrum disorder are, in my opinion, related to very complex transgenerational issues related to the deterioration of culture. The big elephant in the room is that FASD issues in most of the Western countries have to do with the over-representation of FASD in indigenous populations. There is a gift of insight in this observation, because FASD that occurs in non-indigenous populations is also related to deterioration of past culture and of family and community relationships. When we think about a research agenda, we need to take into consideration the complexities of FASD and recognize that there is not going to be a particularly useful recommendation that is fragmented. Instead of fragmentation, which led to where we are today — the silos of funding, the fragmentation of service delivery programs, the fragmentation of educational models — we have to create more

integrated, relationally sound models of education, research, child rearing and many other things. We have to try to recapture those elements that address our neurobiological need to be interconnected. We need to acknowledge that when we are not interconnected, when this fragments, it creates distress and increases the probability of physical health problems and the likelihood that we will use substances to minimize our stress and deal with our pain. My recommendations are related to this.

The fundamental issues of FASD are intertwined with the brain. All of the manifestations of FASD are manifestations of a brain that has been insulted during development, either directly by alcohol or indirectly through attachment issues associated with early caregiving that is impaired by substance abuse, or through domestic violence that influences the stress response systems, which then cause a cascade of problems in the organization of the brain. It is unbelievably complex and our current models of solving problems in this society are inadequate to deal with it.

Let me give you some visual images that will help you appreciate this challenge. This is a cartoon showing different areas of the brain. As you know, the top is the cortex and the bottom is the brain stem. There are certain very important neural networks that originate low in the brain and have direct connections to all other parts of the brain; and these — dopamine, serotonin, norepinephrine — are not the only ones, but they are some of the most important. This lower part of the brain is organizing in utero, so that developmental insults in utero are going to cause abnormalities in the organization of those networks. Because of the central role that these neurotransmitters play in so many functions and in the development of higher areas of the brain, insults to those parts of the brain result in predictable abnormalities in every part of the brain where they send information. This is part of the complexity of FASD: that alcohol exposure in different doses at different times and in different patterns can lead to completely different functional outcomes.

Going from the simple triangle model of the brain, we have been using a functional approach to create a functional map of the brain. Different functions are mediated by different areas of the brain. The functional map is a gross oversimplification of the neuroscience of the brain, but fundamentally it is accurate. We use this for clinical purposes and some research purposes. Each box corresponds to a function or set of functions. The boxes on the top are neocortical functions, and the boxes on the bottom in the red area are brain stem functions. These include sucking, swallowing, gagging, the fundamentals of attention and tracking of information, extra-ocular eye movements, and so forth.

Tommy Doe, whose brain is represented here, is a child who experienced multiple developmental insults: he was exposed to alcohol in utero, his mother was in a domestically violent relationship, and he was sexually abused when he was older. The little brain boxes on the right have numbers — 12s, 11s, 10s, 9s — and are coloured in. Higher numbers and dark colours mean that that area of the brain is organized and functional; lower numbers and lighter colours mean that it is disorganized and dysfunctional. This gives us a matrix picture of Tommy Doe.

This is a SPECT scan, looking at the neuroimaging of Tommy Doe. Any colour on the brain image indicates something that is at least two standard deviations different from a normal brain. It is either overactive or underactive. The dysfunctions indicated by the colours correspond very closely with those found in the functional assessment that was done.

This is Danny Doe, also with prenatal exposure to alcohol, but with a completely different pattern. You can see what his brain should look like, and you can see dysfunction in multiple domains of the brain and the neuroimaging that corresponds with that. This is Jane Doe, affected by prenatal exposure to alcohol and then other cascades of developmental problems. Each of these children, now young adolescents, had been in and out of the special education and mental health systems and given multiple diagnoses — the story that you all know. Only as an afterthought did people say, “Fetal alcohol exposure may be a factor here.” These children’s problems had never been linked to prenatal exposure to alcohol, even though I would argue that alcohol played a significant role in their dysfunctional presentations.

Part of the problem that we face is that these children can walk in the door of the education system, the mental health system, and the juvenile justice system, and at each place they are formulated in the context of the frame of reference, the forms, and the outcome measures that that system uses. They all get inadequate care, because we treat fragments of kids; we treat one part of the brain. We look at Tommy Doe’s stress response systems and see that they are abnormal, his capacity for abstract cognition is abnormal, his self-esteem is abnormal, his psychosexual development is abnormal, his fine motor control is abnormal. And we say, “Fine motor control is abnormal? Oh, you’d better go over to the occupational therapy division.” “Psychosexual/social development is abnormal? You’d better go see the shrinks; we do not do psychosexual here.” “Abstract cognition is abnormal? Clearly, you have to go see somebody in special education.” We fragment these kids. We try to solve their problems in fragments; we do our research in fragments. Everybody here has talked about the need for integration. That would be a brilliant thing. The only way that we are going to solve these problems is by reversing the entire frame of reference that led to these problems, fragmentation.

All of these things are done in the context of ongoing clinical service delivery. These are not research. We will use the data to get a broader picture of these problems and to track the outcomes and the efficacy of the things that we are doing to change a part of the brain. We’ll see whether or not the occupational therapy is going to change the fine motor control parts of the brain. We’ll see if the mental health services are going to change self-esteem. We’ll see if the music and movement therapies are going to improve balance and coordination. We use a standardized assessment process, but what we do with each one of these kids is develop an individualized intervention plan.

My recommendations are the following. We need to integrate research, education, and service. All of the service delivery programs, all of the wonderful things that are going on, need to have elements of both research and capacity-building. We need to have more people in every discipline who understand these things better — who understand development, who understand

risk, who understand attachment issues — and we will do this only if we stop fragmenting. We have schools of social work, we have schools of medicine, we have schools of law, and we all are the blind men feeling this elephant. We've got to take off our blinders and see that we will never have solutions to complex problems unless we develop a more integrated capability.

Many good things can come out of that. Many people who do service delivery are afraid of research. "You are going to do experiments," they say. "You are going to dehumanize." But that is not true. You can do research in a very humane and sensible way. It is immoral to do service delivery in a resource-depleted world when you do not have the ability to comment on what you are doing and self-correct. I don't care how great your program is, it could get better. There are parts of what you do that probably are not very effective, and you can stop doing them; and there are probably parts that are very effective and you can enrich them. We have to build in the capacity to self-correct. Government has to demand that in new programs.

That has to be in combination with a research plan. There has to be some approach to the way we take what we know and use it to effect change. One of the sad things is the way in which data are starting to be used to de-fund programs, the way data are being used in a socio-politically selective way to maintain the status quo and resist change. It is very interesting, for example, that in the mental health field, psychopharmacology is not subject to the same standards of evidence that are applied to cognitive-behavioural interventions or animal-assisted therapies or the use of music and movement. The fact is that there is no evidence for almost any of the psychopharmacology in children. Most of the evidence is the product of drug-company-funded studies that are tainted.

I am not saying that data are not important. They are essential. But we also need to know what to do with data. We do not need to do a study on every single aspect of every single condition of every single age group. We have to be able to do a reasonable study and make plausible extrapolations. If we are not allowed to do that, there would not be enough money in the federal budget of the United States if every dollar were dedicated to child mental health research to study every single aspect of every single problem that needs to be looked at in order to address issues in FAS. We have to look not only to research studies for useful, truthful input, but also to the wisdom of the elders in the Aboriginal community. We have to look to common sense. We have to look to things that are working, and if we have a concern that there is not enough data, we need to have a way to measure and then comment on it in a couple years. We do not need to stop it and then say, "You can have the money back after you prove that it works."

## **Jury questions and answers**

*(Sterling Clarren, Sara Jo Nixon, Bruce Perry)*

**Lee Ann Weaver-Tyrrell** – Dr. Perry, thank you for giving such an appropriate address at the conclusion of the session. Thank you.

**Raisa Deber** – Regarding the research that was mentioned, particularly to validate some of the diagnoses and treatments, how much is in the pipeline now that one might expect could be used and how much is going to have to be set up and started?

**Sara Jo Nixon** – The issue is that we need to develop conceptual models that will allow us to build integrated studies that would link the animal and the human work directly. Obviously, we cannot do in human studies what we can do in animal studies, and right now a great deal of meaningful work for the human condition is being done with animal models. What we need is a strong statement that this is the kind of research that we want to see. We want to see integrated, innovative work that will go beyond developing another catalogue of deficits and will instead focus on intervention, on strengths, and on things that could be used more effectively.

**Raisa Deber** – Is there evidence, for example, that choline and zinc could be safely added to prenatal vitamins and all women encouraged to take them, or is there a potential risk?

**Sara Jo Nixon** – The bottom line is that obviously we need more studies. We do not know what the safe dose is. We do not know the best way to administer it. We cannot administer it in the way we administered thiamine: put it in everything and wait for things to get better. We don't have the answer, but we can get that answer. That's the point. This is an answerable question.

**Malcolm King** – There is a clinical trial going on in choline supplementation, looking at outcomes in normal children. They should have an answer in about a year or so.

**Sterling Clarren** – People have been hoping for 30 years that the studies of basic mechanisms would lead to a simple fix. We all pray every day that one of these things is going to turn out to be the magic bullet that we need. In the meantime, we need to keep doing what we are doing. We cannot just hope the fix will be found. We have to do both at the same time. We have to do the human things we can do now, while we hope for the medical intervention in the future.

**Christine Looek** – In taking on Bruce Perry's comment about embedding research-accepted outcome measures into service delivery, how can we build into our clinical programs ways to link research that supports or helps us understand what we are doing? Sterling Clarren talked about linking clinical diagnosis with prevention. We need to talk about surveillance. How do we make partnerships to do that?

**Bruce Perry** – Whenever we are doing clinical work or consulting with people about program development in clinical areas, we always encourage them to create an information-management model, to use standardized questionnaires or metrics that are resonant with the clinical mission, and to ensure that staff are taught how to use these instruments in a way that is clinically sensitive. You can do your clinical work and at the same time gather data in a way that, over time, will allow you to understand the broader population, not just the children that you work with. The clinics of most academic centres have a process of assessment and ongoing charting that incorporates elements that would be appropriate for tracking outcomes. I think that we have to get better at that in non-academic settings. A network would help us design the template that

we should be using. You can modify or you can add; but the template would define the core information that you should be gathering in a systematic way.

**Sterling Clarren** – Going back to quality assurance and management concepts, there are some human issues that need to be understood. Everyone thinks they are very busy. Most people think they are busier than their co-workers. Most people do not want any more change in their lives. When we attempt to effect change in a system top down, that is the resistance that comes back up. When trying to develop new systems, as we are doing here, what we found most effective in western Canada was recognizing that the early adapters are those at the bottom who understand that there is an issue and want to try to do things differently. If you can capture their experience, you can then motivate other people to change. I think this is an endless, ongoing experiment that is human-based and not system-based.

**Bruce Perry** – One of the reasons we developed that functional brain map was to provide a useful tool to the clinicians, families, and foster parents. Rather than having the research-based assessment elements feel intrusive, the maps were actually helpful and they liked them. Directing thought to that kind of thing is always important. We are asking people to make a cultural shift when we ask them to implement some of these things.

**Malcolm King** – The presenters have made a strong case for integrated interdisciplinary research, networking, and so on. That makes a lot of sense to me, as I am now a funder in a sense. Sterling Clarren, you said that you need to double capacity for evaluation and that you would probably need to triple it, or more, in order to do the catch-up required to handle the people who have not been evaluated. Is that feasible?

**Sterling Clarren** – I don't think we know how much capacity we need for these very complex kids. It is very safe to say that we are enormously under-resourced at the moment. I think that challenges us to do two things. One is to make sure that what we are doing is right. Understand what it costs and understand how we do it before we increase capacity. That's just good planning. At the same time, we need to be working with people that have new ideas, because their ideas could change the way we do business. I would like to respond to one other very important question, which is why should this be FASD-specific? This kind of interdisciplinary complex evaluation of the brain is necessary for a subset of the population as a whole, and I'm sure that a large percentage of those kids are affected by alcohol. Alcohol, therefore, is an effective driver for getting this started. In western Canada, we already know that the way to get into clinic is to have a history of alcohol exposure and a longstanding history of mysterious maladaptation. That's all it takes. In 70% of the cases we find organicity, and that's important. If you do not have alcohol as a marker, you find that there is a much lower percentage of organicity and you have a lot of professionals asking why those children are in clinic. From a pragmatic point of view, if you are interested in helping this very difficult population that is very expensive and very much in need of help, using alcohol as a marker is a practical way to do this. Having said that, should this be limited to people exposed to alcohol? Of course not. We have a long way

to go to understand this. Unless we start collecting data, we aren't going to be any smarter in five years.

**Malcolm King** – Dr. Nixon, were you suggesting that high-risk women who continue to drink during their pregnancy should be given a choline supplement and, since they likely wouldn't take it, you would have to inject it in a time-released form. Is that what you are suggesting, and is that feasible?

**Sara Jo Nixon** – I am saying that if the focus is on the baby, then we have to focus on what would improve the brain capacity of that baby whom we know has been exposed. Can we demand that someone take choline? Can we somehow put a time-release capsule under the skin? I think there are more fundamental questions that have to be asked before we can address that. We have to know whether we are willing to go that route. Where is the line drawn? That is what an integrated research program could do for us.

**Malcolm King** – So you would have to include ethicists on the team?

**Sara Jo Nixon** – Absolutely.

**Rebecca Martell** – Dr. Perry, I'd like to thank you for acknowledging the inherent knowledge and wisdom of First Nations people and the importance of relationship. Myles Himmelreich also spoke to relationship when he talked about the importance of finding his birth family and sustaining connections with his adoptive family and community. Dr. Clarren, will it be possible for First Nations communities to determine their own prevention strategies — for example, on-the-land activities that develop cultural competency, when the programming is not evidence-based?

**Sterling Clarren** – It is an enormous and very important question. Developmental medicine, as you and many people on the jury know, was invented in the 1950s and 1960s by a small group of people who recognized a need to support people with disabilities. It was largely funded by the United States government through the National Center for Child Health and Development. They built three brick buildings, one in Baltimore, one in Boston, and one in Seattle, to do interdisciplinary diagnosis, with the thought that people would then take this diagnosis into the community and there would be all manner of interventions ready to help. The model has not been challenged, and there has been very little work done to see if it works outside of dense urban centres. Western Canada is a wonderful workshop for testing the theory and fetal alcohol is a great topic with which to test it. I think what we are trying to do with children is get them ready for their life, and if the life of folks on reserve or in the north looks different, there is nothing invalid in that; we should be getting them ready for that kind of a life. It might be that the interventions are much simpler, much more effective and quite different. It's all part of organizing more data: You don't have any evidence on that? Well, we don't have any evidence either, so we might as well collect it together.

**Edward Riley** – Is the network that is set up now similar to what a national registry for this part of Canada would be like?



**Sterling Clarren** – A registry collects names and opportunities for people to do research. This is much more active data gathering. We have asked the 40 clinics in Canada to provide us with their data shells. Even though they were collecting over 3,000 pieces of data per child in clinic, most of that data was shredded at the end of clinic, and what was kept could not be compared by a computer. Over the last 18 months, we have worked to develop a common data form that is now computer-ready. Alberta has volunteered to be the pilot site over the next three months, to be followed closely by Manitoba and then the Yukon. We are working with every single clinic in Alberta to see that they like the form, that they understand the questions, and that it is organized to meet their needs. It will be a rich source of information and will give us opportunities to look at antecedent issues before you get to these kinds of clinics: what are the functional diagnoses and what are the treatment opportunities? There will be about 1,000 children a year. The plan is to do a similar collection of information on the Mother Mentoring programs, the Canadian Parent-Child Assistance Program (PCAP) model, as well as among the determinants of women's health groups. It goes way beyond a registry. We hope to create a data set that can be mined.

## **Audience questions and answers**

**Audience, Frank Oberklaid** – As a non-FASD person, I would like to challenge some of these assumptions. The data worldwide suggest that 20% of children have some sort of developmental behavioural issue that gets in the way of their function, and within the 20% there might be 4, 5, 6, or 8% that are severe. If you categorize those, there are literally dozens of categories and comorbidities. It makes no sense to me, with respect to Sterling Clarren, to set up separate programs for each one of them. I'm not saying that children with FASD do not deserve a comprehensive assessment and intervention. Of course they do. But so do children with autism, and cerebral palsy, and mental health problems, and child-protection problems; and there will never be enough resources to set up separate programs for these, nor should there be, because there is significant overlap among these conditions. Yes, we need research into etiology and more research into pathways and interventions, but it seems to me that every one of those 20% of children needs what you are proposing for children with FASD. They need a good comprehensive assessment, done holistically, not categorically. In my country, and the literature suggests this is true worldwide, systems of care set up outside the mainstream are always under stress. Mental health, disability, and child protection systems are always in trouble. There are never enough resources. There's burnout among staff. No matter how much money you pour in, it's never going to make much of a difference because these children and families still have things in common that all children and families need, and they need something else. It is very important that we do not fall into this trap of 'more,' this Mencken's thing — that for every complex problem, there is a solution that is simple, neat, and wrong. I don't think the answer is doubling or tripling the number of programs or clinics. It is thinking differently about how we manage those children. Every one of those children deserves comprehensive assessment.

**Sterling Clarren** – I'm a big fan of Mel Levine, and he talks about doing brain profiles on all of us. All of us have a pattern of strength and weakness. One of the things that Mel Levine says that

I love is that most of us, after we leave high school, never have to deal with our deficits again. We pick a pathway where we can live mostly within our strengths. I think Frank Oberklaid is right that 20% of the population as a whole have a pattern of weakness that is increasingly less easy to avoid acknowledging. But we still help only the people who are at the bottom, who have so many deficits that they cannot make it on their own. It isn't 20%. I don't exactly understand what Frank is saying. I work in a developmental clinic, as he does. He has set up a cerebral palsy program; he has set up an autism program; he has set up a cranial-facial program. He has set up a number of programs because that is a functional way to deal with a large volume of patients with like needs. A lot of people who work with fetal alcohol have found that it is simply so that the team we need and the group of people that we work with is somewhat unique. Having said that, I couldn't agree more with what Frank Oberklaid said. I worry, too, about FASD diagnosis. It doesn't make any sense to me as a doctor to have an etiologic clinic, except that it pragmatically helps us get started. I don't know how many of these very complex assessments we need, but the whole group of people with diffuse brain damage is not being served by his clinics or by mine. We have absolutely ignored this population since we stopped using the phrase "minimal brain dysfunction" in 1964. And this population has been suffering, and everyone who sees them feels their pain. That is the human issue we are dealing with here. I am willing to throw out everything we have built if we have a better model tomorrow, but I don't want this to be misunderstood and to abandon the population again, thinking we are serving them, when we are not.

**Audience, Claire Coles** – I want to comment that there is in fact a study going on in the Ukraine in which women using alcohol are receiving choline supplements. There is no outcome data yet, but if all goes well, there will be.

**Sara Jo Nixon** – Claire, has there been a problem in compliance?

**Audience, Claire Coles** – I'm not the one running it. Tina Chambers is, and she tells me that the women are taking the choline supplements, something like ten pills per day. But they are apparently taking them because they are doing blood work to determine whether it is going into the blood. This study is going on at present, and we will see how it will turn out.

## General Final Conference Questions and Answers

**Audience** – I come from a small northern community. Our goal this year was to diagnosis, and we were given the funding to diagnose 12 children. The pediatrician in my community does 10 a month. Our capacity needs to be broadened quite a bit.

**Audience** – I, too, come from a small northern rural community. I have worked in FASD prevention, intervention, and support for the past 19 years. We have many professionals come as new graduates into our community to practice as social workers, teachers, nurses, probation officers, RCMP. They stay with us for one or two years and then go off to another community. What I'm doing in my community work is trying to educate people so that we are all on the same page, and it baffles me that still to this day we are graduating people who don't have any

understanding of fetal alcohol exposure, yet the population they are working with is over-represented by people who have FASD. I want the jury to come up with a plan or a recommendation so that universities include this in their curricula in a meaningful way, so that when practitioners come into the field they know what they are doing.

**Audience** – I, too, subscribed initially to the social model of social disability. My background is in developmental disability: I have a master’s degree in community rehabilitation and social work and a PhD in education. What I have learned from 8 years of practicing with adults with developmental disabilities and 16 years of work in child welfare is that children with FASD present a very unique complexity. These are often children without a voice. With other disabilities, families, foster parents or substitute caregivers often will act as a voice and an advocate for the person with the disability. We find that people with FASD do not have that voice; they do not have that advocate. I interviewed birth mothers for my doctoral dissertation and one of them phoned me before I was finished my research to ask if I would come to court with her. I asked what was going on. Her children, ages 15 and 16, had been re-apprehended by the system. She said she had nobody to come with her, and would I come? I had to go back to ethics to get clearance to go to court with this birth mother. I watched in the courtroom as the lawyer for child welfare, the system I used to work for, took every opportunity to shame, blame, and degrade that mother. For me, that was a real insight. She was doing the best she could. The kids had run away, but they had come home the following week. We put in all these resources because we are mad at these women, we are mad at these kids, we are mad at people around them that contribute to their problems, and it is unfair. I have to echo what Sterling Clarren said. I do not agree that this is a disability that does not need a unique response. It does need a unique response. Everyone in this room is evidence to that. I have one other point in relation to post-secondary education: I myself created a course in the Faculty of Social Work in 1999, before I was teaching full-time at the university. I have had both undergraduate and graduate students and at least 100 cross-disciplinary students who have taken that course as part of their social work, nursing, or other program degree. It is better when it is cross-disciplinary and people bring different things into the mix. I agree that it is important for students in social work, child welfare, case work, youth, and child care to have this education, but it is just as important for everybody else. We need to increase the infrastructure to provide that education to everyone out in the field, at least to impart knowledge about the distinctions in case management.

**Anne McLellan** – Question for Gail Andrew. What I would like to know is, based on everything you have heard and based on all these recommendations — and the jury will certainly not be able to adopt them all — if you had the opportunity to identify one recommendation that you would like us to take up and deal with seriously in our consensus report, what would it be?

**Gail Andrew** – I was just reflecting on my opening comments. I started this conference thanking the scientific experts who have informed my work and the people and families with FASD who have informed my practice, and talking about the need for us to be the voice and the advocate for this group, because often they don’t have enough energy at the end of the day to be a voice and

an advocate. I think that has been weaving through the whole of the two days' proceedings. I don't think I could identify a recommendation in one area, but in each of the three pillars — diagnosis, intervention, and prevention — there might be one.

In the diagnostic pillar, I would look at having consistency in the diagnostic approach that focuses on functional assessment that has meaning for life, at whatever stage of life that individual is, and for that assessment information to be connected directly with appropriate intervention services that will translate that into action, so that it will not be simply a list of words. That would connect the diagnostic piece and the intervention piece. In intervention, I think we need to keep in mind that we don't have best practices: we have promising practices. We need to establish a consistent way of identifying what the outcomes are, and the outcomes should be functional; and then we need a common set of evaluation tools so that we can evaluate that over time. The third pillar is prevention. As Sterling Clarren illustrated, in the Canada Northwest FASD Research Network we have three prevention pillars. If I had to pick one, I would pick the work with the high-risk mothers, the mentorship program. At the end of the day, those are the mothers that are giving us most of the children, and if I have only a few million dollars, I'm going to put it there. Then hopefully the other parts of prevention will fall into place.

## **Jury chair reads the consensus statement (see Appendix 2)**

### **Questions and discussions after the reading of the jury's consensus statement**

**Anne McLellan** – I am going to call on Malcolm King to inform you of two small but important changes that the jury worked on this morning, but did not have time to add to the text as you have it.

**Malcolm King** – These are additions that we think are particularly important because they identify the need and rationale for a statement about the Aboriginal population. Under Question 2 (“Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?”), we would like to add the following at the end of the first paragraph: *“There is Canadian data that indicates greater prevalence in rural communities, foster care systems, juvenile justice systems and Aboriginal populations.”* We heard that very clearly in this conference. Then, that continues, *“The high prevalence in the Aboriginal population is symptomatic of historical and multi-generational trauma associated with events such as the residential school system.”* The recommendation associated with these statements belongs in Question 5 under Lifelong Services. There, we would like to add a fourth recommendation, as follows: *“There should be special attention and support for Aboriginal people affected by FASD who have experienced societal breakdown due to historical and multi-generational trauma.”*

**Dan Dubovsky** – I greatly appreciate the work of the jury. In the 35 years that the terms FAS and FASD have been recognized, it has been very difficult to come to consensus, and the expectation that all of you would be able to do that in two and a half days is remarkable. I have three things

to add. The first has to do with gathering data, but also with providing appropriate care. There needs to be a requirement that those in systems of care ask about prenatal alcohol exposure. This question should be asked routinely in all intakes, whether it be in the health, corrections, mental health, or child welfare systems. Secondly, I think there are physicians in Canada and the United States who are still telling women that it is okay to drink during pregnancy. A specific point needs to be made in the prevention section about reaching physicians to ensure the delivery of a clear zero-alcohol message. Finally, in research, there needs to be a requirement that part of all research on interventions is looking at who does not do well with that intervention, why they are not doing well, and how we can help those individuals to succeed. One of the problems we have in looking at evidence-based practices is that no evidence-based practice works with 100 per cent of people. It is often those who have an FASD that get lost in the evidence-based practices.

**Jury member** – I think that last point is a good one. It not only applies to research on FASD, but is a very good general comment about how we do, or fail to do, the best that we can in health research in general. We often fail to look at those who do not respond well to treatments.

**Sterling Clarren** – I served on the group that wrote the book for the Institute of Medicine. We spent a year and I do not think our recommendations were as good as the ones you have made. It is an unbelievable job that you have done in the last couple of days and my hat is off to you.

One point seems to have been either missed or ducked. There is a huge discrepancy between the number of people in Canada who may have FASD and the very limited capacity of the quaternary diagnostic approach. We are going to need some leadership by quaternary clinics to determine how the rest of the healthcare system can help deal with this. There will have to be sharing and a parametric system of applying what we learn from the severe cases to dealing with the rest of these kids. All of that is yet to be planned. I do not see a reference to that conundrum in any of the references. Maybe you would consider that point.

**Christine Looock** – Would you please elaborate? Are you discussing issues of capacity building, and could you word that for us? We did struggle with putting more policy on capacity into the research section.

**Sterling Clarren** – The point is that always, with any condition, a group of programs is on the cutting edge, trying to figure out best practices and working with the hardest cases. There has to be a mechanism for expanding from those clinics, which will always be somewhat isolated, to dealing with more patients in the broader system. At this point, doctors have a limited capacity to deal with the complexity of FAS and so all assessments need to be referred to very complex quaternary clinics. That would be fine, except that we have 1,500 places for those assessments and 300,000 people who might need diagnosis. We must find an appropriate way of expanding care. I do not think that we can dump complex diagnoses on family physicians. It is not fair. Neither can we refer 300,000 people to 1,500 slots. Screening is not going to make it better. If we screen without diagnosis, we will label people with a screening test. It is very scary. This is something that needs to be developed over time.

**Raisa Deber** – I am uneasy about the use of the term ‘screening.’ In fact, I am going to ask that we modify it, because that usually implies looking at an asymptomatic population with no particular risk factors. That is putting the cart before the horse. Screening and assessing asymptomatic people who are not presenting a problem, as opposed to getting services to people who are already in some distress, would not be a good use of resources. I do not think we are anywhere close to justification for screening, as opposed to early identification and assessment.

**Gail Andrew** – I want to comment on that. You mentioned surveillance and getting better data, but until we have a more consistent and rigorous diagnostic process and greater diagnostic capacity so that we can better estimate the true numbers of cases, we cannot even begin surveillance. I think they are interconnected. We may need to have a layered approach — to develop, through training or mentoring emerging diagnostic teams, a level two capacity that is more community based.

**Frank Oberklaid** – I would also like to congratulate all of you on this document. I think it is beautifully written and captures what I understood as the essence of the past couple of days. I also want to address the issue of screening. There is a science of screening, and screening for this condition is not supported by science. In the recommendations under Question 2, the wording is “*a simple and consistent screening process.*” I suggest replacing that with the following: “*reliable methods of early detection of developmental disability, including FASD, should be introduced into early school years and be available throughout the lifespan.*” This captures the intent but avoids the clash with the science of screening and early detection.

**Jury** – Thank you. Our intent was to recommend methods of early intervention that would be inclusive of all children who have developmental disabilities and developmental delays, including children with FASD. Thank you for finding a better wording of the recommendation.

**Anne McLellan** – I am sure you all appreciate that in fine-tuning this document we perhaps sometimes did not express what we were trying to achieve in as felicitous a way as possible, so any assistance you have in that regard is gratefully accepted.

**Nancy Poole** – I agree with Dan Dubovsky that the statement about physicians’ responsibility to discuss substance use with women could be strengthened, but I particularly want to do some fine-tuning in recommendation number nine of the prevention section, where you say “*increase the number of women-centred alcohol-dependency treatment beds.*” A great deal of work has been done lately to help women remain in their housing while they come for day treatment. It is a very effective way of ensuring that women do not lose their housing when they come to extended treatment and it offers many opportunities for serving their children as well. Therefore, instead of saying “*beds,*” I wonder if it could say “*alcohol treatment programming and beds,*” so that it is a little wider and we are acknowledging the fact that there are many ways to achieve treatment other than bricks and mortar. I think it is important to leave beds in there, because we can use those, but we need to widen it.

Another thing I wish to comment on is that the conclusion seems focused on those affected by FASD. I would like to see another sentence in the conclusion that acknowledges that we have a great deal of work to do to prevent this disability, as well as to support families and communities living with it.

**Anne McLellan** – In a number of places in the conclusion we presumed that the general included a commitment to prevention, so I take your point. We can certainly add a sentence to focus directly on that. I would not want people to think that in the conclusion we walked away from prevention.

**Nancy Poole** – Great, yes. My concern is about limiting the discussion to “*those living with and affected by FASD*,” such as when you talk about the need for a multi-sectoral approach.

**Christine Looock** – Would you be comfortable adding, as a second sentence after the statement that the lifelong services must be improved, a further statement that “*Ongoing prevention efforts must be expanded*”?

**Nancy Poole** – Yes. Thank you very much.

**Delegate** – Thank you very much for your recommendations. One of the things that makes FASD unique is that parents of children with developmental disabilities do not usually keep having children with the same disability. However, that is the case with FASD, because of the substance-use problems. I thank you for appreciating the uniqueness of FASD and the need for expanding our models.

**Myles Himmelreich** – I want to touch on two things in two different areas. One, as a professional, I would like to say thank you for the work you have done. I very much appreciated that in the conclusion you wrote, “*Government ministries and health systems owe it to everyone to fund and develop programs to explore new ways to help families, researchers and service providers....*” As you know, at the end of the day it does come down to money to fund these programs and that requires acknowledging the importance of and need for these programs, so thank you very much for that.

As an individual with FASD, I would also like to say that we need to be spoken to. I think that many times, and not on purpose, professionals speak over us, they speak about us, they speak around us, they speak for us, but not to us. We need to be heard. We need to let you know what supports we need. I have worked in this field for a while and I have lived with this for quite a while and I have found that some of the best supports are activity-based programs. They were very important for me, and for five or so years I have been running activity-based programs for adults with FASD. These programs give them an opportunity to be in a group where they feel normal and are able to do such things as go bowling. One of the activities that we do with groups is to present a plate of food that is covered and then give everyone play money and ask them to bid on the food. They do not know what it is — whether it is cake or just a glass of water — and at the end of the activity we touch on money management. So they are having fun and it is activity-based, but it is also developing skills. They are learning, but they are learning in new

ways. As we know, we need to find different ways to work with individuals with FASD. Maybe that could be included in the Education and Training section under Question 5, on how to support individuals. It is very important that we support and listen to these individuals and not get caught up in the idea that “We should do this for them, and we should do that for them and point them in that certain direction.” Look back at the people who are holding your hand, and see what path they need to go down.

**Anne McLellan** – We tried to capture a little bit of that in the Education and Training section in Question 5, but I think you are right. We need to accentuate the fact that when one develops an individualized plan, part of individualization is talking to the person affected with FASD and making sure that it truly is an individualized plan based on that person’s aspirations and skills and challenges.

**Mary Kate Harvie** – In the Legal section of Question 5, you have recommended that outcomes be improved and cost be reduced by the utilization of an alternative measures program. I think that is a fabulous concept, but I have a couple of comments about the way in which the recommendation is worded. You limited it to adults and I would invite you to consider including both youth and adults in that. I know that there are already some provisions for alternative measures in the Youth Criminal Justice Act, but I think the more we can emphasize the need for early intervention with youth, at as young an age as possible, the greater the likelihood of success.

I would also invite you to consider whether or not you want to limit alternative measures programs for adults to those with first offences. I say that because if we have learned anything from our experiences with related problem-solving courts — mental health courts, drug treatment courts — it is that there are not very many first offenders who are being diagnosed as adults. If they are in the criminal justice system as adults, they have probably been bumping along in it for a number of years. I also invite you to consider whether you want to limit it to nonviolent offences. I say that because, in other problem-solving courts, alternative measures programs have had significant success with individuals who have a history of criminal activity, sometimes violent offences, but who have the support of family and in other ways meet the criteria of program. I think you might want to consider wording this in a more general way to allow individual programs to screen appropriate people without limiting participation to either first offenders or nonviolent offenders.

**Anne McLellan** – We had a lengthy discussion about the wording of that particular recommendation. As you have noted, it was drafted in such a way that it speaks only to adults, because the youth justice system does have its own measures for diversion out of the system — or even within the system, as exemplified by the program you are running in Manitoba. So this was an attempt to provide direction to courts as they deal with adults. Marguerite, do you want to say anything in relation to this?

**Marguerite Trussler** – We did limit it to adults and to first offences, because we knew that for young offenders there is already the capability of using alternate measures. At the moment, there



is no ability to use alternate measures programs in dealing with adults and so we wanted to add that for adults. We limited it to first offences mainly to make it more politically saleable, knowing that on second and third and fourth offences you can still take FASD into account in the sentencing and that there are ways to ensure that these people are not incarcerated. But on the first offence, it would automatically go to an alternate measures program, and there would be no discretion for those who are laying the charges to do anything else.

**Mary Kate Harvie** – What we are finding is that alternative measures programs and diversion programs are applied very differently from province to province. I would encourage you to consider including something about this, simply because it would be an added incentive. In the mental health courts and drug treatment courts, sometimes even in situations of domestic violence, the court says, “Get them into the diversion program if it is going to help,” because that is what we want at the end of the day.

**Marguerite Trussler** – Maybe we could add another paragraph, because I do not think we should be dealing with young offenders the same as we are with adult offenders.

**Anne McLellan** – Yes, we could work on that.

**Delegate** – I, too, thank the panel. This is an amazing achievement and I think we are all proud to be part of the process. I would like to build on Myles Himmelreich’s comment about listening to people with FASD. With respect to your comment about individualized education plans, I wonder if somewhere we can work in a statement about focusing on “*skill development, inclusion, participation and recognition of existing strengths.*” Right now, the document does not recognize that that is a very important part of education planning.

**Anne McLellan** – Yes, thank you. Mary?

**Delegate, Mary Berube** – Anne and members of the jury, I would like to thank you for the tremendous amount of effort you have put into this. Donna Debolt and I are both social workers, and it is rare to see two social workers cry throughout an entire policy statement. I have never done that before. I have the enormous privilege of having parented two young men who are now in their mid-30s, who are both of First Nations ancestry and who both have FASD. That has inextricably bound me to three categories of people: the First Nations people in our country, whom I have learned to treasure through my work with Health Canada; persons with FASD, for whom I of course have a huge heart; and the birth mothers, with whom I was privileged to participate in the Parent-Child Assistance Program (PCAP). I am also a social worker, and all of those parts of my life collided this morning when you read this document. The tremendous amount of integrity, effort, and professional expertise that is collected in this room is a huge comfort when I think back on those years and struggles. It honours all of those people who worked so hard for so many years to make sure that we paid attention to people like Myles; and it honours First Nations people, in respect to whom it was said so beautifully that the fragmentation of the brain that FASD represents also represents fragmentation in some of our First Nations communities. I offer to you our heartfelt thanks for taking this so seriously and for

offering us comfort and encouragement, because, more than anything else, all of this effort is also about human tears and human cost. It is not just a piece of paper. And you have done that. Somehow, you managed to write that into this, and I so appreciate that. Thank you very much.

**Anne McLellan** – Thank you.

**Richard Amaral** – I commend all of the jury members and the speakers. I have been working the field of FASD, running a prevention program on a reserve near Calgary and this is by far the best conference I have attended. I want to thank everyone for that. I, too, believe in the value of research because, as Sterling Clarren pointed out, it can lead to quality improvement. However, I know that in many First Nations communities the term ‘research’ has a very negative connotation. This has to do with the quantitative methods often used in conducting research. I am thinking about how some of the people on the reserve love to tell stories. Storytelling is the way they impart knowledge; and there are many research methods, such as conducting interviews, that are based on storytelling. So, in Question 6, recommendation number nine, I recommend that “*embed research and evaluation into programs and services...*” be changed to “*embed culturally appropriate research methods and evaluation into programs and services.*” This field has grown a great deal, mostly because of quantitative research, but I want to point out that there is also value in collecting and analyzing stories, rather than analyzing only the numbers.

**Anne McLellan** – Good point.

**Malcolm King** – I certainly agree with the point, and we will try to incorporate it in that section. I am not sure that recommendation number nine is the exact place that I would like to put it, because Sterling Clarren’s point, which is what this was based on, is to make research an integral part of programs and services. But it definitely needs to be there and we will find an appropriate place to bring it in.

**Raisa Deber** – There is a truism in research that the singular of data is anecdote. You have to be extremely careful. I absolutely grant that the qualitative is important, but I have seen too many studies in which a couple of anecdotes are used in a rather self-serving way to push money to particular groups who are trying to sell products for profit. We have had that happen on occasion with the use of pharmaceuticals. I think it is important that we have rigorous research, rather than throw money into unproven and potentially hazardous interventions. So I would want to have the rigor there, particularly if researchers are going to be administering products.

**Delegate** – I agree. I am thinking of the point of view of the mothers, what the mothers can provide.

**Anne McLellan** – You are not suggesting that evaluation and research should not be rigorous. You just want to ensure that it is culturally appropriate.

**Delegate** – Exactly.

**Jury** – I think Malcolm King and I have found a place above where we will add “*culturally and community appropriate*,” recognizing that there is a science and rigor to participatory action research and the involvement of the community voice.

**Delegate, Marilyn Van Bibber** – I would like to commend the jury and their work, and thank them for recognizing the barriers that we face as First Nations. I work in the field of social work, too, and want to give you an example. There is a First Nations family — elderly people in their 60s — who have guardianship of a child from their extended family. You can see the effects of fetal alcohol syndrome in this child, and yet they could not get the support needed because when they took the child for diagnosis, they were told the child did not have FASD.

I want to thank everyone here for listening to our pleas and for feeling the pain that we have experienced for what seems like centuries. We have a long way to go and we need supports in our communities and we need to be heard in our government. I want to advocate for our youth, because they are the ones who are suffering. I suffered too, in the residential school, and at home from violence and alcohol abuse, and I made a promise one day. I said, “I will never raise my children in the way I was raised.” And one day I had a child and what did I do? I did the same thing. Until my conscience pricked me and said, “Where is the promise you made that you will never raise your children in this environment?” And I started searching, and that is when I began to heal.

There is hope for us, but we need more people who have healed. Sometimes when you work in the field of social work, the hopelessness is great. I want to thank Myles Himmelreich and to congratulate him for coming this far. He is from Bigstone Cree Nation and I know his family very well and recognize his features and character. I invite him to come to our community when the Bigstone Cree Nation has its gatherings to discuss the work that we are doing in different departments.

I feel blessed to be here. It has been healing for me just to listen to you. I brought foster parents from my community, because they are dealing with children who have FASD. Some of the words are too high for them to understand, as they have not been to university. But they love and care for our children and it means so much to me for them to be here and to listen to this discussion of FASD. I am grateful to go home with this knowledge and to be able to invite Myles to our First Nations community, because he can help our youth in the schools. I can sense what the youth are going through, because I have been through it. I am a living example, I have been through the system, and I understand where they are coming from. Thank you all.

**Anne McLellan** – Thank you.

**Delegate, Dorothy Hennevel** – I manage some FASD-intervention programs and I want to echo what Richard said about research and to link it to what Marilyn shared with the group. When I started engaging in research to evaluate our programs, I wrestled with such questions as: Where is the voice of our clients and families? And who owns this information? Is it a bunch of people with PhDs in the university? I found two things very helpful that informed that practice. One is

Aboriginal health research ethics, which hold that if research is community-based, it is owned by the community. And the second thing that I found extraordinarily helpful is to have a community-based perspective. That means having longer-term funding, because research cannot be one-off, for a year or two. It requires years and years of engagement in the community. When Lola Baydala presented, I noticed that some of the elders in her community were in the room. Her work is an excellent example of community-based research, which I think can inform the broader spectrum so that we are not talking just about mouse brains, but about community engagement.

**Anne McLellan** – Thank you.

**Delegate** – I want to thank you for responding to the issue of cultural sensitivity in relation to Aboriginal communities and to echo the speaker before me in saying that family and community are of critical importance. I would like to underscore a comment in the paper in relation to services for mothers and children together. In child welfare, we do not have models that support women and children coming together in treatment. I would like women to be able to regard child welfare as an agency to turn to for help, rather than one to run and hide from because they are afraid their children will be taken away. If we shift our thinking about child welfare and the way we educate child welfare workers, that will make a difference. Another key point is that mentorship is required for children, adolescents, and adults, and I think the mental health system can be a support in that regard. My final point is in relation to adult diagnosis. The University of Calgary has worked with the Public Health Agency of Canada to translate a paper reporting on an environmental scan of adult diagnosis and the state of evidence of adult diagnosis in FASD. That is one area that we have not had the opportunity to talk about. It is another missing piece in the policy infrastructure. That paper will be coming out in French with English translation on the Public Health Agency of Canada website.

**Anne McLellan** – Thank you.

**Delegate** – I want to go back to Question 4, “How can FASD be prevented?” In the Canadian Prevention Framework, which describes four levels of FASD prevention, number two is “discussing alcohol use with all girls and women of childbearing age.” The recommendation that it be mentioned in schools is fantastic, but I also wonder about increasing the capacity of healthcare providers, including physicians, nurses, and midwives, to do that. Studies in Alberta have shown that healthcare providers are not comfortable discussing alcohol use with women who are pregnant, but we also know that they are the people that women are going to in order to get that advice. So I wondered about increasing that capacity in post-secondary institutions, medical schools, nursing schools, and midwifery colleges, as well as perhaps providing some screening tools that the literature has shown to be effective.

**Anne McLellan** – Is your focus here physicians and other primary healthcare professionals, and the fact that we need to provide them with the tools to be able to more comfortably and appropriately ask the right questions?

**Delegate** – Yes.

**Anne McLellan** – I think we tried to capture that, probably in recommendation number seven, but maybe we did not do it quite as clearly as we could have. Take a look at seven.

**Delegate** – I did. And I wondered if that point could be strengthened a little bit.

**Anne McLellan** – I think that is what we were trying to get at. Look also at number one of Education and Training. It says, “*Educational instruction and materials should be provided to promote awareness, understanding and knowledge of best practices for those who are or will be working with people affected by FASD.*” We could sharpen the focus there a little bit, too.

**Delegate** – That would be great. Thank you.

**Delegate** – My name is Angela and I am from the Métis Settlement General Council. A key component of education that is missing is that teachers in our educational system should have understanding and awareness of FASD. I think this should be a part of the teacher-training curriculum. After all, they are the ones who are providing education to our children, and many teachers today have a very huge gap of understanding in regard to FASD. Another point I want to make is that when you are talking about Aboriginal cultures, please be aware that there are three distinct Aboriginal groups: First Nations, Métis, and Inuit. Thank you.

**Anne McLellan** – Absolutely.

**Delegate** – I noticed that when you referred to provinces, you did not include territories. I am assuming that is just an oversight.

**Anne McLellan** – It certainly is an oversight, that is for sure. We apologize for that.

**Delegate** – In the third recommendation in Question 3, you talk about development of consistent standards between provinces. Another thing to note is that the regions of Canada are very different and we need the flexibility to provide programs that respond to the needs of our communities. We need to have some consistency, but also flexibility. Second, it might be useful to think of this in the context of disability policy in Canada generally, where we talk about full citizenship and inclusion for people with disabilities. You might consider couching the supports for people with FASD in that kind of language, as the rights of full citizenship. Finally, I suggest adding to the recommendations on page nine a statement that speaks to the need to recognize and build on the strengths of people with FASD and their families, caregivers, and communities. We have heard a great deal about taking a strengths-based approach and recognizing and valuing the strengths of people, and I think that adding something like that would strengthen this document.

**Anne McLellan** – I think we heard a similar concern from someone earlier about adding the recognition of existing strengths of those affected by FASD. I think we can add that. Leave it to us, as to where we put that in.


## Appendix 1: Conference Program

**Jury Members**  
Hon. Anne McLellan,  
Chair  
Judith Bossin  
Jennifer Crippen  
Raine Deter  
David Elton  
Mark Hatori  
James Hees  
Malcolm King  
Christine Looch  
Rebecca Martell  
Ed Riley  
Marguerite Trussler  
Lee Ann Weaver-Tyrell

**Expert Speakers**  
Gail Andrew,  
Expert Chair  
Susan Aclley  
Dorothy Badry  
Lola Baydala  
Brenda Bennett  
June Bergman  
Mary Berube  
Elizabeth Brodberg  
Sharon Brimhall  
Linda Burnside  
Albert Chudley  
Sterling Clavon  
Claire Coles  
Dan Dubovsky  
Ben Gliboff  
Mary Kate Harrie  
Myles Himelstein  
Phil Jacobs  
Diane Mullan  
Philip May  
Audrey McFarlane  
John McLennan  
Sara Jo Nixon  
Frank Oberkald  
Bruce Perry  
Nancy Poole  
Amy Salmon  
Ricki Tharmer  
Suzanne Tough  
Joanne Weinberg  
Nancy Whitney

**Final Program**

**IHE Consensus Development Conference on**  
**Fetal Alcohol Spectrum Disorder**  
**(FASD) – Across the Lifespan**



**October 7 to 9, 2009, The Westin Edmonton, Edmonton, Alberta**

**IHE** **INSTITUTE OF**  
**HEALTH ECONOMICS**  
HEALTH CANADA

**Government of Alberta ■**



Public Health  
Agency of Canada

Agence de la santé  
publique du Canada

The conference organizers gratefully acknowledge the support  
provided by the Public Health Agency of Canada.



## Message from the Ministers of Children and Youth Services and Health and Wellness

On behalf of the Government of Alberta, welcome to the 2009 Institute of Health Economics (IHE) Consensus Development Conference on Fetal Alcohol Spectrum Disorder (FASD): Across the Lifespan.

More than 23,000 Albertans have FASD. The social and economic impacts of the disorder directly or indirectly touch every Albertan. That's why the Alberta government is committed to developing and delivering community-based FASD prevention and treatment programs and services; providing education and training opportunities for those with FASD, their caregivers and their support networks; and supporting research on FASD.

This unique conference features a range of leading national and international experts who will present scientific evidence on FASD to a broad-based, independent panel in order to develop practical recommendations on how to improve prevention, diagnosis, and treatment of FASD. It is a valuable opportunity to hear from diverse stakeholder groups, including professionals, families and service providers, all working or living with individuals affected by FASD.

By participating in this event, you will increase your knowledge on emerging practices in prevention, intervention, care and support of individuals affected by FASD. You will also hear about developments in the field of FASD that are expected to have a positive impact on people affected by FASD in the future.

Thank you to the Institute of Health Economics, conference organizers, partners and sponsors who have helped make this event possible. Working together, we will make positive changes in communities and give hope to those affected by FASD, their families and their caregivers.

More information about FASD services, supports, research and education is available on the FASD Cross-Ministry Committee's website at [www.fasd-cmc.alberta.ca](http://www.fasd-cmc.alberta.ca).



James Tarachuk  
Minister, Children and Youth Services



Ron Liepert  
Minister, Health and Wellness

**Government of Alberta** ■



Welcome to the IHE Consensus Development Conference on Fetal Alcohol Spectrum Disorder (FASD) – Across the Lifespan. The event's unique "jury trial" format features leading experts presenting evidence on FASD to a distinguished jury of citizens and policy experts. Your participation will give you the opportunity to learn about FASD and the policy challenges posed and to join in the debate by asking questions of leaders in the field. You will learn about emerging practices in prevention, intervention, care and support of individuals affected by FASD.

## About FASD

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe the range of disabilities caused by prenatal exposure to alcohol. Along with Spina Bifida and Down Syndrome, FASD is one of the top three known causes of developmental delay in children in Canada. Health Canada estimates that approximately nine in every 1,000 infants are born with FASD.<sup>1</sup> It is a life-long condition that has no cure and is 100% preventable.

Individuals with FASD may require extensive support and services related to health, social services, education and training, justice, addictions, and family supports throughout their lives. Without supports, an individual with FASD may experience a number of secondary disabilities and negative outcomes including homelessness, unemployment, involvement in the criminal justice system, mental health problems, school drop out, inappropriate sexual behaviour, and family and placement breakdown.

According to estimates, each child with FASD may require as much as \$2 million in special care, supports and/or supervision during his/her lifetime. During their lifetimes, individuals with FASD now alive in Canada will cost taxpayers about \$600 billion.<sup>2</sup>

The cost of FASD goes far beyond the financial implications. Other costs include: loss of human potential and employability; services that do not build on an individual's strengths due to a lack of understanding of FASD; and the burden FASD puts on families, caregivers and society in general. Research has shown that a significant number of individuals in the criminal justice, child protection, health and disability systems have FASD.

Providing effective prevention programs and treatment and supports for people affected by FASD is a priority for health policy makers and health care providers in Alberta.

The *IHE Consensus Development Conference on FASD – Across the Lifespan* is an opportunity to consult with experts, to learn why babies continue to be born with FASD and how best to support people affected by FASD, to develop consensus on the most relevant factors, and to tailor interventions to address those contributing factors.

<sup>1</sup> British Columbia, Ministry of Children and Family Development website, retrieved June 10, 2009 from [www.mcf.gov.bc.ca/fasd](http://www.mcf.gov.bc.ca/fasd)

<sup>2</sup> FASWorld Alliance website, retrieved June 10, 2009 from [www.fasworld.com/aboutfasd.asp](http://www.fasworld.com/aboutfasd.asp)

## About the Consensus Development Conference format

The PURPOSE of a consensus development conference is to evaluate available evidence on a health issue and develop a statement that answers a number of predetermined questions. The panel of experts will present evidence to the "jury," which is an independent, broad-based, non-government, non-advocacy group. The jury will listen to and question the experts. The audience will also be given an opportunity to pose questions to the experts. The jury then will convene each evening to develop the consensus statement, which will be read to the experts and the audience on the morning of the final day. The statement will then be widely distributed in the Canadian health care system and to those working in fields related to FASD.

The GOAL of this conference is to develop, in the form of a consensus statement, practical recommendations on how to improve prevention, diagnosis, and treatment of FASD. Across the Lifespan.

The specific questions to be addressed are:

1. What is Fetal Alcohol Spectrum Disorder (FASD) and how is it diagnosed?
2. Do we know the prevalence and incidence of FASD in different populations and can the reporting be improved?
3. What are the consequences of FASD for individuals, their families and society?
4. How can FASD be prevented?
5. What policy options could more effectively support individuals with FASD and their families across the lifespan?
6. What further research into FASD is needed?

### Expert Chair

Dr. Gail Andrew (MBCM FRCP(C), Member, Board of Directors, Canada Northwest FASD Research Network, Medical Site Lead – Pediatrics, Medical Director – FASD Clinical Services and Pediatric Consultant, Pediatric Programs, Glenrose Rehabilitation Hospital) will lead the panel of experts in presenting available scientific evidence on FASD to the jury during public sessions.

### Jury Chair

The Honourable Anne McLellan, QC (former Deputy Prime Minister and federal Health Minister) will lead a distinguished panel of citizens and experts to develop a consensus statement with practical policy recommendations based on these questions.

## Program accreditation

The program is accredited by the following professional organizations:

Canadian College of Health Service Executives

*Attendance at this program entitles certified Canadian College of Health Service Executives members (CHE/Fellow) to 6 Category II credits toward their maintenance of certification requirement.*



Royal College of Physicians and Surgeons of Canada

*The Division of Continuous Professional Learning at the University of Alberta has approved this as an Accredited Group Learning Activity under Section 1 of the Framework of Continuing Professional Development options for the Maintenance of Certification Program of the Royal College of Physicians and Surgeons of Canada.*

The College of Family Physicians of Canada

*This program meets the accreditation criteria of The College of Family Physicians of Canada and has been accredited by the Alberta College of Family Physicians, for up to 13 Mainpro-M1 credits.*

## Learning objectives

The purpose of the conference is to develop a consensus statement on how to improve prevention, diagnosis and treatment of Fetal Alcohol Spectrum Disorder (FASD).

After attending this conference, participants will be able to:

- define FASD and outline how it is diagnosed;
- identify the prevalence and incidence of FASD in different populations;
- outline ways the reporting of FASD can be improved;
- describe the consequences of FASD on individuals, families and society;
- explain how FASD can be prevented;
- suggest policy options that would more effectively support individuals with FASD and their families, across the lifespan; and
- articulate the additional FASD research that is needed.

## Conference Planning Committee

**Egon Jonsson**, Executive Director and CEO, Institute of Health Economics

**Amanda Anyofte**, Project Officer, Alberta Children and Youth Services

**Mary Serube**, Director, Intergovernmental Initiatives, Alberta Children and Youth Services

**Laurie Beavertley**, Executive Director, Community Treatments and Supports, Alberta Health Services

**Jewel Buksa**, President, BUKSA Conference Management and Program Development

**Corinne Frick**, Program Director, Alberta Perinatal Health Program

**Tara Hanson**, Director of Operations, Alberta Centre for Child, Family and Community Research

**Bradon Hirsch**, Acting Director, Community Partnerships, Alberta Services and Community Supports

**Marty Lundrie**, Interim Executive Director, Peadarheiler's Lodge

**Rhonda Lothammer**, Communications Manager, Institute of Health Economics

**Thanh Nguyen**, Health Economist, Institute of Health Economics

**Julie Peacock**, Director, Primary Care, Children and Youth Interventions, Alberta Health Services - Addiction and Mental Health

**Nancy Reynolds**, President and Chief Executive Officer, Alberta Centre for Child, Family and Community Research

**Kesa Shikaze**, Project Manager, Healthy Living, Alberta Health and Wellness

**Rob Skrypnok**, General Management Consulting

**John Sproule**, Senior Policy Director, Institute of Health Economics

**Melissa Wulfsberg**, Executive Assistant, Institute of Health Economics

## Scientific Committee

**Gail Andrew**, Member, Board of Directors, Canada Northwest FASD Research Network; Medical Site Lead - Pediatrics, Medical Director - FASD Clinical Services, and Pediatric Consultant, Pediatric Programs, Glenrose Rehabilitation Hospital

**Jane Bergman**, Associate Professor, Department of Family Medicine, Faculty of Medicine and Dentistry, University of Calgary

**Sterling Clarrin**, Chief Executive Officer and Scientific Director, Canada Northwest FASD Research Network

**Corinne Frick**, Program Director, Alberta Perinatal Health Program

**Denise Milne**, Senior Manager, FASD Initiatives/Children's Mental Health, Alberta Children and Youth Services

**Hannah Puzderka**, Director of Research, CASA Child, Adolescent and Family Mental Health

**Nancy Reynolds**, President and Chief Executive Officer, Alberta Centre for Child, Family and Community Research

**John Sproule**, Senior Policy Director, Institute of Health Economics

**Bonnie Stonehouse**, Coordinator, Program Development for Persons with Disabilities, Alberta Services and Community Supports

**Melissa Wulfsberg**, Executive Assistant, Institute of Health Economics

## Communications Committee

**Roxanne Dabel Collins**, Public Affairs Officer, Alberta (Children and Youth) Services

**Rhonda Lothammer**, Communications Manager, Institute of Health Economics

**Jewel Buksa**, President, BUKSA Conference Management and Program Development

# Conference program

All sessions will take place in the Manitoba/Saskatchewan Ballroom

## Conference Moderator

Nancy Reynolds, *President and Chief Executive Officer, Alberta Centre for Child, Family and Community Research*

## Wednesday, October 7, 2009

7:00 a.m. – 8:00 a.m.

**Breakfast and registration, North Foyer**

8:00 – 8:50 a.m.

### Opening remarks

The Honourable Iris Evans, *Minister of Finance and Enterprise*

The Honourable Janis Tarchuk, *Minister of Children and Youth Services*

8:55 – 9:55 a.m.

### Question 1: What is Fetal Alcohol Spectrum Disorder (FASD) and how is it diagnosed?

#### Overview of FASD

Gail Andrew, *Member, Board of Directors, Canada Northwest FASD Research Network; Medical Site Lead – Pediatrics, Medical Director – FASD Clinical Services and Pediatric Consultant, Pediatric Programs, Glenrose Rehabilitation Hospital*

#### A personal perspective

Myles Himmelfreich, *Director of Programming, Canadian FASD Foundation*

#### Jury question and answer

9:55 – 9:55 a.m.

### Question 2: Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?

#### Prevalence and Incidence in Alberta and Canada

Suzanne Tough, *Scientific Director, Alberta Centre for Child, Family and Community Research*

#### Prevalence and Incidence internationally

Philip May, *Professor of Sociology and Professor, Family and Community Medicine, University of New Mexico; Senior Research Scientist, Center on Alcoholism, Substance Abuse, and Addictions*

#### Jury question and answer

9:55 – 10:15 a.m.

**Break, North Foyer**

10:15 – 12:00 noon

## Question 2 continued

### Extent and impact on child development

Ben Gibbard, *Developmental Pediatrician, Alberta Children's Hospital; Assistant Professor, Department of Pediatrics, Faculty of Medicine, University of Calgary*

### Prevalence of FAS in foster care

Susan Astley, *Professor of Epidemiology/Pediatrics, University of Washington; Director, Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network*

### Genetic pre-disposing factors

Albert Chudley, *Medical Director, Winnipeg Regional Health Authority Program in Genetics and Metabolism; Professor, Department of Pediatrics, University of Manitoba*

### Direct and indirect mechanisms for alcohol damage to the brain

Joanne Weinberg, *Professor and Distinguished University Scholar and Acting Department Head, Cellular and Physiological Sciences, University of British Columbia*

### Jury question and answer

12:00 p.m. – 1:00 p.m.

## Lunch, Devonian

1:00 – 2:00 p.m.

## Question 3: What are the consequences of FASD on individuals, their families and society?

### Economic implications

Philip Jacobs, *Professor, Gastroenterology Division, Department of Medicine, University of Alberta; Director of Collaborations, Institute of Health Economics*

### Consequences on the community

Mary Boruba, *Director, Intergovernmental Initiatives, Ministry Support Services Division, Alberta Children and Youth Services*

### Impact on system usage within foster care

Linda Burnside, *Executive Director, Disability Programs, Manitoba Family Services and Housing*

### Jury question and answer

2:00 – 2:25 p.m.

## Break, North Foyer

2:25 – 3:30 p.m.

## Question 3 continued

### Co-morbidities with mental health for an individual with FASD

Dan Dubovsky, *FASD Specialist for the Substance Abuse and Mental Health Services Administration (SAMHSA), FASD Center for Excellence*

### Consequences on the community supporting adults with FASD

Diane Malbin, *Executive Director, Fetal Alcohol Syndrome Consultation, Education and Training Services (FASCETS Inc)*

### Jury question and answer

## Conference program

2:20 – 4:20 p.m.

### Question 4: How can FASD be prevented?

#### Pre-conception initiatives

Lola Baydala, *Associate Professor of Pediatrics, University of Alberta*

#### Inventory of primary prevention campaigns

Robin Thummeier, *FASD Resources Researcher, Saskatchewan Prevention Institute*

#### Primary care physician perspective

Jane Bargman, *Associate Professor, Department of Family Medicine, Faculty of Medicine and Dentistry, University of Calgary*

#### Jury question and answer

## Thursday, October 8, 2009

7:00 a.m. – 9:30 a.m.

### Breakfast and registration, North Foyer

8:00 – 8:15 a.m.

#### Opening remarks

Gail Andrew, *Expert Chair*

8:15 – 9:40 a.m.

### Question 4 continued

#### Mentoring programs for at-risk mothers

Nancy Whitney, *Clinical Director, King County Parent-Child Assistance Program, University of Washington*

#### Strength and support: A woman's perspective

Amy Salmon, *Managing Director, Canada Northwest FASD Research Network; Clinical Assistant Professor, School of Population and Public Health, Faculty of Medicine, University of British Columbia*

#### Prevention of FASD: A broader strategy in women's health

Nancy Poole, *Research Associate, British Columbia Centre of Excellence for Women's Health; Research Consultant, Women and Substance Use Issues, British Columbia Women's Hospital*

#### Jury question and answer

9:40 – 10:00 a.m.

### Question 5: What policy options could more effectively support individuals with FASD and their families across the lifespan?

#### Educational system, parental, and community support

Frank Oberklaid, *Director, Centre for Community Child Health, Royal Children's Hospital and Professor, Pediatrics, University of Melbourne*

#### Shifting responsibility from the individual to communities of care

Audrey McFarlane, *Executive Director, Lakeland Centre for Fetal Alcohol Spectrum Disorder*

#### Education policy

Elizabeth Bredberg, *Education Consultant, Bredberg Research and Consulting in Education*

#### Jury question and answer

10:30 - 11:00 a.m.

**Break, North Foyer**

11:00 a.m. - 12:25 p.m.

**Question 5 continued**

**Development of life skills: education, parenting, and family mentoring**

*Claire Coles, Professor, Department of Psychiatry and Behavioral Sciences and Pediatrics, Emory University School of Medicine; Director, Fetal Alcohol and Drug Exposure Clinic, Marcus Autism Center, Children's Health Care of Atlanta*

**Life stages and transitions**

*Brenda Bennett, Executive Director, FASD Life's Journey Inc.*

**Social services and corrections**

*Sharon Brintnell, Professor, Department of Occupational Therapy, and Director, Occupational Performance Analysis Unit, Faculty of Rehabilitation Medicine, University of Alberta*

**Jury question and answer**

12:30 - 1:00 p.m.

**Lunch, Devonian**

1:25 - 2:40 p.m.

**Question 5 continued**

**Treatment for FASD**

*John McLennan, Assistant Professor and Child Psychiatry Consultant, Departments of Community Health Sciences, Psychiatry, and Paediatrics, University of Calgary*

**Justice issues**

*Mary Kate Harvie, Associate Chief Judge, Provincial Court of Manitoba*

**Policy development in FASD**

*Dorothy Badry, Assistant Professor, Faculty of Social Work, University of Calgary*

**Jury question and answer**

2:40 - 3:00 p.m.

**Break, North Foyer**

3:00 - 4:30 p.m.

**Question 6: What further research into FASD is needed?**

**Health and social policy**

*Sterling Clatten, CEO and Scientific Director, Canada Northwest FASD Research Network; Clinical Professor of Pediatrics, Faculty of Medicine, University of British Columbia; Clinical Professor of Pediatrics, University of Washington School of Medicine*

**Clinical**

*Sara Jo Nixon, Professor, Department of Psychiatry, University of Florida, Clinical and Translational Science Institute, Biobehavioral Core*

**Child health and well-being**

*Bruce Perry, Senior Fellow, The ChildTrauma Academy*

**Extended jury question and answer**



## Conference program

### Friday, October 9, 2009

8:00 – 9:00 a.m.

**Breakfast and registration** North Foyer

9:00 – 9:30 a.m.

**Reading of the consensus statement**  
The Honourable Anne McLellan, *Jury Chair*

9:30 – 10:30 a.m.

**Open discussion**

10:30 – 11:00 a.m.

**Closing remarks**

The Honourable Anne McLellan, *Jury Chair*

Gail Andrew, *Expert Chair*

Egon Jonsson, *Executive Director and Chief Executive Officer, Institute of Health Economics*

# Jury members



## Jury Chair Anne McLellan

L.L. King's College,  
University of London,  
Alberta Institute for American  
Studies, University of Alberta; Academic Director  
and Distinguished Scholar in Residence, Institute for  
United States Policy Studies

The Honourable A. Anne McLellan, P.C., O.C., joined Bennett Jones LLP in its Edmonton office July 4, 2006. Ms. McLellan provides strategic advice to the firm and its clients. Ms. McLellan serves on the Board of Directors of Nexen, Agrium, Cameco and the Edmonton Regional Airport Authority. She also sits on the boards of the Royal Alexandra Hospital Charitable Foundation and Habitat for Humanity Edmonton Society. Among her many community commitments, she is also involved with the Canadian Blood Services Organ and Tissue Donation and Transplantation Steering Committee. She is a member of the Premier's Council for Economic Strategy where she provides "guidance on actions the Alberta government can take to best position the province for the future."

On May 12, 2006 she was appointed Distinguished Scholar in Residence at the University of Alberta in the Alberta Institute for American Studies. In 2007 the University of Alberta awarded Ms. McLellan an honorary doctorate of laws degree and in July 2008 Ms. McLellan was appointed an Officer of the Order of Canada.

Ms. McLellan served four terms as the Liberal Member of Parliament for Edmonton Centre from October 25, 1993 to January 23, 2009. She served as Deputy Prime Minister of Canada and the first Minister of Public Safety and Emergency Preparedness (December 2003 to January 2006), Minister of Health (January 2002 to December 2003), Minister of Justice and Attorney General of Canada (June 1997 to January 2002) and Minister of Natural Resources and Federal Interlocutor for Métis and Non-Status Indians (November 1993 to June 1997).

She holds a Bachelor of Arts and a Law degree from Dalhousie University and a Master of Laws degree from King's College, University of London. Ms. McLellan was admitted to the Bar of Nova Scotia in 1975.



## Judith Bossé

DAV, MSc, Associate Assistant  
Deputy Minister, Public Health  
Agency of Canada

Dr. Bossé received her veterinary degree from the Faculté de médecine vétérinaire, University of Montreal, followed by a Master of Science degree in clinical science from the University of Sherbrooke. After joining Agriculture Canada in the late 1980s as a research scientist, Dr. Bossé served in multiple policy analyst functions. She moved in 2000 to the Canadian Food Inspection Agency (CFIA), filling senior management responsibilities in which she implemented and optimized national programs on prevention and surveillance, and promoted research development on many national public health issues. In 2006, she assumed an advisory role to the president of the Université de Québec en Outaouais on health and life science academic programs. In May 2009, she joined the Public Health Agency of Canada as Associate Assistant Deputy Minister responsible for the Health Promotion and Chronic Diseases Branch. Throughout her career, her focus has been in fostering partnerships and alliances within and outside of governments for enhanced synergies to maximize results for Canadians.



## Jennifer Coppens

BSc, Medical Student,  
University of Alberta

Jennifer Coppens is a third-year medical student at the University of Alberta. She completed her BSc at McGill University in Microbiology and Immunology.



## Raisa Døber

PhD, Professor, Department of  
Health Policy, Management and  
Evaluation, Faculty of Medicine,  
University of Toronto

Raisa Døber, PhD (MPT), has lectured, mentored, published and consulted on health policy at local, provincial, national and international levels. Professor Døber's current research centres on Canadian health policy. Current projects, conducted with colleagues and students, include: implications of the distribution of health expenditures and public/private roles for financing and delivery of health services; examination of where nurses and other health professionals work, and the factors associated with differential "stickiness" across sub-sectors; issues associated with the movement of care from hospitals to home and community, and approaches to accountability. She is the director of the CHRT team in Community Care and Health Human Resources.



## David Elton

PhD, President, Nelson  
Foundation and Max Bell  
Foundation

Dr. Elton is President of both the Nelson Foundation and the Max Bell Foundation. He is a Professor Emeritus of Political Science, University of Lethbridge and the past President and Director Emeritus of the Canada West Foundation, a public policy think tank. David is the co-founder and former Chair of Philanthropic Foundation Canada, and is a Director of the Arthur Chisholm Foundation and the Alberta Centre for the Child, Family and Community Research.

## Jury members



### Mark Hattori

Acting Assistant Deputy  
Member, Program Quality and  
Standards, Alberta Children and  
Youth Services

Mark Hattori has over 20 years of experience in the field of services to children and families. In 2001, he was the Acting CEO of Diamond Willow Child and Family Services Authority (CFSA) and became CEO of the Central Alberta CFSA when it was formed in 2003. He was recently appointed Acting Assistant Deputy Minister of the Program Quality and Standards division of Alberta Children and Youth Services. Mr. Hattori has a degree in Social Work from the University of Calgary.



### James Hees

Reporter

James Hees is an award  
winning Edmonton

journalist. For the past 25 years his body of work has often focused on social issues. This year, his audio series "Million Dollar Babies" concentrated on the challenges of those with Fetal Alcohol Spectrum Disorder and the societal cost of failing to help them. The 10-part series provided insight into the difficulties faced by people with FASD in such areas as education, the justice system and employment. He also examined ways to deal with FASD and how to prevent it.



### Malcolm King

PhD FRCP Professor,  
Department of Medicine,  
University of Alberta. Scientific  
Director, CH-R Institute of  
Aboriginal Peoples' Health

Dr. Malcolm King is a health researcher at the University of Alberta and since 2001 has been the founding Principal investigator of the Alberta ACADRE Network, a training program for Aboriginal health research funded by the CH-R Institute of Aboriginal Peoples' Health. A member of the Mississaugas of the New

Credit First Nation (Ontario). Dr. King obtained his doctorate in polymer chemistry from McGill University in 1973. After an initial faculty appointment at McGill University, he moved to the University of Alberta in 1985, and was promoted to Professor in the Department of Medicine in 1990. In 2007, he was appointed Adjunct Professor in Public Health, where he co-leads the development of an indigenous public health research training program.

In his career in pulmonary research, he has developed new approaches to treat mucus clearance dysfunction in cystic fibrosis and chronic obstructive lung disease, and is now working on addressing the issues in disease transmission by bioaerosols. He served as Chair of the Faculty of Medicine and Dentistry Aboriginal Healthcare Careers Committee from 1993 to 2009; this training program has graduated more than 70 health professionals. Dr. King served as President of the Canadian Thoracic Society in 1999/2000, and from 2003 to 2004 was a member of the Governing Council of the Canadian Institutes of Health Research. Since January 2009, he has served as the Scientific Director of the CH-R Institute of Aboriginal Peoples' Health. He has been recognized for his achievements by the Alberta Lung Association (1990), the National Aboriginal Achievement Foundation (1999) and the University of Alberta Board of Governors (2003).



### Christine Lookock

MD FRCP, Clinical Associate  
Professor, Department of  
Pediatrics, Faculty of Medicine,  
University of British Columbia,  
Developmental Pediatrics,  
Children's and Women's Centre of British Columbia

Dr. Christine Lookock MD, FRCP, is a developmental pediatrician at Children's and Women's Health Centre of British Columbia, including Sunny Hill Health Centre for Children and BC Children's Hospital. She is an Associate Professor in the Department of Pediatrics, Faculty of Medicine, University of British Columbia (UBC). Dr. Lookock obtained her

MD from Harvard in 1981 with subspecialty training in pediatrics at the University of Washington and UBC. She did fellowship training in Genetics at UBC and was a Fellow in Medical Education at the Harvard Macy Institute, Harvard Medical School in 1996.

Early in her training, she developed an interest in "Social Pediatrics," advocating for innovative approaches for health service delivery to vulnerable children and families. Her clinical and research work has been focused on children and youth with congenital conditions and developmental disorders, including Fetal Alcohol Spectrum Disorders (FASD). She has been a co-investigator on numerous research studies on FAS and other drug effects on children and young adults, including the pioneering studies with Drs. Julie Conry and Diane Paul on identifying youth with FASD in the justice system.

In 2000 Dr. Lookock was invited to sit on Health Canada's first National FAS Advisory Committee, and was subsequently appointed to its sub-committee on Diagnosis and Screening in October 2001. She is the co-author of the Canadian Medical Association's 2005 publication "Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis." She was on the Board of Directors for the Canadian Centre on Substance Abuse (CCSA) from 2000 to 2006. Her credentials as an expert witness on FAS have been accepted in the Provincial and Supreme Courts of British Columbia.

She has received many awards, academic, athletic and in teaching including the 2002 Outstanding Canadian Immigrant of the Year Award from the Canadian Bar Association, Immigration Lawyers Section for her work on FASD. In 1996 she earned the Southern Methodist University (SMU) Distinguished Alumni Award, followed in 2004 by the Silver Anniversary Mustang (SAAW) Award for distinguished service 25 years after graduation. In 2005 she became an Honorary Alumna of the UBC Faculty of Medicine.

## Jury members



**Rebecca Martell**

Clinical Associate, Faculty of Rehabilitation Medicine, University of Alberta

Of Indigenous ancestry, Ms. Martell is a member of Watkins Lake First Nation. With a background in the field of Native Addictions, her work in the area of Fetal Alcohol Spectrum Disorder began with Dr. Jane Stenius in 1975. Ms. Martell continued her commitment to the prevention of FASD through her position as Executive Director of the Alberta Indian Health Care Commission (1985-1989), as well as a Board Member with A Centre for Women and Equal Society in the 1990s. In 2000, Ms. Martell was appointed to the National Advisory Committee on Fetal Alcohol Syndrome and participated as a member of the NACFAS National Working Group: Reaching At-Risk & Previously Unreached Populations with Fetal Alcohol Syndrome. Since that time, Dr. Martell has had the privilege of participating as a member of the Alberta Aboriginal Committee on Fetal Alcohol Spectrum Disorder.

As a Clinical Associate with the Occupational Performance Analysis Unit (OPAU), Department of Occupational Therapy, University of Alberta (1996 to present), Ms. Martell collaborates on a variety of community-based projects. These include Connections to Community (C2C), a Fort Saskatchewan Correctional Centre program that supports and transitions Aboriginal female inmates to the community upon release, as well as the development of Connections & Connections to Community (C2C), a Fort Saskatchewan Correctional Centre-based FASD diagnostic clinic and transition program for male inmates. As an OPAU Clinician, Rebecca also provides seasonal lectures focused on *Cultural Reflection on Being, Doing and Feeling with Occupational Therapy students*. Ms. Martell is a frequent seasonal lecturer to a number of post-secondary programs at the University of Alberta, University of Wisconsin Eau Claire and Trent University Department of Indigenous Studies, as well as Northern College Practical Nurse Program, Kwantlen College Aboriginal Child & Family Services Program and Niche Training, Research & Health Promotions Institute.



**Edward Riley**

PhD, Distinguished Professor, Psychology, Director, Center for Behavioral Teratology, San Diego State University

Edward P. Riley (Ph.D., 1974, Tulane University) is currently a Distinguished Professor in the Department of Psychology and the Director of the Center for Behavioral Teratology at San Diego State University. He has authored over 225 scientific papers and reviews and served as Chair of the U.S. National Task Force on FAS/FAE from 2000-2004. He currently serves on the Expert Panel for the SAMHSA FASD Center for Excellence. He has served as President of the Research Society on Alcoholism, the Fetal Alcohol Study Group, and the Behavioral Teratology Society. He is currently a Reviewing Editor and on the Editorial Board of *Alcoholism: Clinical and Experimental Research* has served on several Editorial Boards. He has received numerous awards for his scholarship and service including the Research Society on Alcoholism Distinguished Researcher Award and the National Organization on Fetal Alcohol Syndrome Research Recognition Award. His work on FASD has been continually funded by the National Institute on Alcohol Abuse and Alcoholism since 1978.



**Marguerite Trussler**

Chairperson, Alberta Liquor and Gaming Commission

The Honourable Marguerite Trussler was appointed Chairperson of the Board of the Alberta Gaming and Liquor Commission in 2007. Prior to that appointment she was a Justice of the Court of Queen's Bench for 20 years. While on the Court she served as the Chairperson of the Family Law Committee of the Court, as a member of the Editorial Board of the *Canadian Bar Review* and as President of the Canadian Chapter of the International Association of Women Judges. Although she heard a wide range of cases as a judge, her particular interest was the effects of divorce on children and what could be done to protect them. She has spoken internationally on this subject. She currently serves as Chairperson of the Provincial AIDS Advisory Committee and Chairperson of the Victoria School Foundation for the Arts.



**Lee Ann Weaver-Tyrrell**

PhD, BSc, MEd, LLB, Child Health Researcher, Lee Ann (Weaver) Tyrrell Corp.

Lee Ann Weaver-Tyrrell obtained her nursing qualifications at the Regina General Hospital in 1963. She completed her BSc in Nursing at the University of Alberta and taught pediatric nursing from 1965 to 1970. She returned to the University of Alberta to complete her law degree in 1981. She articulated with the law firm of Miller and Steer and worked for the Attorney General Amicus Curiae program for two years.

In 1984, she became the Director of Child Welfare for the Yellowhead Tribal Council's child welfare program, the Yellowhead Tribal Services Agency. Her goal was to work with the First Nation children. Following this, she was executed by Alberta Family and Social Services for policy planning and contract management. She retired from this position and became Project Manager for the start up of a new biotechnology company, KMT Hepatoblast.

For many years, Lee Ann has been a legal guardian and co-ordinator of care for a child with a developmental disability. She has served on the board of the Hope Foundation and is currently a board member for CAGA (Child Adolescent and Family Mental Health) and the Board of the TD Canada Trust Friends of the Environment.

Lee Ann's long term interest in the welfare of children has been demonstrated by her nursing experience and legal practice that have focused on children.

# Speakers & Abstracts

## Moderator, Nancy Reynolds



Nancy Reynolds is the Inaugural President and CEO of the Alberta Centre for Child, Family and Community Research. Her expertise in building and maintaining successful partnerships, both public and public/private, led to her moving six years ago from Alberta Children and Youth Services to establish the Centre. As CEO, her goal is to ensure that the Centre is recognized as being a global leader in mobilizing priority research findings in childhood well-being as it strives towards achieving its vision, "To improve the well-being of children, their families and communities in Alberta, Canada and Internationally, by mobilizing research evidence into policy and practice."

Under her leadership the Centre has become a well respected organization within both the academic and policy communities, recognized for its innovative approaches to the generation, gathering, and mobilization of policy-relevant evidence.

Prior to her move over to the Centre in 2003, Ms. Reynolds was the Assistant Deputy Minister of Partnership and Innovation for Alberta Children's Services. In that role, one of her many accomplishments was developing the concept for the Centre.

Joining the Alberta Government in 1993 after many years as a clinician and health service administrator, she held several senior and executive management portfolios in the Ministry of Health including Assistant Deputy Minister Population Health. She was seconded for two years to the role of CEO of the Provincial Mental Health Advisory Board where she was responsible for the mental health service delivery system in addition to developing a strategic policy framework to integrate and align provincial mental health within the newly regionalized health system in the province.

In addition to her role with the Centre, Ms. Reynolds currently serves on the Board of Directors of the Capital Region United Way and is a member of the Child and Youth Advisory Committee to the Mental Health Commission of Canada.

## Question 1: What is Fetal Alcohol Spectrum Disorder (FASD) and how is it diagnosed?

### Expert Chair, Gail Andrew



Pediatric Consultant, Pediatric Programs, Glenrose Rehabilitation Hospital

Dr. Gail Andrew completed her medical and pediatric training at McGill University and did further training and research in neonatology at the University of Alberta. She is currently Site Lead in Pediatrics at the Glenrose Rehabilitation Hospital. Her main interest has been in the area of developmental, behavioral and emotional challenges of children, especially those with known at risk factors. She has been involved in all aspects of Fetal Alcohol Spectrum Disorder, including prevention, diagnostic assessments, interventions, and support of individuals with FASD and their caregivers.

Dr. Andrew has been the Medical Director of the Glenrose FASD Clinical Services since 2000. She is the co-chair of the Alberta Clinical Stakeholders on Diagnosis of FASD that works closely with the Alberta Government Cross Ministries Committee on FASD. She is on the committee with the Alberta Medical Association TCFPS Program focusing on FASD Diagnosis and Prevention. She is a member of the founding Board of Directors of the Canada Northwest FASD Research Network. She has worked on several FASD initiatives with the Public Health Agency of Canada. She is the co-chair of the Knowledge Translation and Exchange committee of the Canadian Network of Child and Youth Rehabilitation Centres (CN-CYRC), a national organization under the Canadian Association of Pediatric Health Centres (CAPHC) that focuses on the rehabilitative needs of children and youth with a variety of disabilities. Dr. Andrew, with Dr. Carmine Pasmussen as the lead researcher, has been involved in research in FASD including diagnosis, neuro-imaging and program evaluation with numerous presentations and publications.

### Abstract

#### Overview of FASD

FASD refers to the lifelong disability resulting from prenatal alcohol exposure (PAE). FASD includes full FAS, partial FAS and ARND (Alcohol Related Neurodevelopmental Disorder). Alcohol consumption in pregnancy puts the fetus at risk for damage to the developing brain and other vulnerable systems. The mechanism of the teratogenic effect of alcohol is informed by animal model and basic science research. However, alcohol impact on the brain in utero is more complex and not a linear relationship. It is compounded by multiple factors: amount, duration and timing of the alcohol exposure; genetic and epigenetic factors of mother and fetus; other prenatal environmental factors (nutrition, other teratogens); and postnatal experience (neglect, abuse, malnutrition).

There are no definitive biological markers for FASD, with research continuing to explore this area including neuroimaging. Diagnosis requires confirmed PAE and assessment of growth deficiency, facial dysmorphism and evidence of organic brain damage. It involves a differential diagnosis to rule out factors that may cause or compound the disability. The characteristic face of FAS occurs with exposure day 19 to 21 of gestation and is found in < 10% of clinic populations. Growth deficiency and hard neurological findings such as microcephaly are infrequently found. Therefore, diagnosis of FASD requires assessment of brain function by a multidisciplinary team of clinicians. Current research and practice is informing tests that best identify the organic brain damage. Assessment of basic cognition, language and motor/sensory skills is not sufficient. Deficits in executive function (judgment, planning, memory, mental manipulation, etc.) and adaptive function (ability to cope independently in day to day life) better define the disability of FASD.

Assessment of brain function is required for the diagnosis and is essential to inform the interventions and supports required after diagnosis across educational, social and medical systems. It also helps caregivers and the individual with FASD understand their unique strengths and weakness patterns. Although brain damage from PAE is static, the difficulties in function become more evident across the lifespan as there are natural expectations in society to function independently. Thus, longitudinal follow up using different assessment tools at various age groups is needed to inform transition points in the system of care. Diagnosis of an individual with FASD is a "Diagnosis for Two" as it identifies a birth mother who was drinking in that pregnancy. She may still be dealing with issues in her life that could put future fetuses at risk for PAE and also impact her own health. Reaching out to her with a positive support system can be preventative.

#### Policy Recommendations

1. Research to identify best assessment tools at each age group.
2. Training of multidisciplinary FASD Diagnostic teams for consistency and increase capacity.
3. Sustainable funding for diagnostic teams to increase rural and urban access and contribute to prevalence and surveillance data.
4. Identify best practice in interventions across the lifespan and implement in local communities.
5. Funding for longitudinal follow up in the system of care.
6. Access to best practice models of care for high risk birth mothers for prevention.

## Question 1: What is Fetal Alcohol Spectrum Disorder (FASD) and how is it diagnosed?

### Myias Himmelreich



Director of Programming,  
Canadian FASD Foundation

Myias Himmelreich is a  
Mentor and Community  
Outreach Worker assisting

young adults in dealing with day-to-day issues characteristic of Fetal Alcohol Spectrum Disorder. Also living with FASD, Mr. Himmelreich has been able to use his own experiences to educate others about not only the challenges but also the strength that comes with facing and effectively dealing with issues common to persons affected by FASD.

Mr. Himmelreich is a much sought after speaker having presented as Keynote Speaker at numerous conferences, is published in the area of FASD, has well represented the FASD community within the media, and serves on the Calgary Fetal Alcohol Network. His lifestyle

includes sports, drawing and supportive friendships, which help him to be a leading example both personally and professionally.

### Abstract

#### A personal perspective

Mr. Himmelreich was born with Fetal Alcohol Spectrum Disorder. Now in his early 30s, Mr. Himmelreich has grown to better understand and cope with living with this disability. Growing up, he did not understand at the time that he was going through and experiencing many of the hardships individuals with living FASD go through. He had trouble concentrating on and understanding school work, making it to school on time and staying focused in the classroom. Just like everyone else, he just wanted to fit in, wanted to be "normal" but though he could not explain it, he knew he was different. Mr.

Himmelreich eventually turned to drugs and alcohol to help him have "friends" and to be accepted. After years of a downward spiral, he decided it was time for a change. Mr. Himmelreich is now a published author, FASD Mentor and the Director of Programming for the Canadian FASD Foundation. Mr. Himmelreich also travels, sharing his life lessons as a motivational speaker. He has come to realize that, though he has FASD, it does not mean he is FASD. He now knows that he has many great talents to offer. Surrounding himself with good friends, supportive family members and understanding co-workers, Mr. Himmelreich is able to live successfully with Fetal Alcohol Spectrum Disorder.

## Question 2: Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?

### Suzanne Tough



PhD, Scientific Director, Alberta Centre for Child, Family and Community Research

Suzanne Tough is a professor with the

Departments of Paediatrics and Community Health Sciences in the Faculty of Medicine at the University of Calgary and holds adjunct appointments with the University of Alberta and the University of Manitoba. She is also the Scientific Director of the Alberta Centre for Child, Family and Community Research.

Her research program focuses on improving health and well-being of women during pregnancy to achieve optimal maternal, birth and early childhood outcomes. She currently co-leads an interdisciplinary team of researchers (Prenatal Birth and Healthy Outcome), funded by Alberta Heritage Foundation for Medical Research, that is learning more about preventing prenatal birth and supporting healthy birth outcomes by looking at the genetic, molecular, clinical, community and population health factors that contribute to prenatal birth. In this team grant we are doing both observational research to understand how women are doing during pregnancy and intervention research to try different models of prenatal care.

The underlying aim of the research program is to create evidence that informs the development of community and clinical programs and influences policy to optimize birth and childhood outcomes, as well as to foster future researchers in the area of maternal and child health research.

### Abstract

#### Prevalence and Incidence in Alberta and Canada

This presentation will highlight current understanding about the prevalence and incidence of Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder in Alberta and Canada with insight into the strengths and limitations of existing information, including the challenges associated with applying the terms incidence and prevalence. Available incidence

and prevalence rates will be described by geography and population. In addition, rates of FASD among those receiving services through public systems, such as foster care and the justice system, will be described.

Current information suggests that among urban North American populations the incidence of FAS is 0.25 to 3 cases per 1,000 live births for FAS, and approximately 0.1 per 1,000 live births for FASD.<sup>1</sup> The reported prevalence in rural communities, foster care systems and juvenile justice systems can be much higher with rates of 7.2 to 233/1,000 found in high risk populations in rural Canada.<sup>2</sup>

During the first trimester, sometimes before pregnancy recognition, 12% to 60% of women report alcohol use.<sup>3-5</sup> We have described a population-based sample of Canadian women of childbearing age, in which 90% consumed alcohol before conception,<sup>6</sup> but of all women continued to drink after conception but before they recognized that they were pregnant, and about 20% had a binge drinking episode during this period.<sup>6</sup> Others have noted that a proportion of women, estimated between 4 and 27%, continue to drink alcohol during the remainder of pregnancy.<sup>4-10</sup> Available evidence suggests that the risk of, and consequently the incidence and prevalence of FAS is higher among children born to "heavy" drinkers, i.e., 2 or more drinks per day or 5-6 drinks per occasion, at 43.1 per 1000 live births.<sup>10</sup>

Control to determining accurate incidence and prevalence estimates, is a diagnosis of FAS/FASD. Critical to the diagnosis of FAS is prenatal alcohol exposure, hence, if the method of identification of alcohol exposure relies on birth record data, the potential to miss cases exists.<sup>10</sup> When case ascertainment is based upon a comprehensive evaluation within a specified population, more accurate rates of prevalence, relative to that population, would be expected. As well, the diagnostic case definition of FAS will influence prevalence estimates; a study incorporating a broader definition is likely to have higher rates than studies with narrow definitions. Finally, if recruitment for a study is based upon referrals, children with mild effects

or those who are unknown to the referral agency will be missed.

The variability in estimates of rates may be accounted for by true variability among populations, the prevalence and detection of alcohol use among populations, detection bias according to socio-economic status of study population<sup>11</sup>, ethnicity of study population<sup>12</sup>, access to a qualified diagnostician<sup>13</sup>, criteria used for diagnosis and the methodological approach used for finding incident cases.<sup>11, 14</sup> Regardless of the reported incidence and prevalence rates, the impact of FASD is wide reaching, touching the life of the individual and the lives of family members and society as a whole with major economic, social, and medical impacts.<sup>15-18</sup>

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**Question 2: Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?**

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**Philip May**



PH.D. Professor of Sociology and Professor of Family and Community Medicine, University of New Mexico Center Research Scientist, Center on Alcoholism, Substance Abuse, and Addictions (CASA)

Philip A. May is a sociologist/epidemiologist who has specialized in public health research and prevention for 40 years. Dr. May was a commissioned officer in the United States Public Health Service from 1969 - 1973 working for the National Institute of Mental Health in Washington, D.C. and the Indian Health Service at Fort Hall Idaho and Pine Ridge, South Dakota. He has been a Professor of Sociology and a Professor of Family and Community Medicine at the University of New Mexico since 1978.

Dr. May's research on Fetal Alcohol Spectrum Disorder (FASD), epidemiology, maternal risk factors, and behavioral traits and educational intervention for children with FASD began in 1979 with the first population-based study of fetal alcohol syndrome (FAS) epidemiology study ever. It was carried out among American Indians in the Southwestern U.S. His work has been funded by several federal agencies including: the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the Indian Health Service (IHS), the Health Resources and Services Administration (HRSA), and the Centers for Disease Control and Prevention (CDC). The populations in which Dr. May's clinical research teams have studied FASD are: New Mexico, Arizona, Southern Colorado, Montana, South and North Dakota, South Africa, and Italy.

**Abstract**

**Prevalence and incidence internationally**

Researching the epidemiology and estimating the prevalence of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorder (FASD) for mainstream populations anywhere in the world have presented challenges to researchers.

Three major approaches to assess the prevalence and characteristics of FASD have been used in the past:

1. surveillance, reporting, and record review systems;
2. clinic-based studies; and
3. active case ascertainment methods.

The literature on each of these methods will be reviewed briefly citing the strengths, weaknesses, prevalence results, and other practical considerations for each method.

Previous conclusions about the prevalence of FAS and total FASD in the United States (U.S.) population are summarized. Active approaches which provide clinical outreach, recruitment, and diagnostic services in specific populations have been demonstrated to produce the highest prevalence estimates. The presentation will describe and review studies utilizing in-school screening and diagnosis, a special type of active case ascertainment. Selected results from a number of in-school studies in South Africa, Italy, and the U.S. are highlighted. The particular

focus of the review is on the nature of the data produced from in-school methods and the specific prevalence rates of FAS and total FASD which have emanated from them.

Work in active case ascertainment studies, including eight completed in-school studies, concludes that FAS and other FASD are more prevalent in school populations, and therefore the general population, than previously estimated. FASD affect many children in the educational system and reduce their potential in life in mainstream society.

The prevalence of FAS in typical, mixed-racial and mixed-socioeconomic populations of the U.S. is at least 2 to 7 per 1,000. Regarding all levels of FASD, we estimate that the current prevalence of FASD in populations of younger school children may be as high as 2 to 5% in the U.S. and some Western European countries. Active case ascertainment methods for identifying FASD are invaluable for use in general populations, particularly in the lower grades of school populations. Such techniques can be used to: accurately assess the prevalence, characteristics, and impact of various diagnoses within FASD; identify children with FASD who suffer from developmental disabilities; and provide intervention plans and educational/management strategies for maximizing the development of affected children.

Question 2: Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?

## Ben Gibbard



MD MSc MSc FRPDC  
Developmental Pediatrician,  
Alberta Children's Hospital,  
Assistant Professor, Department  
of Pediatrics, Faculty of  
Medicine, University of Calgary

Dr. Ben Gibbard completed his undergraduate degree in medicine at the University of British Columbia, pediatric residency training at the University of Alberta, and a fellowship in developmental pediatrics at the University of Calgary. He also holds a master's degree from Robert College which focused on medical ethics, and a Master of Science degree from the University of Calgary in health research. Dr. Gibbard is a developmental pediatrician at the Child Development Centre/Alberta Children's Hospital, and an Assistant Professor in the Faculty of Medicine, at the University of Calgary. Present research interests related to Fetal Alcohol Spectrum Disorder include clarification of diagnostic criteria, psychiatric co-morbidities, intervention, ethics, and social policy. He also has active research interests related to understanding the interaction between cumulative risk and resiliency in populations of children at risk for poor developmental and mental health outcomes, as well as developmental screening practices

## Abstract

### Extent and impact on child development

This presentation will review key knowledge related to developmental, behavioral, neuropsychological, and mental health profiles and trajectories for individuals with Fetal Alcohol Spectrum Disorder (FASD) across the lifespan. Broadly speaking, this can include developmental delays and behavioral difficulties in the early years. As a child develops, specific functional impairment profiles can emerge, and in adolescence and adulthood, mental health disorders can also declare themselves in association with varying neuropsychological difficulties. However, it should be emphasized that individuals with FASD have heterogeneous functional deficit profiles, and many of these difficulties are seen in other developmental, pediatric rehabilitation, and mental health disorders. Because prenatal alcohol exposure is often only one of many prenatal or postnatal exposures that impact developmental outcomes for individuals with FASD, models of cumulative risk and developmental psychopathology will be explored to highlight risk and adaptation promoting factors that contribute to individual outcomes, and describe the variable deficits and strengths seen in this population. More research will be needed to review developmental trajectories of individuals with FASD, taking into account associated risk and adaptation factors

and linked to specific developmental, behavioral, or mental health interventions. Developmental outcomes for individuals with FASD can change, and are responsive to intervention.

Individuals with FASD present with varying neuropsychological and functional deficits and associated mental health disorders. These deficit patterns can change over time, linked to differing risk and adaptation promoting factors. Because developmental trajectories can change over time, individuals with FASD will require careful surveillance and screening for common areas of difficulty, and some may require repeat in-depth functional assessment to guide appropriate treatment and support. The FASD diagnostic process should include functional and treatment-informing data collection related to profiles of deficit and strength for individual clients. Overall, providing all children at risk for adverse outcome due to prenatal or postnatal risk factors with appropriate screening, surveillance and intervention in a timely fashion will ameliorate deficits and improve some developmental trajectories. The functional deficits seen in individuals with FASD are not unique to this population. Therefore, service development should draw upon existing evidence-based strategies from other disciplines or developmental/mental health disorders related to screening, surveillance, intervention, and supports for this complex population.

Question 2: Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?

Susan Astley



PhD, Professor of Epidemiology/ Pediatrics, University of Washington; Director, Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network

Susan Astley, PhD, is a Professor of Epidemiology/Pediatrics at the University of Washington in Seattle, Washington and is the Director of the Washington State FAS Diagnostic and Prevention Network clinics. Dr. Astley has conducted laboratory, clinical, and public health research in the field of FASD since 1987. Current work has been in the development and implementation of FASD diagnosis, screening, surveillance, and prevention tools and programs. This work includes the development of the FASD 4-Digit Diagnostic Code and FAS Facial Photographic Analysis Software, establishment of the WA State FAS Diagnostic and Prevention Network of clinics and Foster Care FAS Screening Programs, and establishment of the FASD diagnostic training program (and online course). She and her colleagues have recently published a study of the diagnostic utility of MRI, MRSpectroscopy and functional MRI for FASD. A recent publication documents Washington State's success in preventing FAS through reduction of maternal alcohol use during pregnancy.

Abstract

FAS Screening in Washington State foster care tracks FAS prevalence over time, provides early intervention for identified cases, and assesses statewide FAS/D prevention efforts.

To assess the effectiveness of Fetal Alcohol Spectrum Disorder (FASD) prevention efforts, one must be able to accurately and efficiently document the prevalence of FAS over time in a population-based sample. With the establishment of the Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS DPN) of clinics, the development of the FAS Facial Photographic Analysis

Software, the creation of the FASD 4-Digit Diagnostic Code, the establishment of the Foster Care FAS Screening Programs, and the collection of CDC Pregnancy Risk Assessment Monitoring System (PRAMS) data on maternal use of alcohol during pregnancy, the tools, methods, and infrastructure for tracking FAS prevalence and assessing primary prevention efforts in Washington State are in place.

The FAS DPN has accurately and efficiently tracked the annual prevalence of FAS in a Washington State foster care population for the past decade.<sup>1</sup> Digital facial photographs are taken of all eligible foster children and analyzed using the FAS Facial Analysis Software. A child screens positive for FAS if they have all three of the following facial features: subnasal fissure length  $\leq -2.50x$ , a smooth philtrum (Rank 4 or 5 on the Lip-Philtrum Guide) and a thin upper lip (Rank 4 or 5 on the Lip-Philtrum Guide). All screen-positives receive a FASD diagnostic evaluation and treatment plan by the FAS DPN interdisciplinary team using the FASD 4-Digit Diagnostic Code. Over 2000 children have been screened to date. This ongoing screening has demonstrated 1) the prevalence of FAS (as defined by the 4-Digit Code) in this foster care population is 10–15/1000, or 10–15 times higher than in the general population; 2) the photographic screening tool performs with 100% sensitivity, 98.8% specificity, 85.7% predictive-value-positive, and 100% predictive-value-negative; 3) the population is highly amenable to this form of screening (>95% of the eligible population consent to participate), leading to highly accurate prevalence estimates; and 4) the children benefit directly from early identification and intervention.

The FAS prevalence estimates generated by this FAS screening program have also been used to assess the WA State's FASD prevention efforts. The State's efforts have spanned the full continuum from public health education and policy to direct intervention targeted to high-risk

women. There is clear evidence of success: CDC PRAMS data documents maternal use of alcohol during pregnancy has decreased significantly in WA State since 1993. If maternal drinking is decreasing, one would expect a decline in the prevalence of children born with FAS across those same years. In 2002, a cross-sectional study<sup>2</sup> using the WA PRAMS data and the WA foster care FAS screening data, confirmed the significant decline in maternal drinking during pregnancy from 1993–98 correlated with a significant decline in FAS among foster children born in those same years.

Tracking the prevalence of FAS over time in a high-risk foster care population offers a more accurate and cost-effective alternative to tracking the prevalence of FASD across a larger, more diverse general population. If statewide prevention efforts and reduction in maternal alcohol use are effectively reducing the prevalence of FAS in a foster care population, similar reductions are being realized in the general population. The same can be said for the impact of prevention efforts on the full spectrum of disorders caused by prenatal alcohol exposure. If maternal drinking during pregnancy is reduced, the full spectrum of disorders (FASD) will be reduced, not just the condition called FAS.

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Question 2: Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?

## Albert Chudley



MD FRCPC FRCMC, Medical Director, Winnipeg Regional Health Authority Program in Genetics and Metabolism; Professor, Department of Pediatrics, University of Manitoba

Dr. Albert Chudley is Medical Director of the Genetics and Metabolism Program with the Winnipeg Regional Health Authority and Professor in the Departments of Pediatrics and Child Health, and Biochemistry and Medical Genetics at the University of Manitoba. He has been a consultant to the Manitoba and Alberta governments on issues related to Fetal Alcohol Spectrum Disorder (FASD). He is a member of the National FASD Screening Tool Development Project on screening. He is a former member of Health Canada's National Advisory Committee on FASD, and a former member of the Canada Northwest FASD Partnership Research Network Board. He is a past President of the Canadian College of Medical Geneticists, and is currently Vice-Chair of the Board of Directors of the Assisted Human Reproduction Agency Canada.

## Abstract

### Genetic pre-disposing factors in Fetal Alcohol Spectrum Disorder

Ethanol-induced adverse effects result from a broad range of complex interactions between environmental, behavioral, social and genetic factors. FASD prevalence varies between populations, with the highest reports coming from Aboriginal populations in North America and mixed race individuals in South Africa. Genetic factors probably influence embryo and fetal damage resulting from prenatal ethanol exposure. Alcohol is first oxidized by alcohol dehydrogenase (ADH) to acetaldehyde, which is oxidized to acetate

by acetaldehyde dehydrogenase (ALDH). Both proteins occur in several isoenzyme forms encoded by multiple families. Specific alleles at the loci ADH1B (previously ADH2), ADH1C (previously ADH3), and ALDH2 can increase the level of acetaldehyde. This causes an adverse response to alcohol consumption the "flushing response" characterized by elevated blood flow, dizziness, accelerated heart rate, sweating, and nausea. Individuals who flush are protected from heavy drinking. Women with these genotypes are at a very low risk of alcoholism and having FASD children.

A PubMed search of Fetal Alcohol Syndrome, alcohol metabolism and genetics was undertaken. Over 260 articles were identified. Several recent key original research and review articles were reviewed.

The literature identifies alcohol's developmental effects in three categories: genes involved in (1) alcohol metabolism, (2) cell proliferation and growth factors, and (3) neurotransmitter systems. Genome wide expression arrays in animals have identified hundreds of ethanol responsive genes. Altered expression belongs to a selected set of pathways including stress response, ethanol metabolism, protein modification, gene regulation and cell signaling. The most studied genes in humans include those involved in alcohol metabolism ADH, ALDH and a subfamily of cytochrome p450, cyp2E1. Allele variants differ in frequency depending on the ethnicity of the population, suggesting that proportions of populations are protected from alcohol effects mainly by low intake because of flushing effect. One study in SW American Indian population reports a low frequency of protective alleles, and a candidate gene ADH1C in a high proportion affects vulnerability to alcoholism.

### Conclusions and Policy Recommendations

1. FASD is not hereditary, the primary cause of FASD is heavy prenatal alcohol exposure in pregnancy.
2. Allele variants and other genetic differences influence risk for, and incidence of, FASD, and these risks likely explain differences between ethnic groups.
3. The genetic differences may be protective resulting in less alcohol exposure (flushing effect), as well as genetic variations that increase drinking (gene variants increasing the likelihood for binge drinking and alcoholism).
4. Further research in genetic risk factors for FASD may lead to better recognition of at risk individuals and the development of more effective prevention strategies.
5. Investigating a single or a small number of candidate genes that are involved in ethanol response does not identify all factors causing FASD.
6. Standardized approaches to determine accurate estimates of maternal alcohol intake and outcome measures are essential in future research.
7. Despite the enormous interest from a biological perspective, studies identifying genetic risk factors for FASD will not likely have a meaningful impact on the prevalence, treatment or prevention of FASD.

**Question 2: Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?**

**Joanne Weinberg**



PhD, Professor and Distinguished University Scholar and Acting Department Head, Cellular and Physiological Sciences, University of British Columbia

Dr. Joanne Weinberg did her undergraduate training at Brown University, a Masters at Harvard University Graduate School of Education, and her PhD in Neuro- and Biobehavioral Sciences at Stanford University Medical School. She did Postdoctoral training at Stanford, UC San Francisco and UBC. Dr. Weinberg joined the Department of Anatomy at UBC as an Assistant Professor in 1982, was promoted to Professor in 1993, and was appointed a Distinguished University Scholar in 2004. She currently serves as Acting Head of the Department of Cellular and Physiological Sciences, and is an Associate Member of the Department of Psychology, the Brain Research Centre, and the Child and Family Research Institute at Children's Hospital, and is a Mentor in the Neuroscience Graduate Program and the IMPART program at UBC.

The research in Dr. Weinberg's laboratory utilizes rodent models to investigate how early life experiences alter brain and biological development, with a major focus on the developmental effects of prenatal exposure to alcohol. Her work has shown that physiological and behavioral deficits seen in alcohol-exposed offspring could result, at least in part, from a disturbance in the balance of critical hormonal systems involved in the stress response. Reprogramming of the fetal stress system by alcohol can increase sensitivity to stressors and over time, increase vulnerability to illnesses, including depression, addiction and behavioral problems. In addition to this research, Dr. Weinberg is also involved in collaborative projects examining the effects of early life pain, stress and medication exposure on the development of preterm and term-born infants.

**Abstract**

**Direct and indirect mechanisms for alcohol damage to the brain**

Children with Fetal Alcohol Spectrum Disorder (FASD) exhibit cognitive, neuropsychological and neurodevelopmental problems, as well as elevated rates of mental health problems, including depression and anxiety disorders. Animal models of FASD have demonstrated biological and neurodevelopmental effects of prenatal alcohol exposure consistent with these clinical findings. Animal models provide control over genetic and environmental variables at a level not possible in human studies and, over the years, have been extremely valuable for examining how and why specific outcomes occur, and for investigating mechanisms underlying these outcomes. Numerous direct and indirect mechanisms of alcohol-induced damage have been identified, and will be discussed in this presentation.

The current research focus in our laboratory is on one major indirect mechanism – fetal alcohol effects on the neuroendocrine system, and in particular, the hypothalamic-pituitary-adrenal (HPA) axis, a key component of the stress system. Dysregulation of the HPA axis is common in depression/anxiety disorders, reflected primarily in increased HPA tone or activity. Studies have shown that prenatal alcohol exposure programs the fetal HPA axis such that HPA tone is increased throughout life, persisting HPA changes seen in depression/anxiety. In the context of the stress-diathesis model, we are testing the hypothesis that fetal programming of the HPA axis by alcohol alters neuroadaptive mechanisms that mediate the stress response, thus sensitizing the organism to stressors encountered later in life, and mediating, at least partly, the increased vulnerability to mental health and stress-related disorders, observed in children with FASD.

Pregnant dams are assigned to prenatal alcohol (ethanol, E), pair-fed (FF, nutritional control), or ad libitum-fed control (C) groups. At adulthood, male female offspring are exposed to chronic mild stress (CMS), or remain undisturbed. CMS consists of exposure to a series of psychological and physiological stressors over 10 consecutive days, twice daily, at random times of day. Animals are then tested in a multidimensional battery of behavioral tests, sensitive to both

depressive- and anxiety-like aspects of behavior, including the open field, elevated plus maze, Porsolt-Arrow swim, sucrose contrast, and social interaction tests. Following testing, blood and brains are collected for analysis.

Overall, we find that:

1. CMS alters both behavioral and endocrine measures in a manner parallel in many respects to that observed in depressive-/anxiety-like disorders.
2. Exposure of E animals to CMS increases depressive-/anxiety-like behaviors relative to those in C animals, and does so in a sexually dimorphic manner, consistent with the finding of gender difference in rates of manifestations of depressive/anxiety disorders in clinical populations. E males exposed to CMS showed greater anxiety (prolonged plus maze, impaired hedonic responsiveness sucrose contrast test), locomotor hyperactivity (open field), and alterations in affiliative and non-affiliative social behaviors (social interaction) compared to control males. By contrast, while E females are similar to males in showing greater anxiety and altered social interactions, they also show greater levels of behavioral despair (forced swim) compared to controls. Brains are currently being analyzed to investigate the possibility that epigenetic mechanisms underlie fetal programming of HPA function.

Overall, this work with an animal model supports the clinical data indicating that problems such as anxiety and depression are a significant issue among adults and children with FASD. Moreover, our data suggest that depression in these individuals may have a neurobiological basis, and thus, at least in some instances, could be a primary rather than a secondary disability, or at least, have a primary component. The stress-diathesis model appears to provide a powerful approach for elucidating mechanisms underlying the increased vulnerability to mental illness among individuals with FASD, and could provide guidance for the development of appropriate treatments or interventions for these individuals.

Supported by grants from MHNAAA, the UBC Human Early Learning Partnership (HCELP), the Canadian Foundation for Fetal Alcohol Research, and the Coast Capital Savings Depression Research Fund.

## Question 3: What are the consequences of FASD on individuals, their families and society?

### Philip Jacobs



CPH, Professor, Department of Medicine, Gastroenterology Division, University of Alberta, Director of Collaborations, Institute of Health Economics

Philip Jacobs is Director of Collaborations at the Institute of Health Economics and Professor of Health Economics at the University of Alberta, Department of Medicine. His research areas are economic evaluation and health finance. He was the project director for the IHE booklet, *Mental Health Economic Statistics* in your pocket, and has conducted several studies on the cost of mental health services in Canada. He is currently working with Drs. Kim Lim and Carolyn Dewar on a booklet entitled, *How much should we spend on mental health?* which will appear later this year, to be published by the IHC. He has worked with co-investigators at the IHE and the former Alberta Mental Health Board in the development of a provincial database for mental health services utilization.

### Abstract

#### Economic implications

In addition to the effects on quality of life, FASD affects the use of resources in terms of treatments, lost productivity, social services, and education. This presentation will examine three aspects of resource use for FASD: economic burden, cost effectiveness of prevention, and the impact of providing prevention services.

Based on a literature review, data was collected on treatment and social service costs, education and lost productivity. Key previous interventions were identified, and a search for cost-effectiveness analyses of these, compared to no intervention was conducted. Based on estimates of incidence, the budget impact of providing prevention services was estimated.

The incidence of FASD is assumed to be 9.1/1000 people. Depending on age, the costs of services related to FASD are between

\$15,000 and \$25,000 for each year of life. Researchers estimate an annual cost of prenatal cases to be \$5 billion. The cost of a specific test for alcohol exposure in pregnancy is approximately \$62,000 for each increment of quality adjusted life year.

The burden of FASD is well established, but the cost effectiveness of prevention is less so. The cost effectiveness is within the range of acceptability.

Current prevention should be considered to determine whether current treatment falls short of optimal treatment.

### Mary Berube



MSW RSW, Director, Intergovernmental Initiatives, Ministry Support Services Division, Alberta Children and Youth Services

Mary Berube (Vancouver) is well known professionally as an advocate, speaker, and programmer regarding the personal and political implications of substance use during pregnancy. In that capacity she has presented over 600 workshops and presentations and participated in numerous media events and videos, the most notable of which is "David with FAS" (filmed by Gill Cardinal in 1992-1993) which has been aired on the CBC networks and used throughout the country for training purposes. She is the adoptive mother of two sons who were both diagnosed with FASD in their late teens. In

2006, Mary was presented with an Alberta Centennial Medal to honour her contributions to the province for her work.

Since 1999, Mary's efforts have focused on the plight of birth mothers and the complexity surrounding prevention of substance use during pregnancy. She brought the Parent/Child Assistance Program to Edmonton and supervised this program as well as four other FASD-related programs for Catholic Social Services for five years.

In the spring of 2005 Mary accepted a position with Health Canada in First Nations and Inuit Health where she was the Early Childhood Development Team Leader responsible for Maternal Child Health, FASD, Head Start and Canadian Prenatal Nutrition Program.

In March 2009, Mary accepted the position of Director, Intergovernmental Initiatives with the Ministry of Alberta Children and Youth Services, where her responsibilities include developing and maintaining relationships with other levels of government, within Alberta and across Canada, including First Nations. She is a member of the Parent/Child Assistance Program Council which oversees the work that the Province and First Nations and Inuit Health fund to assist pregnant substance-using mothers.

### Abstract

#### Consequences for the community

The effect of FASD on the community requires a nuanced response from both a pragmatic and theoretical perspective. For far too long

### Question 3: What are the consequences of FASD on individuals, their families and society?

the simplistic response to the knowledge that gestational alcohol use can cause birth defects has been to afford blame to birth mothers without understanding the complex and painful road traveled by pregnant, substance-using women, and to offer affected individuals limited or inappropriate services.

While it is true that community members weigh the cost to society of this preventable birth defect in terms of lost potential for affected individuals and the high lifetime expenses incurred by caring for them, doing so from a mother-blaming stance often means ignoring the links between mental health problems and substance use, coupled

with a striking lack of compassion and a dearth of affordable mental health services. Antismoking messaging regarding alcohol use in western society, with evidence variously presented as both acceptable and disgusting, and lack of well thought-out instruction for youth with respect to its appropriate use and vulnerability to overuse, has led to flourishing educational awareness campaigns aimed at prevention through shaming and blaming, or placing the onus for harm reduction at the feet of servers in liquor establishments or private parties. Vulnerable women who are at the highest risk for pregnant substance use remain hidden from view, both

out of fear and because they live at the margins of society for many complex reasons. The costly inextricable link between birth mothers and their alcohol-affected offspring is not well served by pitting the rights of the mother against the rights of her fetus, but rather by courageously addressing a value system where mothering is considered an activity akin to producing a product and failure to do well is considered personal moral failure, unrelated to the societal context.

#### Linda Burnside



BSW MEd PhD, Executive Director, Disability Programs, Manitoba Family Services and Housing

Linda Burnside is a social worker and certified counselor with the Canadian Counseling Association who obtained her Bachelor of Social Work, Master of Education (in Counseling) and PhD in social work at the University of Manitoba. Much of her work experience is in child welfare, having worked as a child protection social worker, therapist in sexual abuse treatment, Assistant Program Manager with Winnipeg Child and Family Services, and Director of Authority Relations with the Child Protection Branch, Manitoba Family Services and Housing. Her research interests have focused on children in care with disabilities (especially FASD), intrafamilial child sexual abuse, and decision-making processes of child welfare workers. She was the project lead for the development of the training video *Interviewing Children: A Training Guide for Child Welfare Social Workers and Forensic Interviewers* (2009) under the auspices of PACCA (Provincial Advisory Committee on Child Abuse in Manitoba). Currently, Linda is the Executive Director of Disability Programs with Manitoba Family Services and Housing.

#### Abstract

##### Impact on system usage within foster care

This presentation will provide an overview of the findings from five studies on children in care with FASD conducted in Manitoba. These studies were conducted in partnership between the University of Manitoba (Faculty of Social Work) and Manitoba Family Services and Housing.

Four of the studies were quantitative analyses of data obtained from the Manitoba Child and Family Services database, case files, and financial records. Collectively, the studies provide information about the prevalence of FASD affecting children in care, their trajectories of care, and the cost of providing child welfare care to various sample populations of children in care with FASD. The fifth study was conducted in conjunction with the Manitoba Centre for Health Policy and analyzed the cost and service usage in health, education, and day care for several populations: children with FASD (both in care and not in care), children in care affected by parental alcohol abuse but without a FASD diagnosis, and a matched sample from the general population.

Children in care with FASD are more likely to be permanent wards, come into care at a younger age, and incur higher costs of care on average than other children in care. They also have the highest utilization and cost of health care

services, specifically prescriptions of neuroleptic system drugs. Children with FASD have lower high school graduation rates, lower marks in school, and incrementally higher education costs. They are also more likely to access subsidized child care funding. Children not diagnosed with FASD but affected by parental alcohol abuse are impacted in similar ways as children with FASD.

Children with FASD are disadvantaged as they enter the child welfare system, and disadvantaged when they leave care at adulthood, with implications for their ongoing physical and mental health, education options, employability, and life stability. An important contribution of this research is the evidence that parental alcohol abuse is also a serious driver of services and costs for children without diagnosed FASD but whose parents abuse alcohol.

FASD created significant demands on the resources of child welfare agencies, due to the length of time children with FASD spend in care and the higher costs incurred to provide that care. Increased costs and services for children with FASD are also found in the health care, education and child care systems. Services for children affected by FASD throughout the lifespan are critical. The importance of FASD prevention programs also need to consider that FASD is not the only detrimental outcome of parental substance abuse.

## Dan Dubovsky



MSW, FASD Specialist for the Substance Abuse and Mental Health Services Administration (SAMHSA), FASD Center for Excellence, Rockville, Maryland

### Abstract

#### Co-morbidities with mental health for an individual with FASD

Abstract not available

## Diana Malbin

MSW, Executive Director, Fetal Alcohol Syndrome Consultation, Education, and Training Services Inc. (FASCEITS)

Ms. Diana Malbin is Director of FASCEITS, Inc., a nonprofit organization located in Portland, Oregon. She also provides consultation, education, program and community development including "training of trainers" programs to assure sustainability of evidence-based best practices related to FASD. This work is national and international.

She was principal investigator for a successful FASD interventional study and is currently working as expert consultant for BC and on other public and private FASD initiatives in Canada and elsewhere. The Oregon chapter of the National Association of Social Workers named Ms. Malbin Social Worker of the Year, 2005, and she is in the NOFAS Hall of Fame for her work in the field of FASD. In addition to her professional work, Ms. Malbin is parent of two daughters with FASD.

### Abstract

#### Efficacy of a neurobehavioral construct: interventions for children and adolescents with Fetal Alcohol Spectrum Disorders (FASD)

This three-year preliminary study was funded by the State of Oregon Department of Human Services to explore the efficacy of interventions based on a neurobehavioral construct for children and adolescents with FASD. It was implemented as a multisystems community-based collaborative project.

To explore the effectiveness of a research-informed, theoretically grounded approach that specifically recognizes and addresses neurocognitive issues related to FASD at home, school and in the community.

If FASD is a neurocognitive disorder with presenting behavioral symptoms, then providing information and developing and implementing techniques based on a neurobehavioral perspective in all environments will: in children 1) Reduce secondary behavioral symptoms; and in adults (parents and professionals) will 2) Reduce stress and 3) Increase a sense of personal competency.

Nineteen children ages 3-14 with FASD in foster care generated 19 parent-professional teams of adults who lived or worked with these children. Team size ranged from 3-12. Teams were provided with education and support for developing and implementing neurobehaviorally-based techniques over a three-year period. Child-specific interventions were implemented at home, school and in the community. Annual evaluations were conducted.

Annual written evaluations for all participants and structured individual interviews with all members of each team.

At the end of the three-year project, statistical significance was found for all but one subvariable (trend) analyzed for this study (paired t-tests,  $p < .05$ ). In children and adolescents, 17 of 18 secondary behavioral characteristics, and in parents and professionals, both reduced levels of stress

and improved sense of personal efficacy. Interestingly, findings of improvements in primary behavior variables were not expected since these reflect physiological status, yet 51% of these achieved significance. Improvements were noted in nearly all areas, particularly in school settings, although analyses of these were defined as outside the scope of this study. Impressions from the research process and through structured interviews were that, as adults understood children differently, their relationships changed. Even though primary behaviors did not change, these appeared to be experienced as less challenging.

These findings suggest that a neurobehavioral approach implemented as part of a community-based collaborative design has potential. Development and application of accommodations for those with FASD and creating a "goodness of fit" across environments appears to contribute to improvements in children and adults and in their relationships. The current dearth of research-based theoretically grounded interventional studies and the potential viability of this model suggest the need for further exploration of this construct.

Funding for this study was provided to FASCEITS by the Department of Human Services (DHS), formerly known as the State of Oregon Services for Children and Families (SCFC). For information contact Diana Malbin, MSW, [dmalbin@fasceits.org](mailto:dmalbin@fasceits.org)



## Question 4: How can FASD be prevented?

### Lola Baydala



MD, Associate Professor,  
Pediatrics, University of Alberta,  
Sto. Louis – Perinatal,  
Misericordia Community  
Hospital

Lola Baydala is a consultant paediatrician with Alberta Health Services at the Misericordia Community Hospital and an Associate Professor in the Department of Pediatrics, Faculty of Medicine and Dentistry, University of Alberta. As an advocate for children, she is passionate about Aboriginal child health, disease prevention and health promotion.

Dr. Baydala's research focuses on translating knowledge and building capacity using a community-based participatory research approach (CBPR) [www.cbpr4health.ca](http://www.cbpr4health.ca). Using a CBPR approach Dr. Baydala has developed trust and important research relationships with Aikins Nakota Sioux Nation, Enoch Cree Nation and Edmonton Public Schools, and made significant contributions to the building of capacity which has supported child health in these communities. Dr. Baydala's research is supported by the Canadian Institute of Health Research, the Alberta Centre for Child, Family and Community Research and Covenant Health.

### Abstract

#### Pre-conception initiatives

A number of programs have been recommended to prevent substance use in children and youth. The majority of these programs focus on an educational approach that uses didactic methods to present factual information about the risks of drug and alcohol use. These programs have been able to show

positive changes in knowledge and attitudes towards substance use but have been less successful in documenting significant changes in high-risk behaviors. The most effective substance use prevention programs incorporate resistance skills training and social and personal self-management skills development in addition to factual information about the risks of drug and alcohol use.

The Life Skills Training (LST) program, developed by J. Botvin, Institute for Prevention Research, Cornell University Medical College, is a school-based substance use prevention program that incorporates (a) resistance skills training, (b) social skills development, (c) personal self-management skills and (d) factual information about drug and alcohol use. The LST program has been evaluated in more than 30 scientific studies involving more than 330 schools/sites and 25,000 students in suburban, urban and rural settings. The LST program has earned recognition from the American Psychological Association, the American Medical Association and the U.S. Department of Health and Human Services National Registry of Evidence-Based Programs and Practices as one of the most extensively researched and effective substance use prevention programs available. Broad dissemination of LST began in 1995. Since then, an estimated 50,000 teachers, 10,000 school sites, and 3 million students have participated in the program across 32 countries.

The LST program is a generic program that has been proven to be highly effective with a number of different program providers, with students from different geographic regions, socioeconomic, and racial-ethnic backgrounds.

However, despite the overwhelming success of this program and the noted concerns about substance use among Aboriginal individuals, the program has never been implemented with Canadian Aboriginal children and youth and its effectiveness in this population is not known.

Previous research has shown that cultural adaptations to prevention programs can significantly improve engagement and acceptability of the program. Furthermore there is an ethical imperative to ensure that interventions developed for the dominant culture do not negatively impact the cultural values, competence or language of the non-dominant culture where the program will be delivered. Culturally adapted programs have the potential to have a three-fold effect. First, those who participate in a culturally adapted prevention program are able to relate more closely to the curricula and therefore are more likely to engage in the program. Second, a culturally adapted prevention program can aid in the development of a stronger identity and cultural pride, which in turn function as protective factors against substance use. Third, a community involved in the adaptation and implementation of a prevention program is more likely to feel a sense of ownership and empowerment. The purpose of this presentation is to describe the collaboration between the Aikins Nakota Sioux Nation and the University of Alberta to adapt and deliver the LST substance use prevention program in their community, and to describe outcome of the adapted program.

## Robin Thurmeier



FASD Researcher,  
Saskatchewan Prevention  
Institute

As part of the Canada Northwest FASD Research Network, Robin Thurmeier has been the project coordinator for Network Action Team 3: Primary Prevention Materials since 2006. She is interested in all areas of women's and children's health, qualitative inquiry, health communication and social determinants of health.

### Abstract

#### Inventory of primary prevention campaigns

Government, non-profit organisations, and community partnerships have developed and implemented FASD awareness campaigns within north-western Canada over the past 30 years. An environmental scan was undertaken to examine campaign development and evaluation outcomes of these campaigns.

Campaign materials were collected by contacting key stakeholders in FASD prevention in north-western Canada and accessing material online through FASD-related websites. Primary resources designed to increase knowledge and awareness of FASD throughout a number of audiences (i.e., women, teachers and friends) were collected. The types of materials ranged from print (i.e. posters), to multi-media (i.e.,

public service announcements) to websites (i.e. pin). Campaign evaluations were collected and synthesised to determine positive outcomes and outline where gaps exist.

To date over 300 resources and four campaign evaluations have been collected. The data suggests that while print resources are the most popular type of resource to create, the public is more likely to remember the images and messages related to multi-media resources. The evaluations illustrated an increase in awareness and knowledge of FASD across each of the campaigns, however very little information about whether behaviour change occurred, i.e. abstaining from alcohol use during pregnancy.

It is apparent that awareness campaigns have succeeded in increasing knowledge about FASD within the general population. The next step is to create a strategy that focuses on creating behaviour change. To do this, using a behaviour change model and social marketing strategies is essential in the development of the campaign strategy and evaluation tools. Social marketing is a behaviour change framework that identifies a target group, and uses behavioural theories to understand why target individuals behave in a certain manner and how we could persuade them to adopt new behaviours. In terms of strategy, social marketing offers opportunities for behaviour change in the environment, incentives for new behaviours, makes the new

behaviour convenient, and promotes it in a persuasive manner such that target individuals find the new behaviour attractive. In regards to behavioural change models, Protection Motivation Theory (PMT) has been shown to be effective in explaining and predicting health-related behaviour change. PMT was developed to look at the effectiveness of fear-based messaging compared to messaging that also increased an individual's coping skills and confidence level by examining five variables (vulnerability, severity, cost, self-efficacy, and response efficacy). Coping strategies have been shown to have the greatest impact on behaviour change.

Drawing on the results of the environmental scan, and incorporating the principles of Protection Motivation Theory and Social Marketing, it is surmised that while these awareness campaigns have been successful in creating knowledge about FASD, they do not go far enough in creating the intended behaviour change. Campaign strategies need to be developed based on a behaviour change model, and more thorough evaluations need to be conducted to better determine success. This presentation will highlight policy recommendations for funders and organisations creating campaigns and evaluations to better measure and increase intended behaviour change.

## June Bergman



MD CCFF FRCPC  
Associate Professor,  
Department of Family  
Medicine, Faculty of Medicine  
and Dentistry,  
University of Calgary

Dr. Bergman is a full-service family physician who has been working in the area of primary care referral in Alberta since 1996. She has developed several service-based programs such as hospitalist programs, low-risk maternity

programs and 24/7 urgent care programs. These programs demonstrated high quality care from groups of family physicians. She has also worked in partnership with other health care professionals to develop shared care programs in the areas of mental health, chronic disease and home care. These programs provide services to individuals in their local communities and in their physician's office through a partnership with their family physician.

As well Dr. Bergman has worked with the former Calgary Health Region to develop networks of family physicians who assume accountability for a geographic area of the city, providing full services to patients as a team of physicians in partnership with other health care professionals. This pattern of partnership between groups of physicians and a health region has provided the basis for primary care networks which are now operational within Alberta as part of the tripartite agreement.

#### Question 4: How can FASD be prevented?

Dr. Borgeau also serves as a co-chair for the Towards Optimal Practice committee, a tripartite committee that supports the development of quality practice within community settings. She also has worked with Canadian Institute for Health Information on developing primary care indicators and within Alberta to develop a framework for evaluating the primary care networks. Currently she serves as Chairman of one of the primary care physician groups within Calgary.

### Abstract

#### Fetal Alcohol Syndrome in primary care

Fetal Alcohol Syndrome is a serious condition brought on by alcohol ingestion by the mother at critical times during pregnancy. It can relate to volume of alcohol consumption or to timing of alcohol consumption in the development of the fetus. In Canada primary care is the first contact point that most people have with the health care system. It is also the primary contact point for young women at child-bearing age who come for many issues but particularly those relating to conception and contraception.

Primary care is based on personal relationship between a patient and the caregiver and is rooted in the community. Family physicians follow a biopsychosocial model and are well trained to manage most illnesses. Primary care has also taken on a major role in both primary and secondary prevention of many diseases. Supports put in place to adapt for the main barriers to managing prevention issues will enable our primary care clinics to do exemplary work. A physician's personal relationship with a patient is a long time relationship and can be transferred to other health care professionals.

Many models of care have been developed to support primary care in their engagement at population health and public health issues along with the long time obligation of prevention of disease and promotion of health. This discussion will review some of these and their strengths and weaknesses. Integration of care with secondary and tertiary care is essential to support needs of the patient and the work of primary care physicians. Integration at the primary care level of

caregivers with other defined roles supports timely diagnosis, appropriate intervention and maintenance of the individual in his or her family/community.

As we further develop primary care with multidisciplinary teams, IT support and networks of physicians, we can expect more capacity for illness care. The new direction for primary care at population health will bring more unique approaches to prevention and promotion through timely education, anticipatory counseling and early identification and treatment of illness.

A challenge to primary care and the health care system will integrate appropriate care for individuals who are participating in risky behaviours, for those who are harmed by these behaviours, and the ongoing rehabilitation required for those with Fetal Alcohol Syndrome, their families and the community.

### Nancy Whitney



MS LMHC, Clinical Director, King County Parent Child Assistance Program, University of Washington

Nancy Whitney is the Clinical Director for the King County Parent Child Assistance Program (PCAP) in Seattle, Washington. She is a Licensed Mental Health Counselor and is a Clinically Certified Forensic Counselor. PCAP is part of the Fetal Alcohol and Drug Unit in the Department of Psychiatry at the University of Washington. Ms. Whitney also contributes to ongoing research, developing interventions with high-risk populations. She has co-authored research papers and a book chapter on these issues. Ms. Whitney has been a mental health professional in community for 20 years. She has worked with chronically mentally ill and co-occurring

disorders in all treatment settings. She regularly provides training to community providers on topics relevant to serving the community's most difficult clients, such as FASD, case management, and clinical interventions.

### Abstract

#### Mentoring programs for at-risk mothers

The King County Parent Child Assistance Program (PCAP) began in 1991 as a demonstration project designed to test the effectiveness of an intensive, three-year advisory/case management model with high-risk mothers and their children. The primary goal of the program is to prevent the subsequent birth of children exposed to alcohol and/or drugs. The state of Washington began funding the program in 1995. Since then it has

grown to 10 sites and has been replicated in other states and Canada. Women are eligible to enroll in PCAP who:

1. are pregnant or up to six months post-partum;
2. abused alcohol and/or drugs heavily during the most recent pregnancy; and
3. have difficulty accessing and maintaining connections to needed community services.

At the beginning of the program, the clients' lives are unstable due to ongoing chemical dependency. However, they also have serious problems related to a dysfunctional upbringing and a chaotic life. The majority report childhood trauma and co-occurring mental health problems. The typical PCAP mother did not complete school, began using at a very young age, and has been to jail more than once.

#### Question 4: How can FASD be prevented?

They typically have made several attempts at chemical dependency treatment and have lost custody of other children due to their substance abuse. The majority are poly-substance abusers, with 45% reporting binge alcohol drinking.

PCAP clients work with an advocate/case manager for three years, which is long enough for realistic change to begin. Intensive, individualized case management is offered, rather than a rigid curriculum. Case managers develop a positive, empathetic relationship with the client, while working to address problems that interfere with the client's progress. They help the client identify service providers in the community who can meet their needs, and then connect clients to those providers.

The goal of the program is accomplished in two ways. If a woman is drinking or using drugs, we help her to prevent an exposed pregnancy by supporting her in choosing an effective family planning method. At exit, 62% of PCAP clients are using regular birth control methods; only 12% have a subsequent exposed birth.

The second way is to support the mother in achieving a clean and sober lifestyle, by connecting her to chemical dependency and mental health treatment, health care, school, and housing. PCAP data indicate that 90% of the women complete chemical dependency treatment, with 64% abstinent from drugs and alcohol at program exit. In addition, 74% have achieved permanent stable housing, 41% are

employed to support their families, and 66% have maintained custody of their child.

Despite the belief that women who abuse drugs and alcohol during pregnancy cannot be helped, PCAP does make a difference in their lives. Women can get clean and sober, and parent their children. Gender-specific treatment, where women can be with their children, facilitates change when it's offered in conjunction with supportive services and case management that helps women navigate resources. These services plus a non-judgmental, supportive mentor is a successful formula for preventing the birth of children with FASD.

#### Amy Salmon



Medicine, University of British Columbia

PhD, Managing Director,  
Canada Northwest FASD  
Research Network,  
Clinical Assistant Professor,  
School of Population and  
Public Health, Faculty of  
Medicine, University of British Columbia

Dr. Amy Salmon is the Managing Director for the Canada Northwest FASD Research Network, and a Clinical Assistant Professor in UBC's School of Population and Public Health. Dr. Salmon also leads the Mental Health and Addictions Research Unit of the Women's Health Research Institute at BC Women's Hospital and Health Centre, and holds an adjunct faculty appointment at the University of Victoria's Centre for Community Health Promotion Research. Dr. Salmon is widely recognized for her research on the connections between social determinants of women's health, access to health services, and the prevention of FASD, with a specific focus on the needs of marginalized women with addictions. With

funding from the Canadian Institutes for Health Research, the Michael Smith Foundation for Health Research, and the Victoria Foundation, she is currently collaborating with community-based clinicians, service providers, and peer advocates in Vancouver's Downtown Eastside on studies focused on meeting the primary care, maternity care, social support, and health information needs of women with addictions.

#### Abstract

##### Strength and support: Addressing FASD as a women's health issue

When assessing the impact of Fetal Alcohol Spectrum Disorder (FASD) on individuals, families, and communities, practitioners and policymakers alike generally emphasize the consequences of prenatal alcohol exposure for the fetus or child. However, research has clearly demonstrated that those women

most likely to have a child with FASD are those whose own health is compromised by addictions, violence, mental ill health, and lack of supportive care before, during, and after their pregnancies. The lives of birth mothers of children with FASD have shown that "stigma and blame" approaches to FASD prevention result in many missed opportunities to provide women with the timely, appropriate, and respectful supports needed to reduce the negative impacts of their alcohol use on their health and the health of their children. Thus, developing systems capable of meaningfully, effectively, and compassionately responding to the challenge of FASD and its prevention must include efforts to understand FASD as a women's health issue. This presentation will consider the evidence supporting such an approach, and the accompanying implications for policy development and existing service delivery systems.

## Nancy Poole



MAPHS Research Associate,  
British Columbia Centre of  
Excellence for Women's Health;  
Research Consultant, Women and  
Substance Use Issues, British  
Columbia Women's Hospital

Dr. Nancy Poole is well known for her collaborative work on FASD-related research, training and policy initiatives with governments and organizations on local, provincial and national levels. Since 1998, she has worked with BC Women's Hospital and the British Columbia Centre of Excellence for Women's Health on research relating to policy and service provision for women with substance use problems. On behalf of the Centre of Excellence and BC Women's Hospital, she currently leads province-wide professional training and resource development for the ActNow BC Healthy Choices in Pregnancy initiative. With Dr. Amy Salmon, she is a Co-Leader of the Network Action Team on FASD Prevention of the Canada Northwest FASD Research Network.

Dr. Poole has recently co-edited a book with Dr. Lorraine Grais, entitled *High and Low: Canadian Perspectives on Women and Substance Use*, published by the Centre for Addiction and Mental Health in Ontario. She holds fellowships with IMPART and NECHS and is the 2009 Healthy Health Promotion Visiting Research Fellow sponsored by Curtin University and the Government of Western Australia.

## Abstract

### Prevention of FASD: A broader strategy in women's health

Since 1998, the British Columbia Centre of Excellence for Women's Health has undertaken knowledge translation, network development and research related to improving policy and service provision for women with substance use and addictions, including the prevention of Fetal Alcohol Spectrum Disorder. We have:

- Studied barriers and supports to treatment for substance-using mothers.
- Studied media representation of substance-using mothers and the impact of media and policy discourse on policy, practice and mothers.
- Evaluated the Sheway program, a holistic, harm-reduction-oriented service for pregnant women and mothers in Vancouver.
- Led a province-wide community consultation process towards the development of BC's first FASD Strategic Plan (2008).
- Led a four-year province-wide professional education initiative with over 3600 health/social service professionals in BC (ActNow BC Healthy Choices in Pregnancy web: <http://bc.org>).
- Engaged Aboriginal women's health advocates in virtual and face-to-face discussions on improving care for First Nations and Inuit women.
- Engaged mothers and service providers in developing a resource to assist service providers in discussing alcohol use and FASD prevention with middle class women.
- Co-led a Network Action Team on FASD Prevention for the Canada Northwest FASD Research Network.

This presentation will draw upon this decade of work, as well as the lessons from the previous speaker. It will also be based on the 2008 systematic review entitled *Double Exposure: A*

*Better Practices Review on Alcohol Interventions during Pregnancy*. This review used the UK NICE guidance for systematic reviews for the process of selecting and appraising relevant studies, and also drew upon both the Canadian Better Practices model, as described by the CTCRI, and the wider literature on women's substance use to guide the secondary process of producing program components, approaches and recommendations.

The evidence for four levels of FASD prevention will be outlined. These levels address the needs of women at different levels of risk of having a child with FASD, and include prevention efforts from preconception through the postpartum period. See <http://www.phac-aspc.gc.ca/fasd-wicaf/cp-eng.php>.

There is a considerable distance to go from having the desired type and extent of evidence for FASD prevention. However, significant work has been done and a consensus has emerged among Canadians working on FASD prevention for such a multi-level approach. Such an approach addresses the highly complex issues underlying the promotion of women's and children's health. Further, it is based on multiple sources of evidence – from the peer-reviewed literature, clinical wisdom/validation on best practices in the treatment of women's substance use, and the input of women at risk and health system planners.

FASD prevention requires complex, multi-level initiatives/interventions which address very specific barriers and opportunities for learning, engagement and support of change. If we are to be successful in preventing FASD, it is critical to involve women, their support systems, community advocates, health promotion experts, researchers, health/social system planners, and service providers in designing these initiatives, improvements in practice, knowledge translation and policy, as well as further research and needed.

## Question 5: What policy options could more effectively support individuals with FASD and their families across the lifespan?

### Frank Oberklaid



AOB MD FRACP DCH, Director,  
Centre for Community Child  
Health, Royal Children's Hospital,  
and Professor, Paediatrics,  
University of Melbourne

Frank Oberklaid is the Foundation Director of the Centre for Community Child Health at the Royal Children's Hospital in Melbourne and a Professor of Paediatrics at the University of Melbourne. The Centre is internationally recognised for its research and policy work in early childhood, and is committed to translating and disseminating research findings to inform public policy, service delivery and professional practice.

Professor Oberklaid began his paediatric career at the Royal Children's Hospital, with further studies in child development and behaviour at Harvard University. He is the author of two books and more than 150 scientific papers, is the Editor-in-Chief of the *Journal of Paediatrics and Child Health*, sits on the editorial boards of several international journals, and is the founding editor of a series of national publications directed to professionals who work with young children. He is currently Deputy Chair of the Victorian Children's Council, which advised the Premier and Minister on policy related to young children and their families.

He has been the recipient of numerous research grants, awards, invited lectureships and visiting professorships in a number of countries around the world, and has received a number of prizes and awards for his work.

Dr. Oberklaid's current interests include early childhood development and behaviour, prevention and early detectably intervention, and especially how getting community based services to young children and families can be refocused and better co-ordinated to improve outcomes. He is heavily involved with a number of policy initiatives and service evaluation programs at a state and national level.

### Abstract

#### Educational system, parental, and community support

FASD is a major risk factor for poor developmental and social outcomes in children and throughout the life course. There are significant policy and service challenges in developing effective systems of primary, secondary and tertiary prevention. As recognition of the importance of early childhood development (ECD) and the critical early years gathers traction around the world, there have been innovative policy and service responses in a number of jurisdictions that have been designed to improve ECD outcomes; there are lessons that can be learned from this body of work that can inform efforts to prevent and ameliorate FASD.

Extensive review and critique of literature relevant to evidence and policy frameworks in a number of countries led to the development of conceptual models of service delivery; these were then tested with communities and stakeholders through an ongoing program of seminars, focus groups, service reviews and consultations; critical feedback was obtained from prominent national and international experts.

There are many examples of good to excellent programs geared to prevention and early intervention, especially targeting at risk children and their families. However there are barriers which preclude their translation into effective community-wide prevention and intervention programs. These include small numbers, the difficulty of going to scale, maintaining program fidelity, the absence of local ownership and support beyond the actual program recipients, and short-term funding which threatens sustainability. Finally, FASD is almost invariably associated with other individual, family and community risk factors, so these too need to be addressed.

Narrowly focused, time-limited programs that focus solely on FASD are unlikely to be successful in decreasing the incidence or improving outcomes. Policy and service approaches that are more likely to succeed need to be conceptualized as broad in scope, flexible in delivery, family-focused, and population-based as well as providing individual support. Involving the education system, families and the community in a well coordinated, long-term effort is of critical importance. The most promising conceptual models call for an integrated, easily accessible service system where professionals worked together in partnership, supportive communities that build social environments which promote and facilitate connectedness, and a system that allows the community and service systems to evolve and adapt to the changing needs of families. This should be underpinned by reliable data regarding demographics and need, as well as the mapping of available services and resources at a local community level. A clearly articulated plan formulated by partnerships of key stakeholders increase the chances of local ownership and sustainability.

Achieving significant and ongoing improvement in outcomes for FASD will require linked up responses at multiple levels, from the macro to the micro, from the broad to the specific - government policy, service organization, and professional practice need to be focused on achieving realistic short and long term targets. While federal, state and regional policy levels are important, engagement at a community level is likely to be the most critical variable that will determine success or failure.

**Question 5: What policy options could more effectively support individuals with FASD and their families across the lifespan?**

## Audrey McFarlane



Executive Director, Lifespan Centre for Fetal Alcohol Spectrum Disorder

Audrey McFarlane is currently the Executive

Director for the Lifespan Centre for Fetal Alcohol Spectrum Disorder. She was one of the founders of the Lifespan FASD Committee that led to the development of the Centre and its services. After obtaining a degree in Community Rehabilitation, her past 18 years have been spent working with children and adults with developmental disabilities and providing training on FASD. Part of her duties at the Centre has included development of the rural community-based model for FASD diagnostic services for children and adults, coordination of the Diagnostic, Assessment and Intervention Children's Clinic, development of the rural-based mentorship program for high risk women, assisting other communities in the development of services, developing best practice models for working with challenging families with FASD individuals.

Audrey and the Centre have been recognized by all levels of government for the best practice rural models of service delivery for individuals with FASD and their families. Audrey has presented at the local, regional, and national level on many issues related to FASD. She is currently the Chair of the Canada Northwest FASD Research Network Board of Directors. Fetal Alcohol Spectrum Disorder is a passion that continues to challenge and intrigue Audrey.

### Abstract

#### Shifting responsibility from the individual to communities of care

Individual responsibility is a key cornerstone of our society. If you do harm in society you must take responsibility for your actions. If you make a mistake at work, you are expected to take responsibility. If you mess up as a parent, you will lose your responsibility as a parent. Society expects individuals to follow its rules and if you don't you will be punished. This is based on a belief that we are each able to be responsible

citizens if we try hard enough. When individuals with undetected cognitive disabilities are held to the kind of thinking, it frustrates society that our punishments are not having the desired behavioural changes.

Rethinking our individual responsibilities and moving towards communities of care is explored within the disability of FASD. This will be highlighted in the case examples of the Lifespan Centre for FASD which utilize community-based services for diagnosis, support, mentorship, education, assessment and resource development to build communities of support for individuals with FASD and their families. The 17 years of experience of the LCFASD, 10 years of that being diagnosis and support, has provided many insights into serving individuals with FASD. Several policy considerations will be discussed to encourage more meaningful community engagement.

The common saying "it takes a community to raise a child" could be translated into it takes a community to support an adult with FASD.

## Elizabeth Bredberg



PhD, Research Director, Society for the Advancement of Excellence in Education

Elizabeth Bredberg has worked with people with

developmental disabilities since 1983. In 2000 she began work as education consultant with the multidisciplinary FASD diagnostic team of Sunny Hill Health Centre for Children in Vancouver. Between 2000 and 2006, she participated in over 400 diagnostic sessions at Sunny Hill. As education consultant, she then visited the schools of each child or youth who had come to Sunny Hill, observing in their classrooms, and collaborating with school staff, families and other community members to develop an education plan.

integrating school and community resources with the multidisciplinary team's findings. This work took her across all of British Columbia and enabled her to learn from a wide variety of practices from kindergarten through community college level.

Dr. Bredberg has presented on FASD and education at many workshops. In 2007 she was invited to Scotland and England, where she presented at a meeting of the Scottish Paediatric Society and at the NORDAS UK annual general meeting. She serves on conference planning committees, and consults to provincial and community resources. She is currently teaching in the Department of Special Education at the University of British Columbia and consulting privately.

### Abstract

#### Education policy directions for supporting children and youth with FASD and their families

A review of special education policy within Canadian ministries of education shows little that directly addresses supports for students with FASD. Within jurisdictions using categorical access to services (currently all but two territories), placement and support for students with FASD diagnoses can vary according to an individual student's presentation of the disorder.

Students with FASD continue to show low rates of school completion, high rates of suspension for behaviour and other disciplinary

**Question 5: What policy options could more effectively support individuals with FASD and their families across the lifespan?**

television, peer academic achievement and very limited positive social involvement with their nonaffected classmates.

This presentation focuses on education policy in Alberta. A review of special education currently under way within the province is directed towards an increased emphasis on inclusion. Within this model, special education is situated within the broader mandate of the provincial education system. Although a shift towards a more inclusionary model will potentially eliminate some challenges posed by existing policy, new challenges will emerge.

Realistic and effective support for students with FASD within an inclusive system requires policies mandating:

- Equitable and timely access to diagnosis for students with suspected FASD and channels for communication around diagnostic findings with appropriate education professionals, with the intent of reciprocal sharing of information;

- A FASD diagnosis should not be an exclusive criterion for eligibility to specialized support. A multidisciplinary diagnosis of FASD should, however, be used to inform instructional planning;
- Equitable access available to programming, instruction and evaluation that matches individual learning strengths and needs throughout the course of a learner's education. Assessment should be repeated at points of transition into kindergarten, out of primary grades, into high school and into post-secondary life. The establishment of channels and schedules of collaboration in assessment between medical and educational expertise and caregivers are required;
- Goals related to the development of independence should be replaced by goals addressing growth into contributing and valued community members. Instructional planning needs to be made available that enable individual students to learn

to function as contributing members of their communities. Structures and schedules of communication within community members, including families, caregivers, recreation providers, and potential employers should be recognized as a key element in the development of an individualized curriculum.

- Accountability must be maintained to determine that a student's programming is appropriate and that instruction is provided in a manner that enables them to benefit from programming;
- Needs assessments should be mandated and common and mutually intelligible to all areas of service provision. They should replace age and IQ as criteria for eligibility for services;
- Capacity to support learners with FASD should include university level pre- and in-service instruction for all classroom teachers and other education professionals.

**Claire Coles**



Center, Children's Health Care of Atlanta

PhD, Professor, Department of Psychiatry and Behavioral Sciences and Pediatrics, Emory University School of Medicine, Director, Fetal Alcohol and Drug Exposure Clinic, Marcus Autism

Claire D. Coles is Director of the Maternal Substance Abuse and Child Development (MSACD) Project and Professor in the Department of Psychiatry and Behavioral Sciences, Emory University School of Medicine, Atlanta, Georgia, with a joint appointment in the Department of Pediatrics. The MSACD project carries out research on the effects of maternal substance abuse and cognitive and emotional/social development of offspring from birth through adulthood.

She is also Director of the Fetal Alcohol Center at the Marcus Center, a Division of Children's Health Care of Atlanta University, which provides services to families and

children with developmental, learning and behavior problems. Through the FAS Clinic at the Marcus Institute, Dr. Coles provides diagnostic and clinical services to children primarily exposed to alcohol, cocaine and other drugs. In addition, the Center is conducting intervention studies with alcohol-affected children aimed at remediation of specific effects of prenatal exposure.

Dr. Coles is recognized as an expert on an international level on the effects of addiction and alcoholism and the impact of maternal substance abuse on cognitive, social and emotional outcomes of infants and children and has published a number of books and articles in this area. She was a member of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects, is a past president of the Fetal Alcohol Study Group of the Research Society on Alcoholism, and was a member of the National Academy of Science's Institute of Medicine's Committee to Study Fetal Alcohol Syndrome.

**Abstract**

**Development of life skills: education, parenting and family mentoring**

Until recently, little formal attention was paid to the educational needs of alcohol-affected individuals and their families. However, it was often suggested that standard methods for education and intervention were ineffective with this group of brain-injured individuals and that children with FASD did not respond like others to behavioral interventions and parenting techniques. This assumption places the "blame" for negative outcomes on children and families while ignoring other factors that contribute to educational and behavioral problems. Some of these factors, e.g., early identification and intervention; parenting and substance abuse treatment; training for health care and education providers; support for diagnosis and education; may be responsive to changes in medical, social and educational



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policy. In addition, recent research into effects of intervention and treatment makes it possible to identify educational methods that lead to more positive outcomes.

Review of the recent, and still limited, literature on FASD intervention suggests the following:

1. Positive outcomes are found when programs are designed to meet the specific needs of children with FASD. These needs include attention to the characteristic behavior patterns associated with FASD that are related to neurodevelopment effects of prenatal alcohol exposure on the central nervous system;
2. Successful programs have adapted methods used with other high risk groups to the specific needs of FASD;
3. Caregiver involvement is necessary to support educational and behavioral interventions;
4. Behavioral intervention methods are successful;

5. Educational and behavioral interventions require that all of the "systems" the child experiences provide a consistent experience; and,

6. Research has been limited to preschool and school-aged children.

There is now a small, although pervasive, amount of literature on interventions with alcohol-affected children and their caregivers, but there remains much more to be done. Current information is limited both in the age range studied and in the number and kind of studies. While intervention can be successful for preschool and school-aged children, it is likely that it would be valuable with infants and older individuals as well, and research is necessary to identify programs that will benefit these groups. To provide appropriate educational interventions, teachers and caregivers must be trained to understand the specific needs of alcohol-affected individuals and be provided with the tools needed to help them. In addition, opportunities for screening and diagnosis

are essential to identify FASD and to develop appropriate treatment plans.

Behavioral and academic problems associated with FASD can improve with treatment. Policy implications include:

1. Expanding the intervention research base and include infants, adolescents and adults;
2. Making the assumption that early identification, diagnosis and intervention will be beneficial and cost effective and put mechanisms in place to assure that this occurs. This should include newborn screening as well as access to "FASD Diagnostic Clinics;"
3. Providing caregivers and teachers with the tools they need to effectively change behavior;
4. Educating the educators regarding effectiveness of interventions for FASD; and,
5. Identifying FASD as a category requiring services in educational and social service regulations.

## Brenda Bennett

Executive Director, FASD Life's Journey Inc.

Brenda Bennett is the founding Executive Director of FASD Life's Journey Inc. FASD LJ is a Manitoba community-based, not-for-profit agency focusing on the broad spectrum of individual needs of adolescent and adult Manitobans affected by Fetal Alcohol Spectrum Disorder. Brenda has worked in the disability sector for over 20 years in a number of senior capacities including Disabilities

Consultant, Community and Program Developer, Clinical Case Manager, Program Manager and Executive Director. She has co-developed a direct-service model and a range of neurodevelopmental strengths-based programs for adolescents and adults impacted by FASD. She is a sought after national and international FASD speaker, educator, and consultant. Brenda is a loving mother, foster parent, grandmother and a passionate advocate.

## Abstract

### Life stages and transitions

Abstract not available

## Sharon Brintnell



DEP & OT BOT MSc FCAOT  
CDMP Professor,  
Department of Occupational  
Therapy, and Director,  
Occupational Performance  
Analysis Unit, Faculty of  
Rehabilitation Medicine, University of Alberta

Sharon Brintnell is a Professor in the Department of Occupational Therapy, a past chairperson of the Department of Occupational Therapy, University of Alberta (13 years) as well as a past president of the Canadian Association of Occupational Therapists (CAOT). After serving as the VP Finance for the World Federation of Occupational Therapists' Council for 10 years she was elected President in September 2008.

As Director of the University's Occupational Performance Analysis Unit (OPAU), Sharon maintains an active role in practice and has been qualified seven times in the Alberta Court of Queen's Bench as an expert in occupational performance and functional assessments and is certified as a Disability Management Professional.

Working with students and colleagues,

Professor Brintnell, collaborating on the design and implementation of community models of support and intervention to enable occupational performance for clients of a number of inner city non-governmental organizations. The OPAU team has consulted on a number of community development initiatives with First Nations on mental health, Fetal Alcohol Spectrum Disorder and wellness programs. In the last eight years the output of collaboration with the Psychology Department of the Fort Saskatchewan Corrections Centre and an OPAU cultural consultant resulted in the Mind Body Spirit program. This formed the foundation for the Corrections to Community (C2C) program for FASD female Aboriginal offenders and the recently funded Corrections to Community Connections (C2C) for men. These initiatives arose out of the desire to support community re-integration through pre-release services to Aboriginal offenders.

Professor Brintnell initiated the process and served on all of the Canadian Occupational Therapy Guidelines for Client-Centred Practice task forces with Health Canada, chairing the volume on mental health and was a contributing author to *Enabling Occupation 1*. She is the recipient of a number of prestigious national professional awards.

## Abstract

### Social services and corrections

Numerous studies have identified the presence of adult offenders with Fetal Alcohol Spectrum Disorder in Canada's correctional systems. The range and complexity of the community re-entry needs of these offenders require interdisciplinary and multi-sectoral approaches to determine which offenders have FASD and to connect them with services and supports that match their function explicitly. Introducing services while in jail has the ability to increase the effectiveness of connecting released offenders to community resources. There are few studies identifying the range and kind of social services supports in place for released FASD offenders. Those that exist differentiate between the programs for men and women (based on gender roles or draw on extrapolations from research with the families of youths and children with FASD), offenders in general and other populations with brain damage. The limited evidence available speaks to supported transition of offenders which starts relationship building and planning prior to release and then continues into the community.

## John McLennan



BMSc MD MSc PhD FRCP  
Assistant Professor,  
Departments of Community  
Health Sciences, Psychiatry,  
and Paediatrics, University  
of Calgary

Dr. John McLennan's undergraduate degrees in medical science and medicine were obtained at the University of Alberta. He then completed his residency in psychiatry and child and adolescent psychiatry at the Western Psychiatric Institute and Clinic at the University of Pittsburgh, as well as a Masters in Public Health. He went on to complete a fellowship in community psychiatry and residency in preventive medicine at the

University of North Carolina at Chapel Hill. He also completed a PhD in Health Research Methodology at McMaster University during research fellowship training at the Offord Centre for Child Studies. He is currently an Assistant Professor at the University of Calgary.

Dr. McLennan has held a Population Health Investigator Award from the Alberta Heritage Foundation for Medical Research and a New Investigator Award from the Institute of Health Services and Policy Research at the Canadian Institutes of Health Research. His research interest is focused on examining how society is trying to improve the outcomes of vulnerable

children and to what effect. He is particularly interested in factors that may undermine these efforts, including research-practice, service-practice, and service-use gaps. Vulnerable children of particular interest include those with mental health difficulties and those growing up in poor urban areas in developing countries. In addition to his research activities, Dr. McLennan provides mental health consultation within the Community Outreach in Paediatric Psychiatry and Education program (COPE), a school-mental health partnership program in Southern Alberta. His clinical focus is on children with attention and disruptive behavioural problems.

## Question 5: What policy options could more effectively support individuals with FASD and their families across the lifespan?

### Abstract

#### Treatment for FASD

From a health service delivery perspective, there is no compelling scientific evidence to justify the development of unique or separate treatment programs for children with Fetal Alcohol Spectrum Disorder (FASD). Service and treatment needs of children with FASD and their families should be driven by the specific needs and problems of the individual child and family and not the FASD diagnosis. This could be attained by linking children with FASD and their families to evidence-based interventions for the specific area(s) of need or difficulty.

1. The extent of overlap of difficulties manifested by referred children identified as having FASD with other children with developmental and/or mental disorders likely far exceeds the extent of unique difficulties. This questions the appropriateness of creating unique services or policies specific to FASD.
2. The diagnosis of FASD in and of itself provides little guidance as to the specific needs of individual children and hence it does not directly inform treatment planning. Although children with FASD may be

at higher risk for a variety of problems, it is the specific problems that need to be clearly identified to inform treatment planning for the individual.

3. The needs of different children identified as having FASD and their families are so heterogeneous that grouping them together for specific services or treatments or to inform specific policies is likely to be inappropriate as it will not be optimal for many of the children sharing the FASD label or their families.
4. All the needs and difficulties manifested by a child with FASD are not just a function of the prenatal alcohol exposure but rather a combination of the many factors that influence child development for all children including many genetic and environmental factors and their interaction. Treatments or policies based on the assumption that FASD (or the prenatal alcohol exposure) is always the most important factor for each child sharing this feature will be ill informed.
5. Findings from the very limited number of treatment intervention studies with children with FASD indicate that treatment can lead to improvements. However, these promising treatment approaches work (or are likely to

work) with non-FASD populations that share the difficulty targeted by the treatment, e.g., attention problems, social skill deficits, math disorders. That is, these are NOT unique treatments for children with FASD but treatments that are effective for difficulties that are seen in children with FASD as they are in other populations of children. There is therefore NOT a need to deliver these treatments exclusively to children with FASD; rather these treatments should be available for all children with the given difficulties whether or not they have FASD.

6. Scientific evidence needed to alter these proposed policy recommendations would be findings identifying treatment approaches that are uniquely beneficial to FASD children and not other children with other disorders or their families. This would be an unlikely occurrence, but if such a pattern was found it would support the development of specific treatment tracks and supporting policies specifically for FASD.

### Mary Kate Harvie



J.J.H. Associate Chief Judge  
Provincial Court of Manitoba

Mary Kate Harvie received her Bachelor Laws degree from the University of Manitoba in 1996 and, after passing her bar administration exams, practised as a barrister and solicitor for Myers Weinberg until 2000. She focused on criminal law, civil litigation, and labour law. In July 2000 she was appointed to the Provincial Court of Manitoba, and then was appointed as Associate Chief Judge in 2002.

Since 2002, ACJ Harvie has been working with a multidisciplinary team to establish the FASD Youth Justice Project which has developed a process by which youth involved in the criminal justice system can be assessed for Fetal Alcohol Spectrum Disorder. In June 2006, the FASD Youth Justice Project was awarded the Manitoba Service for Excellence Award – “Partnership” category.

ACJ Harvie has served on a number of community and educational boards, including Rosebrook House Inc., a neighbourhood centre for children and youth in Winnipeg's inner-city and The Nature Conservancy of Canada, a private non-profit organization working for the direct protection of Canada's biodiversity.

### Abstract

#### Justice Issues

In Manitoba, access to FASD assessment for adolescents and adults was very limited. In response to this problem, the Fetal Alcohol Spectrum Disorder Youth Justice Program (FASD YJP) was developed to provide a mechanism for court-ordered assessments and to facilitate more appropriate services for FAS-affected youth in the justice system. This program is a multi-system collaborative approach to assessment, diagnosis, sentencing and intervention for youth and their families who are impacted by FASD. Initiated in September 2004, the program is currently seeking to initiate change within and across systems

**Question 5: What policy options could more effectively support individuals with FASD and their families across the lifespan?**

while accessing existing resources for youth and seeking to develop new ways of providing service to youth with FASD and their families.

Only those youth who have not previously been diagnosed are eligible to participate. To date, 332 referrals have been made to the program, 94 youth have been assessed for FASD, 63 have received a diagnosis, 55 assessed as being ARMED. Significant reductions in the number and severity of charges have been seen after assessment and interventions.

**Challenges**

- Finding FASD knowledgeable, stable and supportive placements.
- Finding resources to support individuals who are living in areas that tend to be affected by poverty, gangs, alcohol and drugs, violence and abuse.

- Accessing assessments and continuing support for individuals over 18 years of age.
- Overcoming the 'stigma' of FASD assessment and addressing women's health and addiction issues.
- Recognizing the vulnerability and victimization of FAS-affected youth and adults.
- Overcoming barriers between departments and organizations providing support.
- Overcoming the time constraints inherent in the criminal justice system.

**Recommendations**

- FASD diagnosis is accepted for Supported Living, rather than on IQ below 70.
- School programming is adapted to provide more knowledge (hands-on learning).

- The zero tolerance policy in schools and programs be re-evaluated when working with children with FASD.
- Secure FASD halfway houses for diagnosed youth and adults to allow for gradual reintegration to the community, improved housing in the community.
- Provide education to lawyers, crown's, judges, corrections staff and group home workers on the brain domains impacted by prenatal alcohol exposure. To provide training on the practical application of this information.
- Amend the Criminal Code to allow for Court-ordered FASD assessments for adults.
- To increase access to assessments for youth and adults.
- Increase the involvement of victims and thereby improve community awareness.

**Dorothy Badry**



PhD RSW, Assistant Professor,  
Faculty of Social Work,  
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Dorothy Badry, PhD RSW, is an Assistant Professor in the Faculty of Social Work (FSW), University of Calgary (U of C). Her research interests focus on Fetal Alcohol Spectrum Disorder (FASD), birth mothers and families of children with FASD and disability advocacy. Dr. Badry is a member of the Canada Northwest FASD Research Network Action Team (NAT) on Women's Health, Co-Lead of the NAT on Mentoring and a member of the Prairie Child Welfare Consortium. Dr. Badry has received funding for projects related to FASD from the Alberta Centre for Child, Family and Community Research (ACCFCR) and the Public Health Agency of Canada.

Dr. Badry, with colleagues from the U of C and FASD Cross-Ministry initiatives, is currently engaged in an interview research project, examining outcomes for children in the care of Alberta Children and Youth Services who are suspected or diagnosed with FASD and receiving enhanced practice supports. This project received \$100,000 from ACCFCR for this two-year project (2009-2011).

Dr. Badry has conducted qualitative research with birth mothers of children diagnosed with Fetal Alcohol Syndrome; evaluation research on FASD-related programs with colleagues from the University of Alberta and Catholic Social Services in Edmonton, including a qualitative study with mentors working with families living with FASD. Another recently completed project, through the Centre for Excellence in Social Work Research was an environmental scan on adult diagnosis of FASD (Badry & Bradshaw, 2009). Dr. Badry is a passionate advocate for children and families confronted by FASD.

**Abstract**

**Policy development and FASD**

The phenomenon of FASD is relatively new in the nomenclature of medical and social problems, having emerged from work disseminated in 1973 from the University of Washington. The challenge of developing social policy in relation to FASD is that its presentation ranges amongst individuals in terms of the severity of its effects. The neurological problems that result from alcohol exposure in utero create challenges for the individual in negotiating many of the social dimensions of life in the community, in order to address policy gaps

there must be a consistent approach to FASD within an interdisciplinary framework. Efforts to address FASD amongst various stakeholders from the community to federal government require collaboration for non-Aboriginal and Aboriginal people of Canada. Policies that consider the detrimental effects of alcohol over a lifespan need to be developed in consideration of ameliorating those concerns and supporting healthy pregnancies within communities. A policy framework for FASD must consider all segments of the population including women and men of all stages of life: childhood, adolescence, adult life and aging. Individuals with FASD require policies to be developed that will support them over the lifespan that recognize their support needs do not change, with each life transition. Policy that determines priority access to supports for conceiving and pregnant women that is long term and shared amongst different sectors of the service system should be developed. Lifespan planning policy should be considered in recognition of FASD as a lifelong disability.

## Question 6: What further research into FASD is needed?

### Sterling Claren



MD FACP, Chief Executive Officer and Scientific Director, Canada Northwest FASD Research Network; Clinical Professor of Pediatrics, School of Medicine, University of Washington; Clinical Professor of Pediatrics, Faculty of Medicine, University of British Columbia

Dr. Sterling Claren is the CEO and Scientific Director of the Canada Northwest FASD Research Network and a clinical professor of Pediatrics at the University of British Columbia and the University of Washington. Since 1975, Dr. Claren has applied his training in dysmorphology, neuropathology, neuromyology, and developmental pediatrics to the problems of fetal alcohol spectrum disorders in clinical diagnosis, clinical evaluation and intervention, and clinical and basic research. Dr. Claren wrote the first major summary article of the clinical pattern of malformation associated with alcohol teratogenesis in the *New England Journal of Medicine* in 1978. He was co-author of the 4-Digit Diagnostic Code for FAS and related

conditions. This last work has recently been accepted, with minor modification, as the Canadian standard for FASD diagnosis. Dr. Claren developed one of the first pediatric clinics focused on the difficult diagnosis of FAS and related conditions in 1978, and has refined the clinical approach over many years. In 2001 he was given the Henry Rosett Award by the Fetal Alcohol Study Group of the Research Society on Alcoholism in recognition of "outstanding clinical insight, leadership and research." In 2006, he received the Award for Career Excellence from the National Organization for FAS in Washington DC. He lectures internationally and has recently been a distinguished visiting professor at both Queen's University and at McGill.

### Abstract

#### Health and social policy

Since Fetal Alcohol Syndrome was brought to public attention in the early 1970s, a natural experiment has occurred as those with an

interest in this topic have tried to improve the life situations for affected individuals as well as create strategies for prevention.

After 35 years or so, the successes and limitations of these endeavours are reasonably clear. Clinical advancements in diagnosis, prevention, interventions, and surveillance can be used to advance public policy and have been, if only to a limited extent. However, without clear direction from government, on the kinds of information that would be truly helpful and sustained funding for that work, much of research that is needed has not and will not be done. This presentation will focus on specific topics in clinical research in FASD that need immediate attention if this field is to move forward, but each requires an active role from government as well as from the community of inquiry.

### Sara Jo Nixon



PhD, President, Research Society on Alcoholism; Fellow, Divisions 26 and 50, American Psychological Society; Professor and Chair, Division of Addiction Research, and Director, Neurocognitive Laboratory, Department of Psychiatry, College of Medicine, University of Florida

Dr. Sara Jo Nixon is an experienced clinical researcher in the area of substance use abuse and dependence. Her research program focuses on the cognitive, psychological and social consequences of substance misuse with a particular interest in women and American Indians. Because of the complex nature of substance abuse, her work uses comprehensive assessments including neuropsychological testing, brain wave examination and clinical research interviews.

Dr. Nixon is the author of over 110 peer-reviewed articles, two edited books, and a number of book chapters. She has made over 200 scientific presentations, including service on a Substance Abuse and Mental Health Services Administration (SAMHSA) panel regarding FASD. Additionally, she is President of the Research Society on Alcoholism, serves on national committees for the U.S. National Institutes of Health, the U.S. Department of Veterans' Affairs, the American Psychological Association and the U.S. National Center for Research Resources.

### Abstract

#### Focusing Research Efforts.... Where?

Over the past three decades, we have made significant advances in describing the dysmorphology and neurobehavioral deficits

associated with FAE. We have conducted essential work regarding neurodevelopmental trajectories and social-behavioral adaptation. These studies, derived from prospective animal studies and observational human studies, have significantly altered medical practice, educational considerations and increasingly, judicial decisions.

Even with these advances, we have much to learn. I have identified three general areas of research which, based on the existing literature, demand additional attention, and I will provide brief overviews of these areas and initial approaches for addressing them.

The first area centers on one of the hallmarks of FASD, heterogeneity in neurobehavioral and structural outcomes among exposed offspring. These findings moved the field from reliance on a

## Question 6: What further research into FASD is needed?

diagnostic dichotomy to a more complex ordinal scale engaging a spectrum of potential outcomes. Yet, the question remains, why are some fetuses relatively spared from alcohol's toxic effects? When exposure dose and timing are accounted for, what are genetic or environmental factors which impact outcome? Does this protection arise from maternal or fetal characteristics? What is the nature of the maternal/fetal interaction and how might addressing this question inform a larger field concerned with fetal development and maternal and child health?

The second area focuses on more effective modeling of the neurobehavioral deficits associated with alcohol exposure. Deficits across a wide range of cognitive and behavioral

tests are reported. However, theoretically driven work focusing on fundamental neurocognitive processes known to underlie these end-point measures is largely lacking. Additional programmatic research using process approaches would significantly enhance the impact of this work and provide comparisons across tasks which appear to be distinct, but actually rely on common processes. Further, process-oriented work lends itself to more effective education and intervention efforts by providing insight regarding both rehabilitation and compensatory processes.

Third, current developments in the neurosciences are not fully applied. Animal and human studies demonstrate enormous plasticity in neural

development throughout infancy, childhood, adolescence and into young adulthood. How might what we know regarding "normal" brain development, the on/off/on-set of systems, the process of neuronal growth and pruning, and the role of environmental factors provide opportunity for pre- and/or postnatal intervention? More directly, how might behavioral and pharmacologic interventions be guided by this work?

We stand at the intersection of cognitive, behavioral and developmental neurosciences. Programmatic, interdisciplinary studies are needed to advance the field toward a more cohesive, richer-driven perspective, thereby enhancing prevention and intervention efforts.

## Bruce Perry



MD PhD, Senior Fellow, The ChildTrauma Academy

Dr. Bruce D. Perry is the Senior Fellow of The ChildTrauma Academy, a

Houston-based not-for-profit organization that promotes innovations in service, research, and education in child maltreatment and childhood trauma ([www.childtraumacademy.org](http://www.childtraumacademy.org)). He is the author, with Maja Szeftel, of *The Boy Who Was Raised as a Dog: What Traumatized Children Can Teach Us About Loss, Love, and Healing*, a popular book based on his work with traumatized children. Over the last 20 years, Dr. Perry has been an active teacher, clinician, and researcher in children's mental health and the neurosciences, holding a variety of academic positions.

## Abstract

### Child health and well-being

Exposure to alcohol in utero can have a range of neurologic and neuro-disruptive effects, the consequences of which will often manifest as functional compromise in a range of key neural networks. The ultimate impact of this intrauterine insult can vary tremendously. Currently the most clinically obvious manifestations of FASD are being elucidated. Not every child exposed to EtOH in utero is unique in multiple ways: the pattern and timing of EtOH exposure, epigenetic and genetic factors, other intrauterine insults (e.g., smoking, poly substance use, domestic violence,

trauma, poor nutrition, perinatal factors (e.g., post-partum depression, attachment disruptions, neglect) and early childhood experiences (both adverse and positive) will interact to create the final phenotype or functional expression of a child's potential.

The very complexity of these inter-related influences on neurodevelopment creates both challenge and hope. The challenge is in the necessity to design and conduct more complex, prospective studies that take these factors into consideration and the hope is that the complexity and plasticity of neurodevelopment suggest multiple potential pathways for influencing development in positive or negative ways.

FASD is a multi-dimensional problem (e.g., other neurodevelopmental insults, compromised neurobiology, individual behavioral and cognitive compromise, impaired maternal dyad, family dynamics within a moving set of problems (e.g., transgenerational trauma, family history of EtOH abuse) within a distressed society (e.g., sociocultural fragmentation, systemic compartmentalization, medical-economic limits). Future research is needed in all of these intersecting and interacting domains. Two key areas in future research should be to begin to address the complexity of FASD by assessment of the differential impact of the full complement of developmental adverse effects (the nature, timing, pattern and intensity which may be co-existing with EtOH exposure, and more detailed

examination of factors which appear to be related to resilience and healing. In this regard a key area is the number and stability of key relationships during development.

Current funding models for traditional research studies are not likely capable of providing the sustained resources for the large numbers of children and families, the multi-dimensional assessments and the longitudinal tracking required to develop a true developmental understanding of FASD with its multiple manifestations and inter-related neurodevelopmental confounds.

1. Build developmentally meaningful outcomes into programs. Future intervention programs and service-delivery practices need to be developed with suitable assessment and outcome elements to allow the acquisition of data simultaneously with the delivery of services. This will allow self-correction of the practices, programs and policy and the capacity for researchers to build the database for better understanding the complex and fragile aspects of FASD.
2. Create the research infrastructure to allow more focused controlled studies to be conducted based upon the theoretical concepts that will emerge from larger well-conceived outcomes from a service-delivery or clinical database.

## The Institute of Health Economics Consensus Development Conference Program

How do you engage citizens, decision-makers and experts in an appropriate way to address complex health issues? One approach is the consensus development conference.

The Institute of Health Economics conducts a number of evidence dissemination activities and deliberative processes designed to get the latest evidence into policy and practice. One approach is our Consensus Development Conference (CDC) Program which engages leading experts in an interactive process with a Jury who develop a consensus response and recommendations on a set of pre-determined questions. The IHE's program is modelled on the successful National Institutes of Health (NIH) consensus development program in the United States.

The past conferences conducted by the IHE are:

### **2008**

#### **Depression in Adults: How to Improve Prevention, Diagnosis and Treatment**

Held in October 2008 in collaboration with the Alberta Depression Initiative Project, Alberta Health and Wellness, the Alberta Mental Health Board and the Mental Health Commission of Canada, this conference focussed on depression in adults and ways to improve prevention, diagnosis and treatment.

### **2007**

#### **Healthy Mothers, Healthy Babies: How to Prevent Low Birth Weight**

Held in April 2007 in collaboration with the Alberta Perinatal Health Program, this conference focussed on factors contributing to the high rate of low birth weight in Alberta, and to develop a consensus on the relevant factors, interventions need to address the contributing factors.

### **2006**

#### **Self-Monitoring in Diabetes**

Held in November 2006, IHE hosted this first-in-Alberta consensus development conference on self-monitoring in diabetes, looking specifically at the cost of testing, whether people with diabetes use test strips to monitor their blood sugar levels and, if so, whether they act on the information generated from these tests.

For further information on this program and other deliberative processes, contact John Sproule, Senior Policy Director at 780-448-4861 or through [info@ihe.ca](mailto:info@ihe.ca). Past statements can be accessed on the Institute's website at [www.ihe.ca](http://www.ihe.ca).

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Appendix 2: Consensus Statement


Consensus Statement on

**Fetal Alcohol Spectrum Disorder (FASD) – Across the Lifespan**



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**Government of Alberta** ■

## Acknowledgment

**The Honourable Anne McLellan** (LL.M, King's College, University of London; Alberta Institute for American Studies, University of Alberta; Academic Director and Distinguished Scholar in Residence, Institute for United States Policy Studies) led a distinguished jury of citizens and experts to develop practical recommendations on how to improve prevention, diagnosis, and treatment of Fetal Alcohol Spectrum Disorder

Expert Chair, **Dr. Gail Andrew**, (MDCM FRCP(C); Member, Board of Directors, Canada Northwest FASD Research Network; Medical Site Lead – Pediatrics, Medical Director – FASD Clinical Services and Pediatric Consultant, Pediatric Programs, Glenrose Rehabilitation Hospital) led a panel of experts in presenting available scientific evidence on Fetal Alcohol Spectrum Disorder.

## Process

This consensus statement was prepared by an independent jury of health professionals, academics, and public representatives based on: 1) relevant published studies assembled by the scientific committee of the consensus development conference; 2) presentations by experts working in areas relevant to the conference questions; 3) information by people who have been touched by FASD; 4) questions and comments from conference attendees during open discussion periods; and 5) closed deliberations by the jury.

The conference was held in the province of Alberta, Canada. The consensus statement therefore often refers to the situation in Alberta, although data were not only drawn from that area, but also from other parts of Canada, the U.S. and internationally.

This statement is an independent report of the jury and is not a policy statement of the conference partners, conference sponsors, or the Government of Alberta.

## Conference Questions

The jury used the evidence presented to them at the conference to determine answers – in the form of a consensus statement – to the following questions:

1. What is Fetal Alcohol Spectrum Disorder (FASD) and how is it diagnosed?
2. Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?
3. What are the consequences of FASD for individuals, their families and society?
4. How can FASD be prevented?
5. What policy options could more effectively support individuals with FASD and their families across the lifespan?
6. What further research into FASD is needed?

## Introduction

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe the range of disabilities caused by prenatal exposure to alcohol. It is a significant Canadian health concern and concerted action is required from all levels of government, researchers, communities, families and individuals if we are to deal with it effectively.

Compared to many other areas of study, FASD is relatively new. It was first identified in 1973 when a similar pattern of malformations among infants born to alcohol abusing women was noted. Since then research has been done, knowledge has been gained, and it is time to move forward, building on the good work that has been done by researchers, clinicians and communities across the country.

It would be a simple but short-sighted strategy to say to all women of child-bearing years – “*just don't drink alcohol.*” That would ignore the complexity of the lives of women and their families and the communities in which they live. This is not only a “women's” issue. It is one for which all of us, women and men, mothers and fathers, families and communities need to take responsibility.

The difficulties for Canadian families living with FASD cannot be overestimated and actions to support them should be comprehensive, integrated and timely. Multidisciplinary assessment and multisectoral responses are necessary.

It is time for a National Agenda integrating research done and lessons learned. The Agenda must increase awareness of FASD and promote the development of effective prevention and treatment programs, as well as family support systems. The time for further action is now.

## Question #1

### What is Fetal Alcohol Spectrum Disorder (FASD) and how is it diagnosed?

#### What is FASD?

Fetal Alcohol Spectrum Disorder (FASD) refers to a complex range of brain injuries that can result from prenatal exposure to alcohol (PAE). It is an umbrella term that has evolved over time and is used to denote an array of developmental, physical, learning and behavioural conditions.

The bottom line is that pre-natal exposure to alcohol, in combination with other risk factors, may cause brain injuries, which are expressed in unique and individual ways.

FASD can occur in all segments of society. Poverty, genetics, maternal stress, poor nutrition and other prenatal exposures can influence the severity of FASD. Prenatal exposure to alcohol, while not the sole component contributing to FASD, is a necessary one and therefore FASD is preventable.

### **How is it diagnosed?**

There are no definitive biological markers for FASD such as a blood test or the use of imaging technology. While there is promising research in a number of areas there is no definitive or cost effective test yet. National guidelines for diagnosis of FASD were accepted across Canada in 2005 and involve a comprehensive multidisciplinary assessment of brain function. The challenge with diagnosis is not simply to identify brain injury but to assess a person's ability in the exercise of judgment, planning, memory and the ability to cope independently in day to day life.

The National Guidelines for FASD Diagnosis include demonstrated maternal alcohol consumption during pregnancy, physical examination for growth and physical features, and neuro-developmental assessment. Early identification and diagnosis can support better interventions and can affect long term outcomes. However, there are shortcomings with respect to the current system and ensuring consistent implementation of the guidelines. There are also administrative challenges, including:

- Limited human and financial resources for neuro-developmental assessment across the country
- Cost in both time and resources
- Lack of training of personnel in conducting assessments

In addition, stigma can create barriers to active participation and accuracy of diagnosis (shame and blame).

### **Recommendations:**

1. There is a need for national funding for research to develop accurate and cost effective neurobiological and/or functional markers of FASD.
2. Comprehensive diagnostic capability needs to be available across the lifespan.

## **Question #2**

### **Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?**

There is clearly a need for major improvement in the reporting of FASD. The current provincial/territorial and national estimate for FASD in Canada is 9 cases per 1000 infants born. This is based on extrapolation of US data. There is some recent international data gathered from a variety of in-school screening and diagnosis studies which suggests that the overall incidence may be higher. There is Canadian data that indicates greater prevalence in rural communities, foster care systems, juvenile justice systems and Aboriginal populations. The high prevalence of FASD in Aboriginal populations is symptomatic of a historical and multigenerational trauma, associated with events such as the residential school system.

Getting accurate information is extremely important as the details of regional and local prevalence and incidence are important to target and determine the effectiveness of prevention and intervention efforts.

Surveillance and screening tools need to be simple, cost effective, and accurate before they can be effectively implemented across the country. A starting point is accurate data regarding prenatal exposure to alcohol. There are impediments to the collection of this data, including stigma, reluctance of care providers, and limited availability of support services once prenatal exposure has been identified.

#### **Recommendations:**

1. A national surveillance strategy needs to be implemented to assess progress in the prevention and treatment of FASD in Canada. Questions on FASD should be included in the regular Canadian Community Health Survey.
2. Registries of non-personalized data for FASD surveillance should be established in each province to increase the capacity for screening, diagnosis, and reporting of FASD nationally. This should build on projects already underway regionally and provincially to increase data collection.
3. Reliable methods of early detection of developmental delays and disorders, including FASD, should be introduced into early school years and be available throughout the lifespan.
4. A strategy to reduce the stigma associated with a diagnosis of FASD is needed in order to ensure maximum participation in screening, prevention and diagnostic processes.

### **Question #3**

#### **What are the consequences of FASD for individuals, their families and society?**

The consequences of FASD are widespread, affecting individuals, their families, communities, and society as a whole. FASD is a highly heterogeneous disorder.

Individuals with FASD are most directly affected. FASD, as a brain disorder, is associated with a high incidence of cognitive and behavioral problems. People affected by FASD may have significant difficulties with memory, attention, self care, decision making and social skills as well as mental health disorders including depression and addiction. They may have problems with organization and planning their activities, difficulty controlling their emotions and completing tasks that would allow them to lead productive lives. FASD is often further complicated by medical issues including a higher rate of heart disease, hearing and vision problems.

FASD has a dramatic impact on families, whether it is the biological, adoptive or foster family. Families must be aware that there will be additional costs in raising a child affected by FASD and this may cause additional family stress. The biological mother is

dramatically impacted regardless of whether she is raising the child or not. Guilt can be considerable. When a woman is under stress or depressed, she may continue to drink. Indeed, a major risk factor for having an alcohol affected child is having a previous child affected with FASD.

FASD also affects all other members of the immediate family, including siblings and the extended family. Emotional, financial, and social burdens can be considerable. Indeed, the stress of living with a child affected with FASD may result in family discord or breakup. Adoptive and foster families confront similar issues in dealing with the needs of affected children. Again, proper supports are essential.

One cost that is more difficult to measure is that of lost human potential. The needs of individuals affected by FASD currently generate considerable costs for the social welfare, educational, medical, judicial and correctional systems and significant challenges for communities.

In Alberta, the annual economic cost of FASD is estimated to be between \$130 - \$400 million per year. Of this total, educational and medical costs take up 60% (including addictions and drug treatments), additional costs to families account for 20%, and the remaining 20% percent is for social services, supportive housing, lost productivity costs and other services such as costs to the justice system. Clearly, addressing this issue is crucial not only from the perspective of social justice but from the economic perspective as well.

#### **Recommendations:**

1. As FASD is a lifelong disability, there should be a commitment by governments to provide seamless and equitable services across the life span.
2. Important transitions from child to adult services need to be pre-planned and allow for effective wraparound services which will support individuals and families and communities at each stage of life.
3. People affected with FASD will require life-long intersectoral services. Consistent standards between provinces should be established to reduce variations in the funding and provision of these services.
4. Adults with FASD will require ongoing life skills and socialization assistance and support.
5. For those children who enter the child welfare system there should be improvements to ensure the ability to provide stable foster care. Multiple placements should be avoided wherever possible.

#### **Question #4**

##### **How can FASD be prevented?**

FASD prevention requires complex, culturally sensitive, multi-level initiatives that address very specific barriers and opportunities for learning, engagement and supportive

change. To successfully prevent FASD, it is critical to involve women, men, their support systems, community advocates, health promotion experts, researchers, health/social system planners, and service providers in designing these initiatives.

The Canadian Prevention Framework describes four levels of FASD prevention: 1) raising awareness for the whole population 2) discussing alcohol use with all girls and women of childbearing age 3) reaching and providing specialized care and support to girls and women who use alcohol during pregnancy and 4) supporting new mothers with alcohol problems.

Coordination and integration of prevention strategies must occur at all levels. We must learn from experience and build on and use existing umbrella strategies where available.

“Shame and blame” approaches to FASD prevention result in many missed opportunities to provide women with the timely, appropriate, and respectful supports needed to reduce the negative impacts of their alcohol use on their health and that of their children. Systems must be meaningful, effective, and compassionate in responding to the challenge of FASD and its prevention.

Because of the negative human and economic impacts of FASD, prevention is a good public investment.

#### **Recommendations:**

1. A national primary prevention strategy must include a clear message consistent with Canadian values. This should include education about the effects and risks of alcohol beginning in elementary school and continuing through post-secondary education. It should also include education about birth control.
2. Prevention programs should target the Social Determinants of Health.
3. Prevention programs should be designed along with evaluation frameworks.
4. Prevention efforts should be community driven, culturally appropriate, and should honour traditional knowledge. This is especially true in Aboriginal and immigrant communities.
5. A high priority should be placed on ensuring that prevention services are provided to women and families at highest risk of having a child with FASD. The Parent-Child Assistance Program (PCAP) has shown great success. Canadian programs based on the PCAP model should be encouraged.
6. Governments should require messaging about FASD in pregnancy testing kits and in contraceptive packages.
7. The reforms being made in primary care have the potential to improve the relationships required for effective prevention and support. Physicians and other primary health providers should take full advantage of “teachable moments” to discuss pregnancy prevention and the risks of alcohol consumption with their patients/clients of child bearing age.



8. Increase the number of women-centered alcohol treatment programs and beds.  
Keeping mothers and children together during interventions should be a priority.
9. National, provincial and territorial alcohol strategies must address FASD.

### Question #5

#### What policy options could more effectively support individuals with FASD and their families across the lifespan?

Ideally, policies and programs should reflect evidence-based best practices. Unfortunately, such evidence is not yet available as to how best to support individuals affected by FASD and their families across the lifespan. However, there are many examples of promising practices which may well be helpful and cost effective. These programs should be nurtured and shared, within the context of evaluation, so that the findings can inform future service delivery. Such evaluations should ensure the outcomes assessed are linked to functional improvements in the lives of those living with FASD and their families.

The heterogeneity of FASD requires the ability to tailor services to the needs of the individuals and their families, and recognize that these needs may change over time. Arbitrary eligibility criteria such as IQ, chronological age and place of residence (e.g. rural/urban, on/off reserve) are counter-productive and can be unjust. FASD is a lifelong condition and special attention needs to be paid to key points of transition.

Since FASD involves so many sectors, an inter-disciplinary approach is critical. Currently, different approaches may be taken by social services, education, health, the courts and the corrections system. The resulting fragmentation can be frustrating to people affected by FASD and expensive for tax payers. There should be '*no wrong doors*' for people affected by FASD who need support; mechanisms need to be in place to ensure such support is seamless. Services should address cumulative risk, both environmental and biological, and not be based on silos of care. Policy and services also need to be culturally sensitive.

Students affected by FASD continue to show low rates of school completion, high rates of suspension, poor academic achievement and limited positive social involvement.

Numerous studies have identified the presence of adult offenders with FASD in Canada's correctional systems. The range and complexity of community re-entry needs of people affected by FASD require interdisciplinary and multisectoral approaches to connect them with services and supports that match their functional capacity. Introducing services while in jail has the ability to increase the effectiveness of connecting released offenders to community resources.

While services and treatments for FASD have unique characteristics, they should be part of a larger system of delivering supports for people with disabilities. The services to individuals and their families should be needs-based. Lessons from effective evidence-based approaches dealing with other developmental disorders should be adopted where

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appropriate to FASD and vice versa. How best to place FASD programming within the broader framework of services for individuals with developmental and behavioural challenges is a matter of debate.

#### **Recommendations:**

##### **Lifelong Services**

1. Services should be (a) based on functional need rather than arbitrary eligibility criteria; (b) lifelong; (c) seamless; (d) individualized; (e) culturally sensitive; and (f) sustainably funded
2. There should be funding for systematic evaluations of programs and sharing of findings to develop best practices.
3. Build communities of support for individuals affected by FASD and their families. In particular, encourage mentorship and activity based programs.
4. There should be special attention and support for First Nations, Inuit and Metis peoples affected by FASD who have experienced societal breakdown due to historical and multigenerational trauma.

##### **Diagnosis/ Assessment**

1. There must be equitable and timely access to diagnosis for individuals with suspected FASD, including appropriate communication of findings with the individual, family, and other service providers.
2. Functional reassessments should be undertaken as needed.
3. Amend the Criminal Code to allow for Court-ordered assessments, including FASD.

##### **Education and Training**

1. Educational instruction and materials should be provided to promote awareness, understanding and knowledge of best practices for those who are or will be working with people affected by FASD.
2. An individualized educational plan needs to be developed focusing on skill development, inclusion, participation and recognition of existing strengths, to facilitate becoming a contributing member of society.

##### **Legal**

1. Improve outcomes and reduce costs to the legal system by utilizing an alternative measures program for adults affected by FASD charged with non-violent first offences. Take into account a FASD diagnosis on subsequent non-violent offences when sentencing.
2. Improve outcomes and reduce cost to the youth justice system by utilizing an alternative measures program for all young offenders affected by FASD, charged with non-violent offences.
3. Pre-release and post release programs for individuals need to be established.
4. Enhance the correctional environments to respond to the special needs of persons affected by FASD to protect them from exploitation and abuse.

## Question #6

### What further research into FASD is needed?

We still do not understand all of the basic mechanisms that create the spectrum of severity within FASD. Effects of exposure are highly variable. For example, the spectrum lies on a continuum from still birth to children with subtle learning and behavioural problems. Nor do we know enough about the factors that may magnify or reduce the risk from prenatal exposure.

What we do know is that research more than pays for itself. It reduces costs by more effective prevention, intervention and treatment of FASD. Current FASD research activities across Canada remain fragmented and underfunded. This leads to risk of omission or duplication of effort. There remain significant gaps in our knowledge, including outcomes across the life span and for special populations. Research is still in its infancy for corrections, justice and social services and is not comprehensive with respect to rates, outcomes, costs and co-occurring conditions. We continue to incarcerate the disabled!

We need new approaches to research to reflect current realities. We must embed research into service delivery. Research must include all levels of evidence including traditional knowledge. Rigorous and culturally appropriate research should include both quantitative and qualitative methodologies. Involvement and participation of the community in research is essential.

We need to support the ongoing development of interdisciplinary, integrated research networks that include health, education, social services, corrections, and communities. Active population-based monitoring must be in keeping with ethical and privacy standards.

Research must include basic as well as translational studies which are relevant to the lived experiences of persons affected by FASD. It needs to encompass issues in diagnosis, interventions, and all levels of prevention. Such research must be culturally appropriate, and address the needs of the individual, family, community, and the nation.

### Recommendations

1. More translational research from basic science to the human experience, such as the beneficial effects of nutrition.
2. More research on prenatal alcohol exposure on brain structure and function with the aim of improving interventions and outcomes.
3. More reliable indicators, biological and/or behavioural, of maternal alcohol consumption during pregnancy are needed.
4. Ongoing research for the development of better screening and surveillance tools, specific and sensitive to prenatal alcohol exposure. These should be adaptable, culturally appropriate and lead to accurate referrals for diagnosis and supports.

5. Encourage uniform approaches to recording clinical findings found during FASD assessments by using standardized forms and definitions.
6. Support intersectoral research with education, health and social services.
7. More research between corrections, justice and social services to identify rates, outcomes, costs and co-occurring conditions.
8. Initiate research into the role of parents, including fathers.
9. Embed research and evaluation into programs and services to allow for self-correction and continuous improvement.
10. Promote research on interventions based on social determinants of health that could modify the incidence and severity of FASD.

## Conclusion

We, the jury, believe that comprehensive and life-long services for people affected by FASD can and must be improved. Ongoing prevention efforts must be expanded.

Fetal Alcohol Spectrum Disorder is a complex issue. It has profound short and long-term consequences – for individuals, families, and communities. A multidisciplinary and multisectoral approach is needed if we are to improve the lives of those living with and affected by FASD.

To be successful - we need to be informed as much as possible by research and evidence but, at the end of the day, we must remember we are dealing with individual persons and families. We must respond with compassion for the challenges they face and respect for the unique capabilities they bring.

Government ministries and health systems owe it to everyone to fund and develop programs and explore new ways to help families, researchers and service providers to address this important issue. It is just. It makes sense. It is an investment in our future.

We, the jury, believe a national agenda to address FASD and its prevention is necessary and are pleased that Alberta is a leader in those efforts.

## Jury Members

**Chair: The Honourable Anne McLellan**, Alberta Institute for American Studies, University of Alberta; Academic Director and Distinguished Scholar in Residence, Institute for United States Policy Studies; LL.M. King's College, University of London

**Judith Bossé**, Associate Assistant Deputy Minister, Public Health Agency of Canada

**Jennifer Coppens**, Medical Student, University of Alberta

**Raia Deber**, Professor, Department of Health Policy, Management and Evaluation, Faculty of Medicine, University of Toronto; Director, CIHR Team in Community Care and Health Human Resources

**David Elton**, President, Norlien Foundation and Max Bell Foundation

**Mark Hattori**, Acting Assistant Deputy Minister, Program Quality and Standards, Alberta Children and Youth Services

**James Hees**, Reporter, CBC Radio Edmonton

**Malcolm King**, Professor, Department of Medicine, University of Alberta; Scientific Director, CIHR Institute of Aboriginal Peoples' Health

**Christine Looek**, Professor, Department of Pediatrics, Faculty of Medicine, University of British Columbia; Developmental Pediatrician, Children's and Women's Centre of British Columbia

**Rebecca Martell**, Clinical Associate, Occupational Performance Analysis Unit (OPAU), Department of Occupational Therapy, University of Alberta

**Edward Riley**, Distinguished Professor, Psychology, Director, Center for Behavioral Teratology, San Diego State University

**Marguerite Trussler**, Chairperson, Alberta Liquor and Gaming Commission

**Lee Ann (Weaver) Tyrrell**, Project Manager, (Initial) Alberta/Prairie Province FASD Strategy; (First) Director, Yellowhead Tribal Services Agency; Retired

## Conference Speakers and Topics

### **What is Fetal Alcohol Spectrum Disorder (FASD) and how is it diagnosed?**

#### **Overview of FASD**

Gail Andrew, *Member, Board of Directors, Canada Northwest FASD Research Network; Medical Site Lead – Pediatrics, Medical Director – FASD Clinical Services and Pediatric Consultant, Pediatric Programs, Glenrose Rehabilitation Hospital*

#### **A personal perspective**

Myles Hummelreich, *Director of Programming, Canadian FASD Foundation*

### **Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?**

#### **Prevalence and incidence in Alberta and Canada**

Suzanne Tough, *Scientific Director, Alberta Centre for Child, Family and Community Research*

#### **Prevalence and incidence internationally**

Philip May, *Professor of Sociology and Family and Community Medicine, University of New Mexico; Senior Research Scientist, Center on Alcoholism Substance Abuse, and Addictions (CASAA)*

#### **Extent and impact on child development**

Ben Gibbard, *Developmental Pediatrician, Alberta Children's Hospital; Assistant Professor, Department of Pediatrics, Faculty of Medicine, University of Calgary*

#### **Prevalence of FAS in Foster Care**

Susan Astley, *Professor of Epidemiology/Pediatrics, University of Washington; Director, Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network*

#### **Genetic pre-disposing factors**

Albert Chudley, *Medical Director, Winnipeg Regional Health Authority Program in Genetics and Metabolism; Professor, Department of Pediatrics, University of Manitoba*

#### **Direct and indirect mechanisms for alcohol damage to the brain**

Joanne Weinberg, *Professor and Distinguished University Scholar and Acting Department Head, Cellular and Physiological Sciences, University of British Columbia*

### **What are the consequences of FASD for individuals, their families and society?**

#### **Economic Implications for individuals and families**

Philip Jacobs, *Professor, Gastroenterology Division, Department of Medicine, University of Alberta; Director of Research Collaborations, Institute of Health Economics*

#### **Consequences on the community**

Mary Berube, *Director, Intergovernmental Initiatives, Ministry Support Services Division, Alberta Children and Youth Services*

**Impact on system usage within foster care**

Linda Burnside, *Executive Director, Disability Programs, Manitoba Family Services and Housing*

**Co-morbidities with mental health for an individual with FASD**

Dnn Dubovsky, *FASD Specialist for the Substance Abuse and Mental Health Services Administration (SAMHSA), FASD Center for Excellence*

**Efficacy of a neurobehavioral construct: interventions for children and adolescents with fetal alcohol spectrum disorder (FASD)**

Diane Malbin, *Executive Director, Fetal Alcohol Syndrome Consultation, Education and Training Services Inc. (FASCE)*

**How can FASD be prevented?**

**Pre-conception initiatives**

Lola Baydala, *Associate Professor of Pediatrics, University of Alberta, Misericordia Community Hospital*

**Inventory of primary prevention campaigns**

Robin Thurmeier, *FASD Resources Researcher, Saskatchewan Prevention Institute*

**Primary care physician perspective**

Jane Bergman, *Associate Professor, Department of Family Medicine, Faculty of Medicine and Dentistry, University of Calgary*

**Mentoring programs for at-risk mothers**

Nancy Whitney, *Clinical Director, King County Parent-Child Assistance Program, University of Washington*

**Addressing FASD as a women's health issue**

Anny Salmon, *Managing Director, Canada Northwest FASD Research Network; Clinical Assistant Professor, School of Population and Public Health, Faculty of Medicine, University of British Columbia*

**Prevention of FASD: A broader strategy in women's health**

Nancy Poole, *Research Associate, British Columbia Centre of Excellence for Women's Health; Research Consultant, Women and Substance Use Issues, British Columbia Women's Hospital*

**What policy options could more effectively support individuals with FASD and their families across the lifespan?**

**Educational system, parental, and community support**

Frank Oberklaid, *Director, Centre for Community Child Health, Royal Children's Hospital and Professor Pediatrics, University of Melbourne*

**Shifting responsibility from the individual to communities of care**

Audrey McFarlane, *Executive Director, Lakeland Centre for Fetal Alcohol Spectrum Disorder*

**Education Policy directions for supporting children and youth with FASD and their families**

Elizabeth Brodberg, *Director, Society of the Advancement of Excellence in Education*

**Development of life skills: education, parenting, and family mentoring**

Claire Coles, *Professor, Department of Psychiatry and Behavioral Sciences and Pediatrics, Emory University School of Medicine; Director, Fetal Alcohol and Drug Exposure Clinic, Marcus Autism Center, Children's Health Care of Atlanta*

**Life stages and transitions**

Brenda Bennett, *Executive Director, FASD Life's Journey Inc.*

**Social services and corrections**

Sharon Brintnell, *Professor, Department of Occupational Therapy, and Director, Occupational Performance Analysis Unit, Faculty of Rehabilitation Medicine, University of Alberta*

**Treatment for FASD**

John McLennan, *Assistant Professor, Departments of Community Health Sciences, Psychiatry, and Paediatrics, University of Calgary*

**Justice Issues**

Mary Kate Harvie, *Associate Chief Judge, Provincial Court of Manitoba*

**Policy development and FASD**

Dorothy Badry, *Assistant Professor, Faculty of Social Work, University of Calgary*

**What further research into FASD is needed?****Health and social policy**

Sterling Clarren, *CEO and Scientific Director, Canada Northwest FASD Research Network; Clinical Professor of Pediatrics, School of Medicine, University of Washington; Clinical Professor of Pediatrics, Faculty of Medicine, University of British Columbia;*

**Focusing Research Efforts... Where?**

Sara Jo Nixon, *President, Research Society on Alcoholism. Fellow, Division 28 and 50, American Psychological Society; Professor and Chief Division of Addictions Research; Director, Neurocognitive Laboratory, Department of Psychiatry, College of Medicine, University of Florida*

**Child health and well-being**

Bruce Perry, *Senior Fellow, The ChildTrauma Academy*



## Planning Committee

**Egon Jonsson**, Executive Director and CEO, Institute of Health Economics  
**Amanda Amyotte**, Project Officer, Alberta Children and Youth Services  
**Mary Berube**, Director, Intergovernmental Initiatives, Ministry Support Services Division, Alberta Children and Youth Services  
**Laurie Beverley**, Executive Director, Community Treatments and Supports, Alberta Health Services  
**Jewel Buksa**, President, BUKSA Conference Management and Program Development  
**Corine Frick**, Program Director, Alberta Perinatal Health Program  
**Tara Hanson**, Director of Operations, Alberta Centre for Child, Family and Community Research  
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**Marty Landrie**, Interim Executive Director, Poundmaker's Lodge  
**Rhonda Lothammer**, Communications Manager, Institute of Health Economics  
**Thanh Nguyen**, Health Economist, Institute of Health Economics  
**Julie Peacock**, Director, Primary Care, Children and Youth Interventions, Alberta Health Services – Addiction and Mental Health  
**Nancy Reynolds**, President and Chief Executive Officer, Alberta Centre for Child, Family and Community Research  
**Kesa Shikaze**, Project Manager, Healthy Living, Alberta Health and Wellness  
**Rob Skrypnik**, Sumera Management Consulting  
**John Sproule**, Senior Policy Director, Institute of Health Economics  
**Melissa Walter**, Executive Assistant, Institute of Health Economics

## Scientific Committee

**Gail Andrew**, Member, Board of Directors, Canada Northwest FASD Research Network; Medical Site Lead – Pediatrics, Medical Director – FASD Clinical Services, and Pediatric Consultant, Pediatric Programs, Glenrose Rehabilitation Hospital  
**Jane Bergman**, Associate Professor, Department of Family Medicine, Faculty of Medicine and Dentistry, University of Calgary  
**Sterling Clarrén**, Chief Executive Officer and Scientific Director, Canada Northwest FASD Research Network; Clinical Professor, Pediatrics, School of Medicine, University of Washington; Clinical Professor, Pediatrics, Faculty of Medicine, University of British Columbia  
**Corine Frick**, Program Director, Alberta Perinatal Health Program  
**Denise Milne**, Senior Manager, FASD Initiatives/ Children's Mental Health, Alberta Children and Youth Services

**Hannah Pazderka**, Director of Research, CASA Child, Adolescent and Family Mental Health  
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### **Disclosure Statement**

All of the jury members who participated in this conference and contributed to the writing of this statement were identified as having no financial or scientific conflict of interest, and all signed forms attesting to this fact. Unlike the expert speakers who present scientific data at the conference, the individuals invited to participate on the consensus panel are reviewed prior to selection to ensure they are not proponents of an advocacy position with regard to the topic.

#### ***Questions or comments can be directed to:***

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## **FASD Research and Resources**

Ongoing research and evaluation of programs will help to determine best practices for preventing FASD and supporting those already affected.

The Institute of Health Economics is currently working on a series of projects related to FASD. This conference also is part of a series of consensus development conferences produced by the Institute. Visit [www.ihe.ca](http://www.ihe.ca) for more information.

The Government of Alberta's Fetal Alcohol Spectrum Disorder Cross-Ministry Committee has a comprehensive website with extensive resources on FASD. Visit their website at [www.fasd-cmc.alberta.ca](http://www.fasd-cmc.alberta.ca)

The Public Health Agency of Canada has also developed a website to provide basic information on FASD and to report what they are doing in the area. Visit their website at [www.phac-aspc.gc.ca/fasd-etca](http://www.phac-aspc.gc.ca/fasd-etca)





**T**he Institute of Health Economics, located in Edmonton, Canada, conducted a consensus development conference on fetal alcohol spectrum disorder (FASD) in October 2009. International and national experts presented evidence to an independent jury about the cause, prevention, diagnosis, and treatment of FASD. Policy options to support those living with FASD through the life-span, as well as topics requiring further research were also presented. This book contains the expert's presentations and the discussions between the jury, the experts, and the audience. After two days of hearings, the jury produced a statement (included in this book) with recommendations for improved prevention and treatment of FASD from a policy perspective. The jury was chaired by the Honourable Anne McLellan, former Deputy Prime Minister, and federal Minister of Health in Canada.

This is the fourth in a series of consensus development conferences conducted by the IHE. Other topics have included Diabetes, Prevention of Low Birth Weight, and Depression in Adults. For more information on consensus development conferences or other IHE research and programs visit [www.ihe.ca](http://www.ihe.ca) or contact 780-448-4881.



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