

IHE Consensus Development Conference on **Fetal Alcohol Spectrum Disorder (FASD) – Across the Lifespan**

Jury Members

Hon. Anne McLellan,
Chair
Judith Bossé
Jennifer Coppens
Raisa Deber
David Elton
Mark Hattori
James Hees
Malcolm King
Christine Looock
Rebecca Martell
Ed Riley
Marguerite Trussler
Lee Ann Weaver-Tyrrell

Expert Speakers

Gail Andrew,
Expert Chair
Susan Astley
Dorothy Badry
Lola Baydala
Brenda Bennett
June Bergman
Mary Berube
Elizabeth Bredberg
Sharon Brintnell
Linda Burnside
Albert Chudley
Sterling Clarren
Claire Coles
Dan Dubovsky
Ben Gibbard
Mary Kate Harvie
Myles Himmelreich
Phil Jacobs
Diane Malbin
Philip May
Audrey McFarlane
John McLennan
Sara Jo Nixon
Frank Oberklaid
Bruce Perry
Nancy Poole
Amy Salmon
Robin Thurmeier
Suzanne Tough
Joanne Weinberg
Nancy Whitney



October 7 to 9, 2009, The Westin Edmonton, Edmonton, Alberta



INSTITUTE OF
HEALTH ECONOMICS
ALBERTA 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.

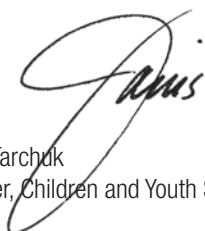
More than 23,000 Albertans have FASD. The social and economic impacts of the disorder directly or indirectly touch every Albertan. That's why the Alberta government is committed to developing and delivering community-based FASD prevention and treatment programs and services; providing education and training 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.



Janis Tarchuk
Minister, Children and Youth Services



Ron Liepert
Minister, Health and Wellness

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.¹ 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.²

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.

¹ British Columbia, Ministry of Children and Family Development website, retrieved June 16, 2009 from www.mcf.gov.bc.ca/fasd

² FASworld Alliance website, retrieved June 16, 2009 from 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 (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) will lead the panel of experts in presenting available scientific evidence on FASD to the jury during public sessions.

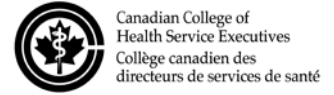
Jury Chair

The Honourable Anne McLellan, OC (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 Amyotte, Project Officer, Alberta Children and Youth Services

Mary Berube, Director, Intergovernmental Initiatives, 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

Braden Hirsch, Acting Director, Community Partnerships, Alberta Seniors and Community Supports

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 Skrypnek, Sumera Management Consulting

John Sproule, Senior Policy Director, Institute of Health Economics

Melissa Waltner, 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

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

Sterling Clarren, Chief Executive Officer and Scientific Director, Canada Northwest FASD Research Network

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

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 Seniors and Community Supports

Melissa Waltner, Executive Assistant, Institute of Health Economics

Communications Committee

Roxanne Dubé Coelho, 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 – 8:20 a.m.

Opening remarks

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

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

8:20 – 9:05 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 Himmelreich, *Director of Programming, Canadian FASD Foundation*

Jury question and answer

9:05 - 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 – 2:05 p.m.

Question 3: What are the consequences of FASD on individuals, their families and society?**Economic implications**

Phillip Jacobs, *Professor, Gastroenterology Division, Department of Medicine, University of Alberta; Director of 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*

Jury question and answer

2:05 – 2:25 p.m.

Break, North Foyer

2:25 – 3:20 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

3:20 – 4:35 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 Thurmeier, *FASD Resources Researcher, Saskatchewan Prevention Institute*

Primary care physician perspective

June Bergman, *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. – 8:00 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 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*

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 – 10:50 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

10:50 – 11:10 a.m.

Break, North Foyer

11:10 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

12:25 – 1:25 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 Clarren, *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

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

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

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 2009 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, 2006. 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 1976.



Judith Bossé

DMV 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 optimised national programs on prevention and surveillance, and promoted research development on many national public health issues. In 2008, 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 maximise 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 Deber

PhD, Professor, Department of
Health Policy, Management and
Evaluation; Faculty of Medicine,
University of Toronto

Raisa Deber, PhD (MIT), has lectured, mentored, published and consulted on health policy at local, provincial, national and international levels. Professor Deber'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 CIHR Team in Community Care and Health Human Resources.



David Elton

PhD, President, Norlien
Foundation and Max Bell
Foundation

Dr. Elton is President of both the Norlien 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 Child Foundation and the Alberta Centre for the Child, Family and Community Research.



Mark Hattori

Acting Assistant Deputy Minister, 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 radio 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 FCCP, Professor, Department of Medicine, University of Alberta; Scientific Director, CIHR 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 CIHR 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 2000 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 CIHR Institute of Aboriginal Peoples' Health. He has been recognized for his achievements by the Alberta Lung Association (1999), the National Aboriginal Achievement Foundation (1999), and the University of Alberta Board of Governors (2003).



Christine Look

MD FRCP, Clinical Associate Professor, Department of Pediatrics, Faculty of Medicine, University of British Columbia; Developmental Pediatrician, Children's and Women's Centre of British Columbia

Dr. Christine Look MD, FRCPC, 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. Look 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 Fast on identifying youth with FASD in the justice system.

In 2000 Dr. Look 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 (SAM) Award for distinguished service 25 years after graduation. In 2005 she became an Honorary Alumna of the UBC Faculty of Medicine.



Rebecca Martell

Clinical Associate, Faculty of Rehabilitation Medicine, University of Alberta

Of Indigenous ancestry, Ms. Martell is a member of Waterhen 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 Silvius 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 (1981-1985), as well as a Board Member with A Centre for Women and Excel 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 Un-reached 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 Corrections 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 Corrections & Connections to Community (3C), a Fort Saskatchewan Correctional Centre-based FASD diagnostic clinic and transition program for male inmates. As an OPAU Clinician, Rebecca also provides sessional lectures focused on *Cultural Reflection on Being, Doing and Feeling* with Occupational Therapy students. Ms. Martell is a frequent sessional 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 NorQuest College Practical Nurse Program, Keyano College Aboriginal Child & Family Services Program and Nechi 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 Alcohol, 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

RN BSc Nsg 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 Milner 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 five Treaty Six bands to develop an education and infrastructure for child welfare services for First Nation children. Following this, she was recruited 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 Hepatech.

For many years, Lee Ann has been a legal guardian and co-ordinator of care for a friend with a developmental disability. She has served on the board of the Hope Foundation and is currently a board member for CASA (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



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

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 TOPS 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 Centers, (CN-CYR), a national organization under the Canadian Association of Pediatric Health Centers (CAPHC) that focuses on the rehabilitation needs of children and youth with a variety of disabilities. Dr. Andrew, with Dr. Carmen Rasmussen 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 experiences (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 pattern. 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.

Myles Himmelreich



Director of Programming,
Canadian FASD Foundation

Myles 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 (Preterm Birth and Healthy Outcomes), funded by Alberta Heritage Foundation for Medical Research, that is learning more about preventing preterm birth and supporting healthy birth outcomes by looking at the genetic, molecular, clinical, community and population health factors that contribute to preterm 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 0.23 to 3 cases per 1,000 live births for FAS, and approximately 9.1 per 1,000 live births for FASD.¹ 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.¹

During the first trimester, sometimes before pregnancy recognition, 12% to 60% of women report alcohol use.^{2,3} We have described a population-based sample of Canadian women of childbearing age, in which 80% consumed alcohol before conception.⁴ Half 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.⁵ Others have noted that a proportion of women, estimated between 4 and 27%, continue to drink alcohol during the remainder of pregnancy.⁶⁻¹⁴ 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.¹⁵

Central 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.¹⁶ 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 population¹⁵, ethnicity of study population¹⁵, access to a qualified diagnostician¹⁷, criteria used for diagnosis and the methodological approach used for finding incident cases.^{17, 18} 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.^{10, 19, 20}

¹ Hicks M, Tough S. The importance of complete abstinence from alcohol before and during pregnancy: enough evidence for justification? 2009.

² Bailey BN, Delaney-Black V, Covington CY et al. Prenatal exposure to binge drinking and cognitive and behavioral outcomes at age 7 years. *American Journal of Obstetrics & Gynecology* 2004;191(3):1037-43.

³ Barr HM, Bookstein FL, O'Malley KD, Connor PD, Huggins JE, Streissguth AP. Binge drinking during pregnancy as a predictor of psychiatric disorders on the Structured Clinical Interview for DSM-IV in young adult offspring. *American Journal of Psychiatry* 2006;163(6):1061-5.

⁴ Tough S, Tofflemire K, Clarke M, Newburn-Cook C. Do women change their drinking behaviors while trying to conceive? An opportunity for preconception counselling. *Clinical Medicine & Research* 2006;4(2):97-105.

⁵ Health Canada. Canadian Perinatal Health Report. 2000.

⁶ Surgeon general's advisory on alcohol and pregnancy. *FDA Drug Bull* 1981;11(2):9-10.

⁷ Department of health and human services. Healthy people 2010. 2000.

⁸ Alberta Medical Association. Recommendations: Prevention of fetal alcohol syndrome (FAS). 1999.

Question 2: Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?

- ⁹ Alberta Medical Association. Preface to the prevention & diagnosis of fetal alcohol syndrome (FAS). 1999.
- ¹⁰ Health Canada. Joint statement: prevention of fetal alcohol syndrome (FAS), fetal alcohol effects (FAE) in Canada. Health Canada; 1996.
- ¹¹ Health Canada. Canadian Perinatal Surveillance System, alcohol and pregnancy. 1998.
- ¹² Health Canada. Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the effects of other substance use during pregnancy. 2001.
- ¹³ O'Leary CM, Heuzenroeder L, Elliot EJ, Bower C. A review of policies on alcohol use during pregnancy in Australia and other English-speaking countries. *Med J Aust* 2006;186(9):466-71.
- ¹⁴ US Department of Agriculture/US Department of Health and Human Services. Nutrition and your health: dietary guidelines for Americans. 1990.
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- ¹⁷ Williams RJ, Odaibo FS, McGee JM. Incidence of fetal alcohol syndrome in northeastern Manitoba. *Canadian Journal of Public Health* 1999;192(4).
- ¹⁸ May PA, Gossage JP. Estimating the prevalence of fetal alcohol syndrome. A summary. *Alcohol Research & Health: The Journal of the National Institute on Alcohol Abuse & Alcoholism* 2001;159(67).
- ¹⁹ Alberta Health and Wellness. Health is Everyone's Business: A Snapshot of some of Alberta's Wellness Initiatives. 2000.
- ²⁰ State BC, Stevens B, Ungar WJ, Beyene J, Koren G. Health-related quality of life of Canadian children and youth prenatally exposed to alcohol. *Health Qual Life Outcomes* 2006;4(81).

Philip May



Substance Abuse, and Addictions (CASAA)

PhD, Professor of Sociology and Professor of Family and Community Medicine, University of New Mexico; Senior Research Scientist, Center on Alcoholism,

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.

Ben Gibbard



MD MCS MSc FRCPC,
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 masters degree from Regent 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 deficits 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 explain 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.

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 1981. Current work has been in the development and implementation of FASD diagnostic, 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 Program, 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, MR-spectroscopy and functional MRI for FASD. A focal 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 Program, 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.¹ 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: palpebral fissure lengths < -2 SDs, 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, 99.8% 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 declining, one would expect a decline in the prevalence of children born with FAS across those same years. In 2002, a cross-sectional study,² 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 diffuse 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.

¹ Astley SJ, Stachowiak, J, Clarren SK, Clausen C. Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population. *J Pediatr* 2002;141:712-7.

² Astley SJ, Fetal alcohol syndrome prevention in Washington State: evidence of success. *Paediatric and Perinatal Epidemiology*, 2004, 18,344-351.

Albert Chudley



MD FRCPC FCCMG, Medical Director, Winnipeg Regional Health Authority Program in Genetics and Metabolism; Professor, Department of Pediatrics, University of Manitoba

Dr. Ab 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 isozyme forms encoded by multigene 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 280 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, s- CYP2E1. Allelic 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. Allelic 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.

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 Center, 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 neurobehavioral problems, as well as elevated rates of mental health problems, including depression and anxiety disorders. Animal models of FASD have demonstrated biological and neurobehavioral 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, paralleling 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 (PF, 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-forced 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 depression/anxiety disorders in clinical populations. E males exposed to CMS showed greater anxiety (elevated plus maze), impaired hedonic responsivity (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 NIH/NIAAA; the UBC Human Early Learning Partnership (BCMCFD); 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



DPhil, 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 Dewa on a booklet entitled, *How much should we spend on mental health?* which will appear later this year, to be published by the IHE. 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 prevention 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 prevalent 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 catalogued 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 (Vandenbrink) 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 Gil Cardinal in 1995-1996) 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

2005, 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

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 fair 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. Ambivalent messaging regarding alcohol use in western society; with overuse 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 floundering 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 counsellor with the Canadian Counselling Association who obtained her Bachelor of Social Work, Master of Education (in Counselling) 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 nervous 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

Diane Malbin

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

Ms. Diane Malbin is Director of FASCETS, 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 on select teams.

At the end of the three-year project, statistical significance was found for all but one subvariable (anxiety) 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 FASCETS by the Department of Human Services (DHS), formerly known as the State of Oregon Services for Children and Families (SCF.) For information contact Diane Malbin, MSW, dmalbin@fascets.org

Question 4: How can FASD be prevented?

Lola Baydala



MD, Associate Professor,
Pediatrics, University of Alberta;
Site Lead – Pediatrics,
Misericordia Community
Hospital

Lola Baydala is a consultant pediatrician 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. Using a CBPR approach Dr. Baydala has developed trust and important research relationships with Alexis 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 26,000 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 schools/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 Alexis Nakota Sioux Nation and the University of Alberta to adapt and deliver the LST substance use prevention program in their community, and to describe outcomes of the adapted program.

Robin Thurmeier



FASD Resources 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

Governments, 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 novelties (i.e. pins). 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 changes 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 CCFP FCFP,
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 renewal 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 trilateral agreement.

Dr. Bergman also serves as a co-chair for the Towards Optimized Practice committee, a trilateral 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 severe 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 of 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.

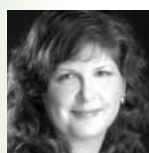
Many models of care have been developed to support primary care in their engagement of population health and public health issues along with the long time obligation of prevention of disease and promotion of health. This discussion will review some of these and their strengths and weaknesses. Integration 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 skills 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 of population health will bring more unique approaches to prevention and promotion through timely education, anticipatory counselling 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 advocacy/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 traumas 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.

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 clients' 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 80% 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



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 "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 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



MA PhD(c), 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 1996, 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 Greaves, entitled *Highs and Lows: Canadian Perspectives on Women and Substance Use*, published by the Centre for Addiction and Mental Health in Ontario. She holds fellowships with IMPART and NEXUS and is the 2009 Healthway 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 (2003).
- Led a four-year province-wide professional education initiative with over 3000 health/social service professionals in BC (ActNow BC Healthy Choices in Pregnancy www.hcip-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 learnings from the previous speakers. 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-etcaf/cp-pc-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/evidence 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 are needed.

Question 5: What policy options could more effectively support individuals with FASD and their families across the lifespan?

Frank Oberklaid



AOM 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 advises 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 detection/early intervention, and especially how existing 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 redevelopment 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 websites 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 consultancies; 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 issues 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 system 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 increases 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 levers are important, engagement at a community level is likely to be the most critical variable that will determine success or failure.

Audrey McFarlane



Executive Director, Lakeland Centre for Fetal Alcohol Spectrum Disorder

Audrey McFarlane is currently the Executive

Director for the Lakeland Centre for Fetal Alcohol Spectrum Disorder. She was one of the founders of the Lakeland 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 this 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 example of the Lakeland Centre for FASD which utilizes community-based services for diagnosis, support, mentorship, education, awareness 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 at Sunny Hill Health Centre for Children in Vancouver. Between 2000 and 2008, 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 NOFAS-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

measures, poor academic achievement and very limited positive social involvement with their nondisabled 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 specialised 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 recognised as a key element in the development of an individualised 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



PhD, 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

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 prenatally 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

Question 5: What policy options could more effectively support individuals with FASD and their families across the lifespan?

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. FASDLJI 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



DipP & 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 collaborated 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 Correction to Community Connections (3C) 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 I*. 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 capacity. 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



BMedSc MD MPH PhD FRCPC, 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-access, 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 Pediatrics/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.

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



LLB, Associate Chief Judge,
Provincial Court of Manitoba

Mary Kate Harvie received her Bachelor Laws degree from the University of

Manitoba in 1986 and, after passing her bar administration course, 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 2008, 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 Rossbrook 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 carefully seeking to mobilize change within and across systems

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 ARND. 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 addictions 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 an IQ below 70.
- School programming is adapted to provide more kinesthetic (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, counsellors, 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,
University of Calgary

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 (ACCFRC) 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 extensive 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 affects. 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 these concerns and supporting healthy pregnancies within communities. A policy framework for FASD must consider all segments of the population including women and men at 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 recognizes 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 Clarren



MD FAAP, 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 Clarren 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. Clarren has applied his training in dysmorphology, neuropathology, neuroembryology, and developmental pediatrics to the problems of fetal alcohol spectrum disorders in clinical diagnosis, clinical evaluation and intervention, and clinical and basic research. Dr. Clarren 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. Clarren 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 diagnoses, 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 28 and 50, American Psychological Society; Professor and Chief, 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 concomitants 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

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-set/off-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, model-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.childtraumaacademy.org). He is the author, with Maia Szalavitz, 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 maltreated 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 neurotoxic 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 classified. Yet each 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 reparative 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 relationship 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 tragic 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 780-448-4881 or through info@ihe.ca. Past statements can be accessed on the Institute's website at www.ihe.ca.

For more information

Consensus Development Conference Secretariat
BUKSA Conference Management and Program Development
307 10328 - 81 Avenue NW
Edmonton AB T6E 1X2

Phone: 780.436.0983 ext 227

Fax: 780.437.5984

Email: consensus@buksa.com

www.buksa.com/fasd