

# Consensus Statement on **Fetal Alcohol Spectrum Disorder (FASD) – Across the Lifespan**



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**Government of Alberta** ■

## Acknowledgment

### **The Honourable Anne McLellan**

(LL.M, King's College, University of London; Alberta Institute for American Studies, University of Alberta; Academic Director and Distinguished Scholar in Residence, Institute for United States Policy Studies) led a distinguished jury of citizens and experts to develop practical recommendations on how to improve prevention, diagnosis and treatment of Fetal Alcohol Spectrum Disorder.

### Expert Chair, **Dr. Gail Andrew,**

(MDCM FRCP(C); Member, Board of Directors, Canada Northwest FASD Research Network; Medical Site Lead – Pediatrics, Medical Director – FASD Clinical Services and Pediatric Consultant, Pediatric Programs, Glenrose Rehabilitation Hospital) led a panel of experts in presenting available scientific evidence on Fetal Alcohol Spectrum Disorder.

## Disclosure Statement

All of the jury members who participated in this conference and contributed to the writing of this statement were identified as having no financial or scientific conflict of interest, and all signed forms attesting to this fact.

# About the Consensus Statement

This consensus statement on fetal alcohol spectrum disorder is the product of a unique conference: *The IHE Consensus Development Conference on Fetal Alcohol Spectrum Disorder – Across the Lifespan* held in October 2009. The event featured a range of leading national and international experts who presented scientific evidence on FASD to a broad-based, independent panel in order to develop the following practical recommendations on how to improve prevention, diagnosis, and treatment of FASD.

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 series modelled on the successful National Institutes of Health (NIH) consensus development program in the United States.

It is hoped that this consensus statement will be a useful guide to policy and decision makers in order to provide effective prevention programs, treatment, and supports for people affected by FASD.

# Process

This consensus statement was prepared by an independent jury of health professionals, academics, and public representatives based on: 1) relevant published studies assembled by the scientific committee of the consensus development conference; 2) presentations by experts working in areas relevant to the conference questions; 3) information by people who have been touched by FASD; 4) questions and comments from conference attendees during open discussion periods; and 5) closed deliberations by the jury.

The conference was held in the Province of Alberta, Canada. The consensus statement therefore often refers to the situation in Alberta, although data were not only drawn from that area but also from other parts of Canada, the U.S. and internationally.

This statement is an independent report of the jury and is not a policy statement of the conference partners, conference sponsors or the Government of Alberta.

# Conference Questions

The jury used the evidence presented to them at the conference to determine answers – in the form of a consensus statement – to the following questions:

1. What is Fetal Alcohol Spectrum Disorder (FASD) and how is it diagnosed?
2. Do we know the prevalence and incidence of FASD in different populations, and can the reporting be improved?
3. What are the consequences of FASD for individuals, their families and society?
4. How can FASD be prevented?
5. What policy options could more effectively support individuals with FASD and their families across the lifespan?
6. What further research into FASD is needed?

# Consensus Statement

## Introduction

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe the range of disabilities caused by prenatal exposure to alcohol. It is a significant Canadian health concern and concerted action is required from all levels of government, researchers, communities, families and individuals if we are to deal with it effectively.

Compared to many other areas of study, FASD is relatively new. It was first identified in 1973 when a similar pattern of malformations among infants born to alcohol abusing women was noted. Since then research has been done, knowledge has been gained, and it is time to move forward, building on the good work that has been done by researchers, clinicians and communities across the country.

It would be a simple but short-sighted strategy to say to all women of child-bearing years – “just don’t drink alcohol.” That would ignore the complexity of the lives of women and their families and the communities in which they live. This is not only a “women’s” issue. It is one for which all of us, women and men, mothers and fathers, families and communities need to take responsibility.

The difficulties for Canadian families living with FASD cannot be overestimated and actions to support them should be comprehensive, integrated and timely. Multidisciplinary assessment and multisectoral responses are necessary.

It is time for a National Agenda integrating research done and lessons learned. The Agenda must increase awareness of FASD and promote the development of effective prevention and treatment programs, as well as family support systems. The time for further action is now.

# Question 1: What is Fetal Alcohol Spectrum Disorder (FASD) and how is it diagnosed?

## What is FASD?

Fetal Alcohol Spectrum Disorder (FASD) refers to a complex range of brain injuries that can result from prenatal exposure to alcohol (PAE). It is an umbrella term that has evolved over time and is used to denote an array of developmental, physical, learning and behavioural conditions.

The bottom line is that pre-natal exposure to alcohol, in combination with other risk factors, may cause brain injuries, which are expressed in unique and individual ways.

FASD can occur in all segments of society. Poverty, genetics, maternal stress, poor nutrition and other prenatal exposures can influence the severity of FASD. Prenatal exposure to alcohol, while not the sole component contributing to FASD, is a necessary one and therefore FASD is preventable.

## How is it diagnosed?

There are no definitive biological markers for FASD such as a blood test or the use of imaging technology. While there is promising research in a number of areas, there is no definitive or cost effective test yet. National guidelines for diagnosis of FASD were accepted across Canada in 2005 and involve a comprehensive multidisciplinary assessment of brain function. The challenge with diagnosis is not simply to identify brain injury but to assess a person's ability in the exercise of judgment, planning, memory and the ability to cope independently in day to day life.

The National Guidelines for FASD Diagnosis include demonstrated maternal alcohol consumption during pregnancy, physical examination for growth and physical features and neuro-developmental assessment. Early identification and diagnosis can support better interventions and can affect long term outcomes. However, there are shortcomings with respect to the current system and ensuring consistent implementation of the guidelines. There are also administrative challenges, including:

- Limited human and financial resources for neuro-developmental assessment across the country
- Cost in both time and resources
- Lack of training of personnel in conducting assessments

In addition, stigma can create barriers to active participation and accuracy of diagnosis (shame and blame).

## Jury Recommendations

1. **There is a need for national funding for research to develop accurate and cost effective neurobiological and/or functional markers of FASD.**
2. **Comprehensive diagnostic capability needs to be available across the lifespan.**

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

There is clearly a need for major improvement in the reporting of FASD. The current provincial/territorial and national estimate for FASD in Canada is 9 cases per 1000 infants born. This is based on extrapolation of US data. There is some recent international data gathered from a variety of in-school screening and diagnosis studies which suggests that the overall incidence may be higher. There is Canadian data that indicates greater prevalence in rural communities, foster care systems, juvenile justice systems and Aboriginal populations. The high prevalence of FASD in Aboriginal populations is symptomatic of a historical and multigenerational trauma, associated with events such as the residential school system.

Getting accurate information is extremely important as the details of regional and local prevalence and incidence are important to target and determine the effectiveness of prevention and intervention efforts.

Surveillance and screening tools need to be simple, cost effective and accurate before they can be effectively implemented across the country. A starting point is accurate data regarding prenatal exposure to alcohol. There are impediments to the collection of this data, including stigma, reluctance of care providers and limited availability of support services once prenatal exposure has been identified.

### Jury Recommendations

- 1. A national surveillance strategy needs to be implemented to assess progress in the prevention and treatment of FASD in Canada. Questions on FASD should be included in the regular Canadian Community Health Survey.**
- 2. Registries of non-personalized data for FASD surveillance should be established in each province to increase the capacity for screening, diagnosis, and reporting of FASD nationally. This should build on projects already underway regionally and provincially to increase data collection.**
- 3. Reliable methods of early detection of developmental delays and disorders, including FASD, should be introduced into early school years and be available throughout the lifespan.**
- 4. A strategy to reduce the stigma associated with a diagnosis of FASD is needed in order to ensure maximum participation in screening, prevention and diagnostic processes.**

## Question 3: What are the consequences of FASD for individuals, their families and society?

The consequences of FASD are widespread, affecting individuals, their families, communities, and society as a whole. FASD is a highly heterogeneous disorder.

Individuals with FASD are most directly affected. FASD, as a brain disorder, is associated with a high incidence of cognitive and behavioral problems. People affected by FASD may have significant difficulties with memory, attention, self care, decision making and social skills as well as mental health disorders, including depression and addiction. They may have problems with organization and planning their activities, difficulty controlling their emotions and completing tasks that would allow them to lead productive lives. FASD is often further complicated by medical issues including a higher rate of heart disease, hearing and vision problems.

FASD has a dramatic impact on families, whether it is the biological, adoptive or foster family. Families must be aware that there will be additional costs in raising a child affected by FASD and this may cause additional family stress. The biological mother is dramatically impacted regardless of whether she is raising the child or not. Guilt can be considerable. When a woman is under stress or depressed, she may continue to drink. Indeed, a major risk factor for having an alcohol affected child is having a previous child affected with FASD.

FASD also affects all other members of the immediate family, including siblings and the extended family. Emotional, financial, and social burdens can be considerable. Indeed, the stress of living with a child affected with FASD may result in family discord or breakup. Adoptive and foster families confront similar issues in dealing with the needs of affected children. Again, proper supports are essential.

One cost that is more difficult to measure is that of lost human potential. The needs of individuals affected by FASD currently generate considerable costs for the social welfare, educational, medical, judicial and correctional systems and significant challenges for communities.

In Alberta, the annual economic cost of FASD is estimated to be between \$130 - \$400 million per year. Of this total educational and medical costs take up 60% (including addictions and drug treatments), additional costs to families account for 20%, and the remaining 20% is for social services, supportive housing, lost productivity costs and other services such as costs to the justice system. In Canada, the cumulative life-long cost of those currently living with FASD is estimated to be \$600 billion. Clearly, addressing this issue is crucial not only from the perspective of social justice but from the economic perspective as well.

## Jury Recommendations

1. As FASD is a lifelong disability, there should be a commitment by governments to provide seamless and equitable services across the life span.
2. Important transitions from child to adult services need to be planned and allow for effective wraparound services which will support individuals and families and communities at each stage of life.
3. People affected with FASD will require life-long intersectoral services. Consistent standards between provinces should be established to reduce variations in the funding and provision of these services.
4. Adults with FASD will require ongoing life skills and socialization assistance and support.
5. For those children who enter the child welfare system there should be improvements to ensure the ability to provide stable foster care. Multiple placements should be avoided wherever possible.

## Question 4: How can FASD be prevented?

FASD prevention requires complex, culturally sensitive, multi-level initiatives that address very specific barriers and opportunities for learning, engagement and supportive change. To successfully prevent FASD, it is critical to involve women, men, their support systems, community advocates, health promotion experts, researchers, health/social system planners and service providers in designing these initiatives.

The Canadian Prevention Framework describes four levels of FASD prevention: 1) raising awareness for the whole population, 2) discussing alcohol use with all girls and women of childbearing age, 3) reaching and providing specialized care and support to girls and women who use alcohol during pregnancy and, 4) supporting new mothers with alcohol problems.

Coordination and integration of prevention strategies must occur at all levels. We must learn from experience and build on and use existing umbrella strategies where available.

“Shame and blame” approaches to FASD prevention result in many missed opportunities to provide women with the timely, appropriate and respectful supports needed to reduce the negative impacts of their alcohol use on their health and that of their children. Systems must be meaningful, effective and compassionate in responding to the challenge of FASD and its prevention.

Because of the negative human and economic impacts of FASD, prevention is a good public investment.

## Jury Recommendations

1. A national primary prevention strategy must include a clear message consistent with Canadian values. This should include education about the effects and risks of alcohol beginning in elementary school and continuing through post-secondary education. It should also include education about birth control.
2. Prevention programs should target the Social Determinants of Health.
3. Prevention programs should be designed along with evaluation frameworks.
4. Prevention efforts should be community driven, culturally appropriate and should honour traditional knowledge. This is especially true in Aboriginal and immigrant communities.
5. A high priority should be placed on ensuring that prevention services are provided to women and families at highest risk of having a child with FASD. The Parent-Child Assistance Program (PCAP) has shown great success. Canadian programs based on the PCAP model should be encouraged.
6. Governments should require messaging about FASD in pregnancy testing kits and in contraceptive packages.
7. The reforms being made in primary care have the potential to improve the relationships required for effective prevention and support. Physicians and other primary health providers should take full advantage of “teachable moments” to discuss pregnancy prevention and the risks of alcohol consumption with their patients/clients of child bearing age.
8. Increase the number of women-centered alcohol treatment programs and beds. Keeping mothers and children together during interventions should be a priority.
9. National, provincial and territorial alcohol strategies must address FASD.

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

Ideally, policies and programs should reflect evidence-based best practices. Unfortunately, such evidence is not yet available as to how best to support individuals affected by FASD and their families across the lifespan. However, there are many examples of promising practices which may well be helpful and cost effective. These programs should be nurtured and shared, within the context of evaluation, so that the findings can inform future service delivery. Such evaluations should ensure the outcomes assessed are linked to functional improvements in the lives of those living with FASD and their families.

The heterogeneity of FASD requires the ability to tailor services to the needs of the individuals and their families, and recognize that these needs may change over time. Arbitrary eligibility criteria such as IQ, chronological age and place of residence (e.g. rural/urban, on/off reserve) are counter-productive and can be unjust. FASD is a lifelong condition and special attention needs to be paid to key points of transition.

Since FASD involves so many sectors, an inter-disciplinary approach is critical. Currently, different approaches may be taken by social services, education, health, the courts and the corrections system. The resulting fragmentation can be frustrating to people affected by FASD and expensive for tax payers. There should be 'no wrong doors' for people affected by FASD who need support; mechanisms need to be in place to ensure such support is seamless. Services should address cumulative risk, both environmental and biological, and not be based on silos of care. Policy and services also need to be culturally sensitive.

Students affected by FASD continue to show low rates of school completion, high rates of suspension, poor academic achievement and limited positive social involvement.

Numerous studies have identified the presence of adult offenders with FASD in Canada's correctional systems. The range and complexity of community re-entry needs of people affected by FASD require interdisciplinary and multisectoral approaches to connect them with services and supports that match their functional capacity. Introducing services while in jail has the ability to increase the effectiveness of connecting released offenders to community resources.

While services and treatments for FASD have unique characteristics, they should be part of a larger system of delivering supports for people with disabilities. The services to individuals and their families should be needs-based. Lessons from effective evidence-based approaches dealing with other developmental disorders should be adopted where appropriate to FASD and vice versa. How best to place FASD programming within the broader framework of services for individuals with developmental and behavioural challenges is a matter of debate.

## Jury Recommendations

### Lifelong Services

1. Services should be (a) based on functional need rather than arbitrary eligibility criteria; (b) lifelong; (c) seamless; (d) individualized; (e) culturally sensitive; and (f) sustainably funded.
2. There should be funding for systematic evaluations of programs and sharing of findings to develop best practices.
3. Build communities of support for individuals affected by FASD and their families. In particular, encourage mentorship and activity based programs.
4. There should be special attention and support for First Nations, Inuit and Métis peoples affected by FASD who have experienced societal breakdown due to historical and multigenerational trauma.

### Diagnosis/Assessment

1. There must be equitable and timely access to diagnosis for individuals with suspected FASD, including appropriate communication of findings with the individual, family and other service providers.
2. Functional reassessments should be undertaken as needed.
3. Amend the Criminal Code to allow for Court-ordered assessments, including FASD.

### Education and Training

1. Educational instruction and materials should be provided to promote awareness, understanding and knowledge of best practices for those who are or will be working with people affected by FASD.
2. An individualized educational plan needs to be developed focusing on skill development, inclusion, participation and recognition of existing strengths, to facilitate becoming a contributing member of society.

### Legal

1. Improve outcomes and reduce costs to the legal system by utilizing an alternative measures program for adults affected by FASD charged with non-violent first offences. Take into account a FASD diagnosis on subsequent non-violent offences when sentencing.
2. Improve outcomes and reduce cost to the youth justice system by utilizing an alternative measures program for all young offenders affected by FASD charged with non-violent offences.
3. Pre-release and post release programs for individuals need to be established.
4. Enhance the correctional environments to respond to the special needs of persons affected by FASD to protect them from exploitation and abuse.

## Question 6: What further research into FASD is needed?

We still do not understand all of the basic mechanisms that create the spectrum of severity within FASD. Effects of exposure are highly variable. For example, the spectrum lies on a continuum from still birth to children with subtle learning and behavioural problems. Nor do we know enough about the factors that may magnify or reduce the risk from prenatal exposure.

What we do know is that research more than pays for itself. It reduces costs by more effective prevention, intervention and treatment of FASD.

Current FASD research activities across Canada remain fragmented and underfunded. This leads to risk of omission or duplication of effort. There remain significant gaps in our knowledge, including outcomes across the life span and for special populations. Research is still in its infancy for corrections, justice and social services and is not comprehensive with respect to rates, outcomes, costs and co-occurring conditions. We continue to incarcerate the disabled!

We need new approaches to research to reflect current realities. We must embed research into service delivery. Research must include all levels of evidence including traditional knowledge. Rigorous and culturally appropriate research should include both quantitative and qualitative methodologies. Involvement and participation of the community in research is essential.

We need to support the ongoing development of interdisciplinary, integrated research networks that include health, education, social services, corrections and communities. Active population-based monitoring must be in keeping with ethical and privacy standards.

Research must include basic as well as translational studies which are relevant to the lived experiences of persons affected by FASD. It needs to encompass issues in diagnosis, interventions, and all levels of prevention. Such research must be culturally appropriate, and address the needs of the individual, family, community and the nation.

## Jury Recommendations

1. More translational research from basic science to the human experience, such as the beneficial effects of nutrition.
2. More research on prenatal alcohol exposure on brain structure and function with the aim of improving interventions and outcomes.
3. More reliable indicators, biological and/or behavioural, of maternal alcohol consumption during pregnancy are needed.
4. Ongoing research for the development of better screening and surveillance tools, specific and sensitive to prenatal alcohol exposure. These should be adaptable, culturally appropriate and lead to accurate referrals for diagnosis and supports.
5. Encourage uniform approaches to recording clinical findings found during FASD assessments by using standardized forms and definitions.
6. Support intersectoral research with education, health and social services.
7. More research between corrections, justice and social services to identify rates, outcomes, costs and co-occurring conditions.
8. Initiate research into the role of parents, including fathers.
9. Embed research and evaluation into programs and services to allow for self correction and continuous improvement.
10. Promote research on interventions based on social determinants of health that could modify the incidence and severity of FASD.

# Conclusion

We, the jury, believe that comprehensive and life-long services for people affected by FASD can and must be improved. Ongoing prevention efforts must be expanded.

Fetal Alcohol Spectrum Disorder is a complex issue. It has profound short and long-term consequences – for individuals, families and communities. A multidisciplinary and multisectoral approach is needed if we are to improve the lives of those living with and affected by FASD.

To be successful - we need to be informed as much as possible by research and evidence but, at the end of the day, we must remember we are dealing with individual persons and families. We must respond with compassion for the challenges they face and respect for the unique capabilities they bring.

Government ministries and health systems owe it to everyone to fund and develop programs and explore new ways to help families, researchers and service providers to address this important issue. It is just. It makes sense. It is an investment in our future.

We, the jury, believe a National Agenda to address FASD and its prevention is necessary and are pleased that Alberta is a leader in those efforts.

## Jury Members

**Chair: The Honourable Anne McLellan**, Alberta Institute for American Studies, University of Alberta; Academic Director and Distinguished Scholar in Residence, Institute for United States Policy Studies; LL.M, King's College, University of London

**Judith Bossé**, Associate Assistant Deputy Minister, Public Health Agency of Canada

**Jennifer Coppens**, Medical Student, University of Alberta

**Raisa Deber**, Professor, Department of Health Policy, Management and Evaluation, Faculty of Medicine, University of Toronto; Director, CIHR Team in Community Care and Health Human Resources

**David Elton**, President, Norlien Foundation and Max Bell Foundation

**Mark Hattori**, Acting Assistant Deputy Minister, Program Quality and Standards, Alberta Children and Youth Services

**James Hees**, Reporter, CBC Radio Edmonton

**Malcolm King**, Professor, Department of Medicine, University of Alberta; Scientific Director, CIHR Institute of Aboriginal Peoples' Health

**Christine Loock**, Professor, Department of Pediatrics, Faculty of Medicine, University of British Columbia, Developmental Pediatrician, Children's and Women's Centre of British Columbia

**Rebecca Martell**, Clinical Associate, Faculty of Rehabilitation Medicine, Occupational Performance Analysis Unit (OPALI), University of Alberta

**Edward Riley**, Distinguished Professor, Psychology; Director, Center for Behavioral Teratology, San Diego State University

**Marguerite Trussler**, Chairperson, Alberta Liquor and Gaming Commission

**Lee Ann (Weaver) Tyrrell**, Project Manager, (Initial) Alberta/Prairie Province FASD Strategy, (First) Director, Yellowhead Tribal Services Agency, Retired.

# Conference Speakers and Topics

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

### Overview of FASD

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

### A personal perspective

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

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

### Prevalence and incidence in Alberta and Canada

**Suzanne Tough**, Scientific Director, Alberta Centre for Child, Family and Community Research

### Prevalence and incidence internationally

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

### Extent and impact on child development

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

### Prevalence of FAS in Foster Care

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

### Genetic pre-disposing factors

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

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

**Joanne Weinberg**, Professor and Distinguished University Scholar and Acting Department Head, Cellular and Physiological Sciences, University of British Columbia

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

### Economic Implications for individuals and families

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

### Consequences on the community

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

### Impact on system usage within foster care

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

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

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

### Efficacy of neurobehavioral construct: interventions for children and adolescents with Fetal Alcohol Spectrum (FASD)

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

## How can FASD be prevented?

### Pre-conception initiatives

**Lola Baydala**, Associate Professor of Pediatrics, University of Alberta; Misericordia Community Hospital

### Inventory of primary prevention campaigns

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

### Primary care physician perspective

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

### Mentoring programs for at-risk mothers

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

### Addressing FASD as a women's health issue

**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

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

### Educational system, parental, and community support

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

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

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

### Education policy directions for supporting children and youth with FASD and their families

**Elizabeth Bredberg**, Director, Society of the Advancement of Excellence in Education

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

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

### Life stages and transitions

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

### Social services and corrections

**Sharon Brintnell**, Professor, Department of Occupational Therapy, and Director,

Occupational Performance Analysis Unity, Faculty of Rehabilitation Medicine, University of Alberta

### Treatment for FASD

**John McLennan**, Assistant Professor, Departments of Community Health Sciences, Psychiatry, and Paediatrics, University of Calgary

### Justice issues

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

### Policy development and FASD

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

## What further research into FASD is needed?

### Health and social policy

**Sterling Clarren**, CEO and Scientific Director, Canada Northwest FASD Research Network; Clinical Professor, Pediatrics, School of Medicine, University of Washington, Clinical Professor, Pediatrics, Faculty of Medicine, University of British Columbia

### Focusing research efforts...where?

**Sara Jo Nixon**, President, Research Society of Alcoholism Fellow, Divisions 28 and 50, American Psychological Society, Professor and Chief, Division of Addictions Research and Director, Neurocognitive Laboratory, Dept. of Psychiatry College of Medicine, University of Florida

### Child health and well-being

**Bruce Perry**, Senior Fellow, The ChildTrauma Academy

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**John Sproule**, Senior Policy Director, Institute of Health Economics

**Melissa Waltner**, Executive Assistant, Institute of Health Economics

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**Nancy Reynolds**, President and Chief Executive Officer, Alberta Centre for Child, Family and Community Research

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**Melissa Waltner**, Executive Assistant, Institute of Health Economics

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# FASD Research and Resources

Ongoing research and evaluation of programs will help to determine best practices for preventing FASD and supporting those already affected.

The Institute of Health Economics is currently working on a series of projects related to FASD. This conference is part of a series of consensus development conferences produced by the Institute. Visit [www.ihe.ca](http://www.ihe.ca) for more information.

The Government of Alberta's Fetal Alcohol Spectrum Disorder Cross-ministry Committee has a comprehensive website with extensive resources on FASD. Visit their site at [www.fasd-cmc.alberta.ca](http://www.fasd-cmc.alberta.ca).

The Public Health Agency of Canada has also developed a site to provide basic information on FASD and to report what it is doing in the area. Visit their site at [www.phac-aspc.gc.ca/fasd-etca](http://www.phac-aspc.gc.ca/fasd-etca).

# Jury Recommendations Summary

## Question 1

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

1. There is a need for national funding for research to develop accurate and cost effective neurobiological and/or functional markers of FASD.
2. Comprehensive diagnostic capability needs to be available across the lifespan.

## Question 2

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

1. A national surveillance strategy needs to be implemented to assess progress in the prevention and treatment of FASD in Canada. Questions on FASD should be included in the regular Canadian Community Health Survey.
2. Registries of non-personalized data for FASD surveillance should be established in each province to increase the capacity for screening, diagnosis, and reporting of FASD nationally. This should build on projects already underway regionally and provincially to increase data collection.
3. Reliable methods of early detection of developmental delays and disorders, including FASD, should be introduced into early school years and be available throughout the lifespan.
4. A strategy to reduce the stigma associated with a diagnosis of FASD is needed in order to ensure maximum participation in screening, prevention and diagnostic processes.

## Question 3

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

1. As FASD is a lifelong disability, there should be a commitment by governments to provide seamless and equitable services across the life span.
2. Important transitions from child to adult services need to be planned and allow for effective wraparound services which will support individuals and families and communities at each stage of life.
3. People affected with FASD will require life-long intersectoral services. Consistent standards between provinces should be established to reduce variations in the funding and provision of these services.
4. Adults with FASD will require ongoing life skills and socialization assistance and support.
5. For those children who enter the child welfare system there should be improvements to ensure the ability to provide stable foster care. Multiple placements should be avoided wherever possible.

## Question 4

*How can FASD be prevented?*

1. A national primary prevention strategy must include a clear message consistent with Canadian values. This should include education about the effects and risks of alcohol beginning in elementary school and continuing through post-secondary education. It should also include education about birth control.

2. Prevention programs should target the Social Determinants of Health.
3. Prevention programs should be designed along with evaluation frameworks.
4. Prevention efforts should be community driven, culturally appropriate and should honour traditional knowledge. This is especially true in Aboriginal and immigrant communities.
5. A high priority should be placed on ensuring that prevention services are provided to women and families at highest risk of having a child with FASD. The Parent-Child Assistance Program (PCAP) has shown great success. Canadian programs based on the PCAP model should be encouraged.
6. Governments should require messaging about FASD in pregnancy testing kits and in contraceptive packages.
7. The reforms being made in primary care have the potential to improve the relationships required for effective prevention and support. Physicians and other primary health providers should take full advantage of “teachable moments” to discuss pregnancy prevention and the risks of alcohol consumption with their patients/clients of child bearing age.
8. Increase the number of women-centered alcohol treatment programs and beds. Keeping mothers and children together during interventions should be a priority.
9. National, provincial and territorial alcohol strategies must address FASD.

## Question 5

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

### Lifelong Services

1. Services should be (a) based on functional need rather than arbitrary eligibility criteria; (b) lifelong; (c) seamless; (d) individualized; (e) culturally sensitive; and (f) sustainably funded.
2. There should be funding for systematic evaluations of programs and sharing of findings to develop best practices.
3. Build communities of support for individuals affected by FASD and their families. In particular, encourage mentorship and activity based programs.
4. There should be special attention and support for First Nations, Inuit and Métis peoples affected by FASD who have experienced societal breakdown due to historical and multigenerational trauma.

### Diagnosis/Assessment

1. There must be equitable and timely access to diagnosis for individuals with suspected FASD, including appropriate communication of findings with the individual, family and other service providers.
2. Functional reassessments should be undertaken as needed.
3. Amend the Criminal Code to allow for Court-ordered assessments, including FASD.

### Education and Training

1. Educational instruction and materials should be provided to promote awareness, understanding and

knowledge of best practices for those who are or will be working with people affected by FASD.

2. An individualized educational plan needs to be developed focusing on skill development, inclusion, participation and recognition of existing strengths, to facilitate becoming a contributing member of society.

### Legal

1. Improve outcomes and reduce costs to the legal system by utilizing an alternative measures program for adults affected by FASD charged with non-violent first offences. Take into account a FASD diagnosis on subsequent non-violent offences when sentencing.
  2. Improve outcomes and reduce cost to the youth justice system by utilizing an alternative measures program for all young offenders affected by FASD charged with non-violent offences.
  3. Pre-release and post release programs for individuals need to be established.
  4. Enhance the correctional environments to respond to the special needs of persons affected by FASD to protect them from exploitation and abuse.
2. More research on prenatal alcohol exposure on brain structure and function with the aim of improving interventions and outcomes.
  3. More reliable indicators, biological and/or behavioural, of maternal alcohol consumption during pregnancy are needed.
  4. Ongoing research for the development of better screening and surveillance tools, specific and sensitive to prenatal alcohol exposure. These should be adaptable, culturally appropriate and lead to accurate referrals for diagnosis and supports.
  5. Encourage uniform approaches to recording clinical findings found during FASD assessments by using standardized forms and definitions.
  6. Support intersectoral research with education, health and social services.
  7. More research between corrections, justice and social services to identify rates, outcomes, costs and co-occurring conditions.
  8. Initiate research into the role of parents, including fathers.
  9. Embed research and evaluation into programs and services to allow for self correction and continuous improvement.
  10. Promote research on interventions based on social determinants of health that could modify the incidence and severity of FASD.

## Question 6

*What further research into FASD is needed?*

1. More translational research from basic science to the human experience, such as the beneficial effects of nutrition.



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