

Report

National Roundtable On The Development of a Canadian Model for Calculating the Economic Impact of FASD

**March 21-22, 2007
Ottawa, Ontario**

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Roundtable Executive Summary

As part of the work supporting the development of Canadian data on FASD, the Public Health Agency of Canada hosted the first national Roundtable on the Economic Impact of FASD in Canada. The Roundtable included a broad range of representatives in the FASD field: researchers, provincial and territorial representatives, national Aboriginal organizations, Government of Canada (GoC) partners as well as experts and economists.

The Roundtable took place on March 21-22, 2007 in Ottawa, Ontario. Presentations were given by Jan Lutke (Inconvenient Economics: What's the real cost of FASD Systems interface?), Brenda Stade (Revised Estimate of the Cost Burden of Prenatal Exposure to Alcohol in Canada) and Brian Grant (Measuring the Economic Impact of FASD in Canada: Criminal Justice Issues).

The goal was to come to an agreement on the common components which would be included in an economic impact calculation to support eventual cost/benefit analyses of interventions. The emphasis of this first meeting was to achieve an agreement on the elements of a model, rather than developing the model itself. The cost of FASD to society is an important issue which consistently arises throughout discussions in Canada; however, there is limited Canadian and international research focussed on assessing the economic impact. Gaps relate to subjects' age, scope and methodology. Hence, there is a need for Canadian data illustrating the costs of different life pathways taken by those affected by FASD (e.g. correctional institutions, homelessness, independent living etc.). These data are important in identifying potential intervention points, and the cost-benefit of various interventions.

1. Presentations

The Roundtable consisted of four presentations, each distinct in focus. Jan Lutke gave a macro representation of the costs that FASD gives rise to. The costs were divided in themes such as physical and mental health, the justice system, social services, education and many more. Brenda Stade presented the results of her research on the cost-burden of FASD in Canada. Her study found the adjusted cost to be just over \$24,000 per child annually. Although the study was not designed at the population level, Stade extrapolated her data for a “very conservative” national FASD cost of nearly \$600 million. She explained that in her study, data for infants under one year of age, individuals in the judicial system, the homeless, and children in institutions were not included.

Brian Grant and Patricia MacPherson spoke from the perspective of the federal correctional services, which handles the more serious offenders who have sentences of two years or more. The presenters demonstrated that the management of FASD

individuals uses extensive resources that could be used in other areas. Other research shows that 23% of young offenders had symptoms of fetal alcohol syndrome (FAS) or fetal alcohol effects (FAE). In her longitudinal study in the US (2004), Dr. Streissguth found that 60% of FASD-affected adolescents and adults had had some contact with the law. Since keeping someone in a Canadian institution costs from \$72,000 to more than \$150,000 per year, interventions that can keep a person out of an institution for even six months can produce significant savings.

Finally, Kim Meawasige gave a presentation on the status of FASD research in Aboriginal communities. When analyzing the economic cost and impact, Meawasige commented on the difficulty of putting a price tag on loss of culture, hope as well as spiritual, mental and emotional effects.

2. Results of the Discussions

Participants divided into break-out sessions to discuss four of the systems: Social Services, Education and Employment, Criminal Justice and Health, Mental Health and Addictions.

2.1 Social Services

Participants argued that a broad approach should be taken to calculate the economic impact of FASD

There is a need to focus on “the bigger picture;”

Among the costs of FASD participants identified were:

- the cost of child welfare to the system as well as the family
- costs associated with access to services for families living in remote areas
- per diem costs for families and the system while away from home
- costs associated with the process of finding appropriate foster parents for FASD children.

Other costs include those linked with possible addictions, teen pregnancies, sexuality, and sexually transmitted diseases (STDs) for youth or adolescents with FASD.

The economic model should also include:

- home support services to assist FASD affected individuals and their families
- residential care for FASD affected individuals
- respite care for those affected by FASD
- cost of providing transition into adulthood from adolescence
- cost of independent living to the system for FASD individuals

2.2 Education and Employment

Some of the Education Costs identified by the participants were:

- Assessment of special needs for preschool children is required.
- Cost of low teacher to student ratio.
- Cost to the other students if interventions are not put in place, as disruptive children really influence other children
- There is economic loss for every year that high school isn't completed, and there are long term losses when a child is expelled from school as well.
- The education system can provide data on costs such as assessment, suspensions, and staff time and salaries.

Employment Costs identified by the participants were:

- The cost to employers: to adapt and accommodate for FASD-affected staff, such as the cost of training coworkers and managers to ensure a positive workplace environment, and
- The cost of training FASD-affected employees for efficiency and productivity.
- The cost of lost wages needs to be determined for different age groups: between 17-21, and 22-65 years of age.
- Cost of repeated job training due to repeated job loss.
- Lost productivity

2.3 Criminal Justice

The participants in the criminal justice group stated that the first step is to define “cost”. To them, costs represent anything that uses resources in the criminal justice system, or any event, program or intervention that causes resources to be used.

Also, they argued that costs should be organized chronologically as most people with FASD are not diagnosed in jail but usually after being convicted several times.

Research Needs:

- A criminal justice profile for people with FASD.
- Developing a neuro-psychological profile of offenders with FASD.
- Need to follow FASD people through the criminal justice system and measure the costs-proper consents would need to be in place to conduct research with youth.
- Recidivism support for individuals on parole.

2.4 Health, Mental Health and Addiction

Life history approach should be applied to the issue starting from neonatal to late adulthood.

Costs to the System:

- Costs of improving screening tools and developing diagnostic guidelines.
- Children with FASD are more prone to illnesses and injuries and therefore require more trips to the Emergency Rooms.
- Costs of visiting specialists

- Costs of language barriers, getting an interpreter

Costs to parents/caregivers:

- Costs associated with travel and for medical care.
- Costs of medication

3. Overall Research Needs

Better surveillance is needed to determine the prevalence of FASD.

Comparability between data sets needs to be addressed

Costs for different data on various procedures and facilities, such as children's hospitals and speciality clinics.

Information about costs could be borrowed from other developmental disabilities and the applied to children with FASD- sleep disorders could provide some data.

4. Aboriginal Issues

There is a need for a parallel but a separate Aboriginal study.

Ownership of process by communities is important

5. General Issues

There should be a National Lead

A national strategy is needed, not pockets of provincial strategies.

All studies should be culturally appropriate.

The model will need to show the difference in the system's costs for people who were diagnosed early and received the necessary supports and those who were not diagnosed until later and therefore did not receive early interventions.

As an overarching model component, participants noted "the costs of not doing things on the part of the parent or other non-FASD children." There are also the opportunity costs of "lost money that could have been invested for financial return."

Information about people with FASD who access the system has to be recorded with greater accuracy.

The model should account for the cost of assisting FASD affected people for the rest of their lives.

6. Moving Forward

Moving forward would involve getting FASD on the political agenda. The need for a champion to bring the cause to the attention of the government, and to lobby for funds.

The establishment of a working group was suggested

There is a need for Literature Review to determine what data exists and where to find it.

Determine whether to take a macro or a micro approach to calculating the economic impact of FASD. Involving economists who have been working in this area to provide information regarding the work entailed in developing a model.

An MOU should be established for data sharing indicating what type of data may be shared, and under what circumstances.

Under next steps, one participant identified the International Classification of Disease (ICD), which has a code for pregnancy complicated by alcohol exposure, which is underutilized.

Welcome

Kelly Stone, Director, Division of Childhood and Adolescence, PHAC
Claude Rocan, Director General, Centre for Health Promotion, PHAC

Kelly Stone welcomed the participants to the first roundtable on Fetal Alcohol Spectrum Disorder (FASD). The purpose of the roundtable was to discuss the “process of developing a model for measuring the economic impact of FASD in Canada.”

With approximately nine out of every 1000 babies born in Canada affected by FASD, the disorder touches every sector of the population. FASD has an impact on not only health care treatment of individuals with FASD, but on education, social services, employment, and the legal/criminal justice system. Further, the person with FASD shares its effects with his or her family and, to a different degree, society in general.

Stone expressed her pleasure at the representation from such a broad range of groups. She said their efforts during and after the roundtable would be key to ensuring the success of the enterprise.

Claude Rocan said FASD’s cost to society is consistently raised in consultations across the country, but research to assess the disorder’s economic impact is limited. Therefore, Canadian data is needed to illustrate costs. Such information also will assist in identifying potential intervention points and the cost-benefit of various interventions.

Rocan referred to the commitment of the Public Health Agency of Canada (PHAC) to continue to work collaboratively with the provinces and various stakeholders to develop an economic model. He said the emphasis of the next two days would be on achieving agreement on the elements of an economic model rather than on developing the model itself.

Ross Hammond, the facilitator, outlined the goals and objectives as well as the format for the roundtable.

Presentation 1: FASD—People and Systems

Inconvenient Economics: What is the *Real* Cost of FASD Systems Interface?

Jan Lutke, Co-chair, National Advisory Committee on FASD

Jan Lutke is a professional in the field and the adoptive parent of 13 children with FASD, ranging in age from 15 to 35.

Speaking from more than 30 years of experience with FASD, Lutke said she would be considering the establishment of an economic model of costs in a number of areas, such as physical health, mental health, and education. Each area could be broken down into numerous subcategories.

From a physical health care perspective, obvious concerns arise about the effect of low birth weight on development, the diagnosis and treatment of FASD, as well as complications related to FASD. Some costs are not as readily apparent. Because the disorder is not always diagnosed and is sometimes misdiagnosed, costs can result from not knowing that the individual is ill and that improper treatment –or no treatment at all—is being offered. Expenses also may arise from the assumption of capacity, when it may not exist or may be impaired. In addition, there are “huge interface issues between physical health care and homelessness, mental health, and addiction.”

Lutke referred to the cost of mental health services, family as well as individual; crisis intervention and management; and prescription medications. Under real costs, she included isolation, ineffective treatment, being reactive rather than anticipatory, and the misuse of medications, such as improper medications and over- or undermedicating.

Social services costs encompass child protection and apprehension, adoption, care agreements, and specialized training. Hidden expenses in this area relate to uninformed adoption, multiple placements, and poorly trained service providers, among others. These all have emotional ramifications as well.

Within the justice/legal system, quantifiable costs occur in such areas as law enforcement, youth and criminal court, legal aid, and the expense to society of maintaining someone with FASD in a detention facility. Non-quantifiable costs can include the effects of institutionalization and/or institutional abuse of individuals with FASD, the impact of negative media attention, and use of the justice/legal system as “the de facto social safety net.”

Lutke also identified costs, both obvious and hidden, in addiction services, education, employment and income systems, and housing and homelessness. Costs also exist in other systems, such as transportation, volunteer systems, and trusts and trustees.

Perhaps one of the most important areas affected is the family system itself. FASD touches not only the individual with the disorder, but every family member. While stress and financial debt are the most obvious effects, loss of time with the rest of the family, difficulty in finding skilled respite careworkers, and the mental health of the parents, are a few less obvious effects. There are also the real, but incalculable, costs, such as diminished quality of life and the emotional toll a disorder has on the family.

One of the main concerns is that funding for some services ends at an arbitrary age, while many other services end when the individual reaches the “age of majority.”

Unfortunately, individuals do not “age out” of FASD, and the services are still needed.

“The cost to the system becomes the cost to the family when system response is inadequate, unprepared, and unable to meet needs,” said Lutke.

People with FASD will be adults for 40–60 years. Because no real safety net exists, there is a very real danger that they will fall through the cracks, be marginalized by society, and excluded—what Lutke termed “denial by design.” Because FASD is a relatively “new” disorder, almost no knowledge has been accrued about its long-term costs and consequences. What is known is that there is no miraculous cure for FASD, and children with FASD likely are likely to outlive their parents. “The cost to the family becomes the cost to the system when the family is no longer able to provide,” said Lutke. “It is not a question of ‘if,’ but of ‘when.’”

The question is whether to pay now to put the necessary systems and safety nets in place or to pay later, when the costs to society in all these areas will be much higher. It is extremely likely that the costs of paying later will be many times the cost to the system of paying now. Lutke said it is a question of “funded interdependence versus the ‘bottomless pit’ of high-cost failure for both the system and the adult with FASD.”

Lutke said she found it “unconscionable” that this is an issue. Society has the skills to solve the problem, but it is necessary to do the costing so that society will have the reason to do so.

A participant said she was the guardian of a younger brother with autism and faced similar costs. She asked how to make the case to government that FASD and autism are different from other developmental disabilities. Lutke replied that in some ways there is no difference, but the problem is that FASD has been stigmatized and, therefore, does not have a vocal advocacy base. Proactive support, such as early intervention, costs much less than reactive support.

Another participant commented that, unlike other developmental disabilities, people with FASD have increased medical complications throughout their lives, for example, a heart condition. There are pieces that are similar, and there are pieces that are dissimilar.

Several participants spoke about the problem of people with autism who may not take advantage of the health care system. Although a lot of money goes into autism support, a stigma is attached to the diagnosis. Lutke said people can mistakenly assume that

individuals with FASD understand what is being asked of them and what they are assenting to or refusing to do. But this is not always the case. There are examples of deficits in treatment, and the information is not always there. Costs in all categories can seem to “morph” together. Therefore, early diagnosis and intervention are essential to minimizing costs.

Presentation 2: What Has Been Done in Canada?

Brenda Stade, Director, FASD Clinic, St. Michael’s Hospital, Toronto

“My Ph.D. study only looked at one aspect of the cause of FASD,” explained Brenda Stade, but it is clear that the “impact on quality of life is substantial.” FASD is the leading cause of developmental and cognitive disability among Canadian children.

Summarizing past FASD cost burden research, Stade said a 2003 study found the adjusted cost to be just over \$14,000 per child—close to \$350 million to Canada as a whole. She explained that in her study, data for infants under one year of age, individuals in the judicial system, the homeless, and children in institutions were not included.

Stade’s study was based on reports provided by parents and caregivers, which included adoptive and foster parents, as well as biological grandparents. She also noted the difficulty in measuring the productivity loss of parents who reported a change in career or the loss of career opportunities.

The purpose of her study was to estimate the total annual average cost associated with FASD specifically by looking at the total direct costs and productivity losses due to FASD and the factors influencing those costs. With this study, “we hope to provide a more accurate estimate of the costs of FASD but also expect that the articulation of the cost burden may help children with FASD across Canada.”

In a cross-sectional study design, Stade administered questionnaires to 200 parents and caregivers from rural and urban settings who lived with one or more children affected by and diagnosed with FASD. The Health Services Utilization Inventory–FASD (HSUI–FASD) assessed direct costs, including medical and education, as well as losses in productivity, such as days of missed work.

Stade reported that about 28% of respondents completed the questionnaire in full, while the remainder had to be queried again. The questionnaire asked about residential facilities and homelessness.

In outlining her methods of data analyses, Stade said all costs incurred were assigned to the child as the unit of analysis. The mean age of the children was 12.5 years. They were predominantly adopted (58%), both sexes were equally represented, and most children had a Euro- or Aboriginal Canadian background. Study participants were relatively equally distributed among eastern (Quebec and the Maritimes), western (Alberta,

Saskatchewan, British Columbia, and the Territories) and central (Manitoba and Ontario) Canada.

The total adjusted annual cost of FASD was close to \$24,000 per child—a cost that is above and beyond the normal costs associated with raising non-FASD children. The lion’s share of that cost was related to education (30%) and medical expenses (36%). Stade noted, “Parents and caregivers pay a significant 21% of that total cost.”

The severity of the condition, the child’s age (i.e. between six and eight years of age), and whether or not the child was in an adoptive or a foster family were major contributing factors to Stade’s revised cost estimate. She explained that child protection agencies had extended the time children could be in foster care by three years, which increased the costs for social services in this segment. The fact that there was no significant difference among regions, as was noted in her 2003 study, indicates “that the other regions are catching up.”

Although the study was not designed at the population level, Stade extrapolated her data for a “very conservative” national FASD cost of nearly \$600 million. “I am not very confident in this number, given the difficulty in determining FASD prevalence and incidence.”

Stade called for “more emphasis on prevention strategies,” noting that in the context of evaluating prevention interventions, the costs of intervening to prevent the birth of one child with FASD should be investigated. She also said, “Decision makers should be aware of the substantial long-term economic impact on the parent/caregiver.”

Stade recommended that future studies include individuals who are incarcerated. “We need a better estimate of the costs going into the prison system.” In her clinic, Stade said she sees adults in “shackles and orange suits” and collects data on them and other clients up to age 55. In addition, she said, “We need greater age ranges.” She also suggested a study to look at cost differences in the first two years of life of alcohol-exposed versus non-exposed infants.

Asked to reconcile the cost factors that Stade had considered in her study and the broad range measured by Lutke, Stade said she had localized the FASD costs. Therefore, Stade had considered only related costs, such as external behaviour (e.g., property damage) and early childhood surgery. She added that “these were the costs as perceived by the parents/caregivers,” and since there were open-ended questions, the parents/caregivers could add other costs.

“What about the populations that can’t access FASD services?” asked one participant. That variable cannot be measured, replied Stade, just as “you can’t measure those who have not been diagnosed.” Yet as more people are diagnosed, more accurate costs will be available.

Stade was asked whether her study had captured costs incurred later in an individual's life even within Stade's age range. Stade was not able to account for this in her study, but suggested that prospectively following the individual from birth onwards would be another research project and could "come up with very different costs."

There was also a discussion about the difference in views of costs between children and their parents. "The patients would tell you something very different." Stade said individuals in her age groups consistently deferred to their families to answer questions. She also noted that there "was good agreement between her clinical reports from parents and actual FASD costs." Stade said she agreed, however, that it would have been good to have information from patients directly had they felt more comfortable.

A participant noted that while Stade's study estimated real dollar costs of FASD, Lutke's study took into account much broader impacts. "It will take more work to associate a dollar value with those impacts," noted Stade. But she said her team had conducted a quality-of-life study for children (0–21 years old) and their parents, from which subsequent research could be planned.

Presentation 3: What Do We Know About the Link to the Criminal Justice System?

Measuring the Economic Impact of FASD in Canada: Criminal Justice Issues

Brian A. Grant, Ph.D., A/Director, General Research, Correctional Service of Canada (CSC)

Patricia MacPherson, Research Manager, Addictions Research Centre, CSC

Brian Grant said that while one should always try to achieve the best model possible for analysis, one needs to start using the models available now. If people wait until the perfect model is developed, they will never get started.

Grant's perspective was from the federal Criminal Justice Canada department, which handles the more serious offenders who have sentences over two years.

It is necessary to measure the economic costs of FASD to demonstrate the magnitude of the problem for Canada, get governments' attention, develop effective policies, and identify gaps in knowledge. Over the longer term, this baseline can show the impact of policies and programs. While there has been a Canadian survey estimating the cost of tobacco, alcohol, and drug use, no research has assessed the impact on criminal justice and corrections systems specifically.

Potential health care costs of FASD include those of mental health, social welfare that continues throughout the adult life of the FASD patient, and education. High costs of lost productivity encompass the FASD-affected person's reduced potential to earn a living;

the impact on caregivers (usually family members); and the person's reduced ability to contribute to their own quality of life, to their families, and to their communities.

Also needed is a way to account for the time and other resources spent by caregivers and families, including hours, dollars, and stress. How does one measure stress?

Law enforcement and criminal justice costs include police, courts, and corrections services. FASD management uses resources that could be used in other areas. Because developing a program to treat offenders can cost up to \$1 million, it must be based on facts.

Collecting this data poses several challenges. Centralized data systems like Statistics Canada do not serve the needs of this project well: they do not break out information for the correctional services population. Attributing costs to FASD also requires incidence and prevalence data.

Conry and Fast found in 1999 that 23% of young offenders had symptoms of fetal alcohol syndrome (FAS) or fetal alcohol effects (FAE). In 2004, Streissguth found that 60% of FASD-affected adolescents and adults had had some contact with the law.

People with FASD are often assigned to higher levels of security than necessary, at higher costs; community-based corrections, at much lower costs than institutional corrections, are often more effective. Since keeping someone in an institution costs from \$72,000 to more than \$150,000 per year, interventions that can keep a person out of an institution for even six months can produce significant savings.

Estimating the economic impact is challenging, but necessary to show the magnitude of the problem in language that everyone can understand, to develop appropriate policies and programs, and to allocate limited resources effectively.

Grant concluded by asking the audience to consider the total cost of inappropriately criminalizing people with FASD, not just over the years until they reach age 18, but throughout adulthood: 60–80 years.

Having seen evidence that the incidence of FASD was higher among offenders than in the general population, Patricia MacPherson measured the incidence in Stony Mountain Institution, north of Winnipeg.

In consultation with corrections, health, FASD, and Aboriginal stakeholders inside and outside of the CSC, MacPherson's team developed a screening system to identify individuals at risk for FASD. This would also give people so identified a way to get a diagnosis. Participation was voluntary.

Ethical issues existed: the team did not want the study to increase the risk for people it would first identify with FASD. Consent forms for minors were often unavailable, because mothers had died.

Of the 91 participants, 66% were Aboriginal, 25% were Caucasian, and the remainder were a mix of other ethnicities. This mix closely paralleled the overall correctional population.

Some 9% to 10% of the sample were identified with FASD, and a further 16% to 18% were found to be “possibly” affected by FASD. Those with or possibly with FASD had higher-than-average occurrences of behavioural issues; their criminal history was also significantly longer. The FASD-identified were 10 times more likely than the “normal” population to have 15 or more convictions.

However, the sample size of this study was very small. More research in larger groups and in other centres across Canada is needed. Information on female offenders and on older offenders is also needed, as is a refined screening tool to identify those with FASD.

MacPherson suggested broadening the funding support to involve more partners and expand the study.

Addressing FASD in correctional services requires

- Screening and support, such as liaison officers in institutions and in the community
- Diagnostic supports for physicians and psychologists
- Staff training in diagnostic tools, and identifying and implementing programs
- Community services, such as residential facilities, specialized parole officers, and work placements
- Incidence research and screening tool development
- Program development and evaluation research
- Specialized living units, where staff understands the unique needs of offenders with FASD.

Discussion

One participant said 91% of individuals in Toronto with FASD reported some involvement with the law.

MacPherson explained that the FASD diagnosis was based on Canadian standard CNS deficits, which allow separating the disorder from other mental health issues. However, she noted that many people with FASD also have other issues. For example, only 30% of people with FASD have normally functioning central nervous systems.

Asked whether a diagnosis could lead to further incarceration or restrictions because of concern about cognitive limitations, the presenters replied that they had decided to offer participants a choice about informing the corrections system. Part of the role of a liaison officer is to intervene with the system on behalf of persons with FASD, for example, at parole hearings.

Presentation 4: What Do We Know About Aboriginal Communities?

Kim Meawasige, Chair, FASD Task Force, Toronto, and FASD Policy Analyst, Ontario Federation of Friendship Centres, Toronto

Kim Meawasige gave a presentation on the status of FASD research on Aboriginal communities. She has four children with FASD.

Meawasige first noted that there are “only a handful of Aboriginal researchers” and that no baseline exists of the number of Aboriginal children with FASD, as many go undiagnosed. Northern communities are particularly disadvantaged, because they lack many of the services that people and families affected by FASD need, including housing, education, and cultural services.

Wait times are long, and many must go off-reserve to access services. Most children have to leave by Grade 7 or Grade 8 to attend high school, resulting in many youth with FASD who must live without their families. Many FASD-affected individuals also have Attention-Deficit Hyperactivity Disorder (ADHD), as reported by a US study, and a direct link to an increase in suicide and heart disease can be seen.

When analyzing the economic cost and impact, Meawasige commented, “It’s very difficult to put a number on the lost culture, hope, and parents, and spiritual, mental, emotional, and physical impact of FASD.” Aboriginal people have the highest rates of suicide, children with disability, child poverty, obesity, and FASD—“in anything you can mention.” Thus there is a much larger picture to the cost and impact.

It really requires Aboriginal people to develop and be part of the research, Meawasige said. “The research that needs to be done needs to be done by Aboriginal people.”

Meawasige quoted a study of Aboriginal communities that reported high prevalence rates of FASD in BC and northern Manitoba. The study also found that more than 50% of the women there used drugs or alcohol throughout their pregnancies.

Meawasige invited Paul Masotti to speak. Masotti, a researcher at Queen’s University, told the participants that “FAS[D] is not an Aboriginal issue.” He described a study that had taken place in four communities in BC and Ontario, whose purpose was to develop culturally appropriate interventions and healthy community methods for Aboriginal mothers.

Participatory research was the methodology used. All research was done in the community by community members, while the university provided the template for a structured approach. The study identified leaders in each community, who then surveyed the women of childbearing age. Masotti noted that some of the people identified as leaders were themselves from dysfunctional families, which was surprising. The research

took into consideration the needs and characteristics of the women, a high degree of community involvement, and the level of feasibility and sustainability of interventions.

A key finding was that there must be a strong sense of ownership to any intervention. It must adopt local indigenous knowledge and use local available resources. Moreover, interventions must begin by addressing the most pressing issues in the community, which may not necessarily be FASD. The underlying principle is that “the first step toward a healthy lifestyle is the first step toward addressing FASD,” Masotti said.

Further, such a model of a “healthy community,” with healthy mothers and children, can be applied to any community, not just to Aboriginal communities. The healthy community model also may be applied to any problematic issue, not just FASD, whether it is diabetes, smoking, substance abuse, or some other problem.

Discussion

A participant noted the high cost of transition when huge numbers of children must move on their own from a smaller, community-based school to a larger, urban high school environment, where it is much more challenging to access assessment and support. More than three-quarters of the children, especially boys, do not stay past Grade 9.

Meawasige said most do not leave on their own, but are expelled. Behavioural problems mean that the children often need the care of either a relative or a specialized sitter. FASD has a huge impact on the educational system. If no specialized program or placement is found, the result may be no education.

There are also people who are institutionalized their whole lives, and gangs are a huge problem. Many are prescribed drugs such as Ritalin, and even parents take these drugs just to cope. In many communities, young people self-medicate, are in isolation, and have very little support. Communities are struggling. To keep youth, families, and children active, communities need both support and recreational activities, Meawasige said.

Another delegate expressed agreement that it is “extremely important” to have Aboriginal researchers involved from the actual design of research to its implementation.

Meawasige said, “Aboriginal people want to be involved in research.” However, their proposals to be more active and part of research teams were being turned down, and Aboriginal people were doing no research on FASD in Aboriginal communities. She called for attention from the research community to this issue.

Group Table Check-in: What Did You Hear?

Hammond said the four presentations provided concepts to be considered in creating an economic model. He asked participants at the various tables to think about what they had

heard with respect to measuring costs and what links there might be to other research of which they were aware.

In the “report back” segment, one group recommended focusing on what can be done now, looking at what tangible items are involved. Costing information is key for policy decisions.

Another table emphasized the need for a multi-level study, using a control group and comparing the costs associated with early diagnosis and treatment with those situations where treatment is not easily accessible. Although it is not possible to put a dollar value to each piece, it is important to indicate what can be quantified.

One group quoted Judge Barry Stewart, who described the criminal justice system as an overwhelming failure into which an ever-increasing amount of money is placed. In the recent federal budget, a great deal of money was allocated to providing four more correctional facilities. A convincing argument should be mounted to ensure that money goes to prevention rather than to punishment.

Another group said consideration should be given to the less tangible effects of FASD, such as the individual’s lost quality of life and the family’s emotional life.

For one group, the emphasis was on the existing gaps in the system. It recommended considering the incremental costs associated with FASD, doing a cost-benefit analysis of doing something as compared with not doing it, and building on research that is being done.

Another group recommended studying First Nations and Inuit peoples on reserves and contrasting them with urban Aboriginals, because their issues are different. The group referred to the power in community-based studies and those that involve follow-up interventions. Another group referred to the importance of considering all perspectives.

It will be important to cost the identifiable items in an economic model and to specify a series of interventions. Funding for research is available from various sources, especially the Canadian Institutes for Health Research (CIHR).

Holly MacKay, a Senior Program Consultant, expressed her appreciation to the roundtable organizers, to all those performing roundtable-related tasks, and to the FASD team. She said the participants represented a wide variety of facets of the FASD field, and they had been invited to provide a broad perspective of what was happening. All the invitees who were unable to attend had asked to be included in future activities. MacKay stressed the need to move forward.

Breakout Group Set-up and Day 2 Start-up

Hammond advised participants that the remainder of the roundtable would be dedicated to attempting to boil down a huge issue into measurable pieces without losing the sense of its vastness and complexity. Participants were not expected to create the costing model then, but only to identify those components it should contain. Therefore, it was important to remember the questions that had been raised during the morning session.

The assembly was divided into four smaller groups to deal with the subjects of social services; education and employment; the criminal justice system; and health, mental health, and addiction. Participants in each group would answer a set of questions, but from the perspective of the issue to which they had been assigned.

The first task, said Hammond, was to identify the kinds of things that should be looked at to give a complete picture of the economic impacts of FASD. Attention was to be paid to efforts that should be made then and to those that should be made later. The second question the groups were asked to consider was what needed to be measured, with an emphasis on devising a research agenda. Following the report back, the smaller groups would reconvene to discuss the questions to be used in creating a research agenda.

Hammond said the second day's agenda was to continue the small group work to finalize the discussion from the day before, based on Day 2's feedback in the plenary. The three questions to be discussed on Day 2 were

- Who else should be involved in the development of the model for measuring economic impact in each group's theme?
- How long would this reasonably take? Participants were to discuss the length of time between when the work starts and when there is something to report, including the time frame of scheduling, funding, and so on. Additionally, there may be different versions to report and a number of iterations to provide different layers.
- What are the key next steps for moving the agenda forward? Day 1 had been an opportunity to explore ideas and cover a broad range of useful research. The focus on Day 2 would be on the key economic impact pieces and the immediate next steps over the next three to six months.

Although the event was structured as described above, the report will follow a different order to facilitate reading. The breakout session discussion will be divided by subject in an effort to avoid repetition and so that the flow of the discussions is clear throughout. The group discussions will be followed by feedback reporting of day one and two.

Breakout Group 1: Defining Model Components—Social Services Theme

The group brainstormed about what social services components to include in a cost model for FASD. One participant working with Ontario's Ministry of Children and Youth noted that one of the key considerations for costs is child welfare. Costs in this category include adjudicating costs, getting children into court, per diem costs, and the

expensive process of finding appropriate foster parents. Another group member added that “one extension would be residential care.” Those figures, according to her, are easy to get.

The next speaker said, “We could not get figures for exactly which kids taken into care have FASD.” This is not a question of whether or not they had been diagnosed, but rather a data collection problem. Data availability with respect to First Nations depends on what information First Nations want to share with government.

A participant pointed to the problem of utilization rates. “The problem in measuring costs is the link to patient identifiers. There could be 15 events identified, but all are related to only one person.”

Another delegate said many parents put their children into care because it is the only way to get services. This highlights the importance of regional context. A family is more likely to get services in Alberta than in Newfoundland, for example. Perhaps different service delivery models are needed for different regions.

One delegate wondered how access to services can be teased out at different times in the life of a patient. “How do we avoid double or triple counting?”

Other participants suggested that model components also should include home support services (funding does not provide for this or may differ across jurisdictions); housing costs (e.g., for independent living arrangements); and income assistance (e.g., hiring and equitability). Some referred to qualification criteria for assistance programs. Many individuals with FASD have IQs in the normal range and present very well and therefore, may not qualify for funding.

When patients become non-compliant, they also fall through social service cracks. Anyone who has lost their job due to non-compliance may use assistance as well.

The group also suggested that diagnostic teams for the patient should be included in a cost model, as should access to leisure and recreation activities.

In terms of respite, one participant mentioned the move to a parent-managed model in Saskatchewan, which could have a significant emotional toll on families. Other delegates noted that the cost of not offering respite, as well as direct costs and costs related to training, should be specified under the respite component.

Coming back to housing costs, one participant said some families are not able to “scrape up a damage deposit.” Other delegates added that they would like to see costs included for items that address safety issues around the home (e.g. door alarms), as well as costs related to long-term care. Another delegate suggested that another model component should be legal aid.

Under the intervention model component, parent training was discussed. One participant said that in Ontario, “we are profiling parenting as a prevention that would save money.” Agreeing, another delegate said there were parenting skills programs, which may be relevant in a cost model.

Home care also should involve associated medical and social costs, as well as some of the general work that needs to be done around the home.

The group established a miscellaneous model component, which included the transportation costs associated with going to appointments and interviews, as well as child care costs, emergency or otherwise.

One participant pointed out the huge number of resources that parents of FASD-affected children “have to connect with, and it’s always the mom that does the case management.” Parents need a one-stop shop. The participant also maintained that health and social aspects are very difficult to separate.

As an overarching model component, participants mentioned “the opportunity costs of not doing things on the part of the parent or other non-FASD children.” There are also the opportunity costs of “lost money that could have been invested for financial return.”

Several participants also wondered how the emotional costs of such family stresses as divorce are measured. “As a parent, you have to advocate so hard to keep them out of prison,” said one. In addition, parents fear having their children taken into custody; this has repercussions throughout the family.

One participant said many of the costs that the group had noted were measurable, such as housing. Information on the type of facility and its associated budget, for instance, could be readily obtained.

The group wondered how the model would cross over into provincial, federal, and municipal systems. Some members raised a question about the costs of the lack of services. Participants acknowledged that a regional breakdown of the costs would be necessary, such as rural versus urban, and on-reserve versus off-reserve.

One participant said they wanted to see a reference to multi-staged intervention, given that FASD-affected children, for example, have no understanding of consequence. The costs associated with the death of a child with FASD can also be substantial, given the subsequent loss of productivity.

Breakout Group 1: Planning a Research Agenda—Social Services Theme

The group approached the discussion from a broader perspective, choosing to focus not only on the social services component of an FASD cost model, but on a model for all costs. The group reflected on existing data and studies related to social services. Participants said Stade’s study was the only Canadian one of which they were aware. A

recent American study on the economic impact of FASD was mentioned as being relevant as well.

One participant said the first step was to determine what data existed at the “the higher scale” level. The group said a “huge literature review,” like the American *RAND Report*, is necessary to determine what data exists and where it can be found.

In terms of an actual research study, one delegate strongly advocated for parallel but separate Aboriginal studies with common, comparable indicators. Most participants said that “it’s too big for one study” and envisaged research teams with expertise in different areas, including social services. Information could then “be teased out to get to the local level,” suggested the next speaker.

The question of reliable, quality data was raised with respect to gathering existing data. Provincial databases, for example, have many blank fields, making it difficult, if not impossible, to collect data. An inability to use historical data may mean that “we have to create a model and then get the data that gives us a baseline in the future.”

There was some discussion about the type of data that could be readily collected, such as for housing and per diems.

One participant suggested expanding Stadel’s model to beyond age 21 and into the justice sector. Her initial model can be expanded by other studies.

Some participants said they wondered what this information would be used for. Is it to inform policy? If so, every tiny detail does not to be included to get a general idea. “We need multiple surveys for different purposes,” said one group member, who suggested focusing initially on the minimum information needed. Ideally, however, data gathered at different levels would be interrelated, countered another participant.

One participant proposed approaching the model “from a secondary characteristic point of view. We should build the business case for saving money.” The more data one has at different government levels, the better; ultimately it is the service deliverer that needs the most detail.

There was some discussion about FASD client identification, which would facilitate linking cases and costs. First Nations, however, “don’t feel comfortable sharing that information; they are the controllers of data and the deliverers of services.” It means First Nations’ child and family services need to “buy in” to the model.

In Alberta, patients with FASD are diagnosed by different agencies and are assigned different numbers. Thus “lots of kids may be identified, but the information is not coordinated.” People with FASD access services from multiple agencies, which fall under the jurisdiction of multiple ministries. In Alberta, there is no unique personal identifier shared by all service providers, which makes it difficult to track individuals

and limits the information available to provide accurate estimates of the prevalence of FASD.

One participant suggested that the funding of diagnosis in Ontario constitutes a form of research, given the need for more accurate incidence data. She added, “Without diagnosis you can’t carry out good retrospective studies, which are more powerful [than prospective ones].” Another delegate mentioned a recent Queen’s University study on FASD diagnosis by eye movement as an interesting diagnostic avenue.

One participant said it is necessary to ensure that any research carried out is culturally appropriate.

Another indicated that “even the Canadian estimates are dubious; at the very least, they are conservative.” Another delegate added that while much research seems to be focused on “full-blown FASD,” milder presentations are less studied. “There are many more of those kids, and that financial impact could be important.” The Ontario Federation of Friendship Centres published a community-based diagnostic guide that could be useful for such a study.

In terms of who could carry out the research, one participant suggested that the Canadian Northwest FASD Partnership (British Columbia, Alberta, Saskatchewan, Manitoba, Nunavut, and the three territories), could be a potential research partner. It looks at issues in health, as well as prevention. While the partnership does not conduct research itself, it has a well-established research network. “It is a high-level group and an important one from the buy-in perspective.”

A lead at the national level would be required and as someone suggested, the CIHR, whose mandate is to fund health research in Canada, could fill such a role, with the partnership “doing a regional piece.” Others from the group said they agreed, noting that the CIHR includes social determinants of health in its research mandate, and thus research in this area would be “quite relevant.”

A national lead would need to be a credible, academic institution, and the CIHR is just that. It has arrangements between different bodies and can put together specific calls on FASD. Given that FASD is a diagnosis, it is logical that FASD research would start out health-based, with social services “tying in subsequently.” The key, according to one participant, “is getting a team of experts together for this kind of project.”

Another participant said the government seems to operate in silos, but this kind of research needs to involve all Ministries. The establishment of an advisory body that could put specific requirements into research proposals or RFPs was suggested.

One participant questioned whether basic research was needed before any new data could be collected. If so, what are the research questions? Who would take the lead for this research?

Another participant suggested that members of an advisory body must have a good understanding of FASD. Specifically, participants called for a federal/provincial/territorial (FPT) representative for the data—someone who understands the “economic piece” and how to design the study, a field worker who knows what kind of information can be obtained.

Rather than one model, maybe several models might be operating at different levels, but they would be ultimately cohesive.

The advisory body must incorporate certain principles and develop terms of reference for any research to be done. It was agreed that the data needs to be comparable. The Aboriginal component of data collection would be important, and the OCAP principle would have to be respected.

The group summarized the highlights of its discussion. The establishment of an advisory body was a key emerging idea, as were the need for a national lead such as the CIHR. How would this work? What would it look like? Also important to the group were the desire to avoid silos; the need for partnership (e.g., the National Aboriginal Health Organization (NAHO)); and the need for a combination of model development and data collection, especially for social aspects. The group also said it would like to see a large-scale review to determine what is missing, who can do it, and whether it is feasible; an assurance of cultural appropriateness; respect for the OCAP principle; and an Aboriginal component, or a parallel but compatible process.

The group also posed some questions. Can new data be collected? If so, from where, and who would take the lead on defining and collecting the data? What will be the cost of generating the new data, and what sources are available to fund the work?

Breakout Group 1: Revising the Research Agenda Based on Participant Input—Social Services Theme

Participants did not agree at which level a cost model should be discussed; some wanted to focus on the micro level, while others said the macro level should be addressed first before the social service component could be looked at. These opposing views permeated the subsequent discussions and extended into the question of who should be involved in the research.

One participant emphasized that “we need the bigger picture.” Municipalities, for example, need to be involved, as do the five national Aboriginal organizations and the regional ones.

Another delegate added, “When we talk about a parallel Aboriginal strategy, we need to have a liaison function,” so that the research principles and the basic indicators are developed in common. The previous speaker said such a linked structure already existed within Indian and Northern Affairs Canada; there were the political and service delivery aspects to every project. She reiterated the necessity for Aboriginal people to work on the research model and design.

If, as suggested in the previous day’s discussions, research bodies like the CIHR and the NAHO are the leads, “then the politics get left out,” cautioned one participant. If that happens, it could be a repeat of the Kelowna Accord.

A parallel system must exist for Aboriginal people, reiterated some participants, who noted that the five national organizations work at the political level and do not necessarily represent “everybody.” Perhaps it should go to the treaty level.

Other groups—like the National Association of Friendship Centres, the National Aboriginal Health Organization, the Federation of Saskatchewan Indian Nations, the First Nations Child and Family Caring Society of Canada, and the Association of Manitoba Chiefs—could be included. Non-Aboriginal organizations need to be considered, as do provincial child and family services authorities.

Parents of FASD-affected children need to be specifically included, because there are no national organizations but only small, dispersed groups. Another participant said the Canada Mortgage and Housing Corporation “would be critical for many of the model components,” as it is the lead in housing issues, on- or off- reserve.

Certainly researchers “who have done the groundwork,” such as Albert Chudley, Lindsay Crowshoe, Sterling Clarren, Brenda Stade, and Ann Streissguth, should be included as well.

Another participant said that if every province was represented, it could be an impetus to bring together, if provinces had not already formally done so, FASD parent or advocacy groups.

The next delegate added that HRSDC local bodies that deliver employment programs under the Aboriginal Human Resources Development Agreement (AHRDA) would be good candidates for involvement. Another speaker said they wanted to see Statistics Canada on the list.

Whether or not economists should be involved was a point of debate. Some said they could make a contribution, while others stated that economists do not develop models. Statisticians do, and the former should, therefore, be kept distant. It was agreed to tentatively add economists.

In terms of the timing of this process, one participant suggested that the first part would involve consultations that would signify a “start from the ground up.” For this, “we need

to decide who to engage at the local level.” Some suggested developing an organizational chart to accomplish this.

One delegate said an advisory body, perhaps in conjunction with the PHAC, could develop such an organizational chart. She was, however, unclear “as to who is the lead in the government.” The delegate suggested that the process could be designed within six months, and then the provinces could hold local consultations.

Disagreeing with this potential outline of the process, another participant said researchers should “do the consultations,” while either or both the CIHR and the PHAC should develop the model, which the advisory body would feed into. Group members said they agreed to disagree on the specific function of an advisory body, research teams, and the lead government agency.

What is the time frame for putting an advisory body together and for letting the model “filter down and filter back up?” One participant said that while it “takes years for Aboriginal group consultations,” the macro data will not take that long to collect. For instance, data for FASD incidence and cultural diversity will be readily available.

Group members said that in 2007/08, the organizational chart could be created. A foundational meeting could occur in 2008/09, consultations could be held the following year, and in 2010/11, there could be reporting back “with some products.”

An immediate next step would be the consideration of who would form the advisory body, the selection (and therefore, deciding on the criteria for membership) of who would sit on the advisory body, and the identification of researchers to develop the model. It was the general sense of the group that the PHAC would start the actual preliminary invitations.

A broad range of knowledge and expertise would be required for members of the advisory group. That body would issue an RFP, after advising on it, and would identify researchers, suggested one participant. She added that perhaps an RFP would be from the PHAC.

Returning to the discussion of macro and micro levels, a delegate said that, while “we need to have a sense of where we are going,” the research eventually has to get to the micro level.

Participants then reviewed the flip chart notes and made several additions:

- Should there be only one model or many? The group said there could be several.
- Brenda Stade and Robin LaDue were added to the experts list.
- While the “Aboriginal piece is well represented” under “who else to involve,” other non-Aboriginal groups had not been mentioned. Thus the group added that “this is not an exhaustive list.” Provincial governments, for example, could be engaged.
- The Atlantic Intergovernmental FASD Partnership should be involved.

Breakout Group 2: Defining Model Components—Education and Employment Theme

The group discussed the components of an economic model for FASD under the themes of education and employment.

Noting that access to support is a communal issue, the group began the discussion with infant development programs. Problems potentially can be recognized early on (between ages zero and three) in such programs, so that interventions can be made available. The larger the number of children identified as needing services, the more it will warrant the cost. However, it may be problematic to get infants into the programs in the first place if the parent is addictive or not advocating for the child. Also, FASD may not be obvious for those children whose language is not delayed.

Thus a system of broad screening, monitoring, and surveillance is needed to identify at-risk families and infants. The economic impact of finding these children includes the cost of intensive training for paediatricians and the cost associated with a team- and family-oriented approach.

Children are more likely to go to assessment in the preschool age, between three and five, a delegate said. This is the first direct cost known. Another cost is support for parents, who may be youth or FASD-affected themselves. This support includes general parenting training. Foster parents also need special education, as do teachers, social service staff, and daycare workers. Daycare workers often are paid minimum wage, a participant said, which does not correlate with “what we are told: that it’s the most important time in your child’s life.”

Special needs preschool, child needs assessment, speech or language intervention, support with childcare to help manage behaviour—the salaries and assessment costs of these services and programs all need to be known. A delegate suggested arriving at a provincial/territorial average of differences across jurisdictions. Another participant recommended comparing the cost of providing support with the cost if the support were not in place. Another delegate added that the ability to compare across jurisdictions is important. Not only costs and programs but assessment instruments and indicators vary across jurisdictions, including on- and off-reserve. Standardized assessments are needed, participants said.

Most provinces, except the western provinces, have a self-identification policy and can differentiate between Aboriginal and non-Aboriginal people in terms of FASD diagnosis. Those without this policy rely on school assessment, a participant said.

Better data collection can lead to program evaluation, but the cost of gathering data and maintaining databases must be factored into the economic model, said a delegate.

A participant suggested developing specialized high school programs leading to a certificate that qualifies graduates for vocational training, apprenticeship programs, or employment. Another participant added that work-study programs in high schools are valuable. Tax credits, subsidies, and annual rebates are some examples of economic incentives that encourage employers to participate in these programs or to hire FASD-affected people.

Participants said the cost of a low teacher-to-student ratio is high, but there should be a way to measure the economic benefits of employing people to provide services to those in need. Moreover, the government already has youth employment programs in place; the issue is making them more specialized for FASD. The difference, however, is that “we expect the youth to grow up, but cannot expect FASD youth to grow up and be productive.” They need support their entire lives, and thus a mentality change is needed.

A delegate said economic loss accrues for every year that high school is not completed. Families experience long-term loss when a child is expelled from school. She suggested adapting exams to do appropriate knowledge assessment, such as those that test for dyslexia. This would allow FASD-affected youth to complete high school and university.

Another participant noted that such accommodation requires self-identification. “If they do not come out, they will not get it.”

Participants said three or four assessments should take place at regular intervals throughout high school. The assessments would include full FASD evaluation, as well as assessment to update progress and provide transition to adulthood and independent living. In the workplace, delegates suggested providing training for “job coaches” for special needs employees and paying appropriate wages to retain staff.

It is either pay for programs and interventions now, or pay more later for FASD-affected individuals to be in jail or on unemployment, a delegate said. The big cost from the employment perspective is the lost opportunity and income.

Especially in communities where the FASD rate is high, the economic impact is a community phenomenon, not simply a loss for individuals, participants noted. Therefore, before getting to costing, needs at the community-wide level must be fully understood; the interventions must take place at a broad societal level as well. Moreover, on-reserve and off-reserve communities face different issues.

Breakout Group 2: Planning a Research Agenda—Education and Employment Theme

The group began by noting the following additions to the earlier discussion on model components of education:

- There are models of FASD-specific classrooms and schools. One example is the David Livingstone School in Winnipeg, which has a Bridges program. In

Saskatchewan, teachers and assistants take workshops on specific disabilities, including FASD, hearing, and vision. The cost of teacher training is an important model component.

- The cost of specialized classroom equipment and the salaries of teaching assistants are other important components.
- Specialized college-level programs are needed for FASD-affected students.
- Education programs should be adapted to the local customs and traditions of Aboriginal communities, utilizing or developing local resources.
- Programs need to provide language- and culturally appropriate responses for Aboriginal peoples.
- Another component is the cost of attaching psychologists specifically to clinics rather than using community psychologists paid for by schools or parents.
- The public school system needs to address the impact of stigma and segregation on the other students.

The group also discussed components of employment:

- The model must take into account the cost to employers to adapt and accommodate for FASD-affected staff, such as the cost of training co-workers and managers to ensure a positive workplace environment, and the cost of training FASD-affected employees for efficiency and productivity.
- The economic impact study should encourage more research and research capacity on disabilities in general and on FASD in particular. (Make involvement in this area more “trendy.”)
- Employers need more ways to understand FASD and to organize work appropriately for FASD-affected employees. Lost wages need to be determined for different age groups, such as between 17 and 21 years of age and between 22 and 65.
- There are costs associated with raising workforce awareness to increase the number of potential employers.
- More effective behavioural modification programs are needed. Women may know about FASD, but stopping drinking is hard. Programs should incorporate other concerns, such as poverty, addiction, and low self-esteem. Such programs on the impact of alcohol and drug abuse should start early in schooling.
- The model should include the cost of repeated job training due to repeated job failures if appropriate supports are not provided.
- Lost productivity needs to include not only unemployment but also underemployment and loss of expertise in the community.

The group launched a discussion on planning a research agenda. Four aspects were addressed: existing data and studies, the need for basic research, defining and collecting new data, and the cost of generating new data and possible sources of funding.

Do data and studies exist in this area? If so, is the information available and accessible?

A participant said good data is available, but there are no consistent performance measurements across jurisdictions. For example, it is difficult to compare trends when jurisdictions use different age groupings. There needs to be greater comparability between data sets and more common indicators. Moreover, the existing studies are small, making it hard to extrapolate information. More research is needed.

Another delegate said she doubted there is relevant data about levels of employment and income related to FASD. In terms of Indian and Northern Affairs Canada's (INAC) funded educational programs, she said dollars for special education is very minimal.

A participant noted a lack of data on FASD intervention. Specialized programs, such as in high school, need to be developed first before they can be evaluated. Meanwhile, the cost of implementing such programs must be addressed.

Another issue, said one participant, is the cost of modifying existing programs versus creating new programs. She also raised the need for studies to be broad enough to cover more than one area of the country.

The group concluded that very little, if any, data exists, and there are very few studies.

Is basic research needed before any new data can be collected? If so, what are the research questions? Who should take the lead?

A participant pointed to research on interventions as an area of focus. Research into every step is needed, as is information on how every party involved—employers, parents, teachers, the children themselves—can be helped to make the intervention work better. Research needs to capture broad knowledge for different age groups.

In addition to provincial/territorial knowledge collection, there needs to be standardized and transferable research across different jurisdictions.

A delegate said that previously the focus had been on surveillance to prove that the problem existed. However, FASD was starting to be accepted, and new research is needed to more precisely define the issues.

A participant emphasized that research should be based on community access, strength, and response. Further, a key focus should be on contributing factors such as poverty, dysfunction, and cultural context.

The group discussed the need for culturally appropriate interventions. For example, when identifying the issues that lead expectant mothers to drink while pregnant, or when formulating public education programs, taking into consideration cultural context can help build stronger and more targeted education for parents, schools, and employers.

Participants said different social classes all represent legitimate cultures, as do different parts of the country. As terminology varies across cultures, the group said it is important to develop a standardized lexicon.

Another area of focus is basic research on employment, a delegate said. Currently it is understood that support in the early years is needed, but the view lingers that FASD is no longer a problem once an individual turns 21. This is when programs typically end.

In terms of data on employment and training programs for Aboriginal people, a participant said Human Resources and Social Development Canada (HRSDC) and INAC are doing little tracking. At the same time, FASD-affected people are among those most in need of job-readiness skills. The amount of money involved in these programs warrants tracking, she remarked.

A delegate said school districts have data—for example, the number of FASD-affected students and contact information—and can break down programming and assessment costs into individual components. It is the group that has left school that is lacking data. Another delegate added that there must be means to allow access to the data after an individual leaves the program.

Another participant said research is needed to identify the employment skills concurrent with FASD-affected people's strengths. This will help programs provide the proper training and direction to enable them to join the workforce. A delegate said some of this information already exists, for example, for diagnostics, and speech and language programs.

A participant raised the need to do longitudinal research to determine the cost along the lifespan of FASD-affected people.

Another issue was the ethics of having a control group for which no interventions are provided. One possibility was to use natural control groups in parts of the country where certain interventions are unavailable.

A delegate said the Conference Board of Canada had some data on the general socio-economic cost of having low levels of economic engagement in the workforce by Aboriginal people. This might be a control group that can provide a baseline, she suggested.

Moreover, the Royal Bank published a royal commission report that encourages corporate Canada to target programs for the engagement and retention of Aboriginal peoples. The report concludes that the “cost of doing nothing” is very substantial and climbing. Parts of that study can be used as another kind of control group.

Some results are there, said a participant, although they appear to be highly dependent on government programs. She suggested INAC as a potential partner and funder that could take the lead for basic research.

A participant said that although the information exists, it might frame FASD as an Aboriginal problem. Along with advocacy for Aboriginal children, she said there must be acknowledgement that FASD also exists in other cultures. The presentation needs to be balanced.

Another delegate cautioned that surveillance without subsequent intervention could lead to community dysfunction rather than strengthening. Moreover, labelling must not occur after the study. Rather, post-study support programs will help achieve effective results.

Can new data be collected? If so, from where, and who would take the lead on defining and collecting the data?

To facilitate longitudinal tracking and broad-based comparison, a participant suggested expanding the Canadian census form to collect data on indicators of unemployment.

Another delegate recommended adding specific disability-related questions to the census, such as whether an individual has an FASD diagnosis or suspects FASD. This would be a way for people to self-identify. There could be a range of questions to determine the number of Canadians who live with different disabilities. The census could also ask whether an individual would be interested in participating in specific studies on disabilities.

The participants summarized the key points discussed so far:

- Some existing databases are available to help track economic impact, and some comparisons can be done.
- Before assessments can be conducted to evaluate different interventions, money first needs to be invested in implementing intervention programs.
- Cultural context is key. Canada is a multicultural country, and FASD is not limited to First Nations. Women from some cultures are subjected to a great deal of isolation and restrictions, and communication among cultures must take this into consideration.

What will be the cost of generating the new data, and what sources are available to fund the work? First, referring back to the previous two questions, a participant said income support and assistance programs across Canada for persons with disabilities should be able to provide cost data. A basic research question might be: “How many people who are not on these programs should be on, but cannot jump through the hoop?”

A delegate said some communities could not look at employment, because they have no labour market. Such communities should begin with engagement of economic activity, for example, volunteer work to fix the community arena. The work then becomes a community job readiness activity that has both an income-support component and a quality-of-life component. She recommended this type of model that uses a strength- and interest-based community access approach.

The participant further suggested conducting research on models of community asset development and mapping. The ultimate aim is to break the cycle, as “fewer [people with] FASD is the goal.” The research must look at the community level, not just the individual level.

Society tends to expect everyone to be independent, but participants said there is opportunity to convey the worth of a person and to enable people to take their place in the community, to participate and contribute in whatever form they can. The group called for a redefinition of education so that it looks for a more contributing person in society rather than a person in the conventional sense of employment, vocation, or independence.

In terms of engaging communities in framing the research, a participant referred to the Institute of the Environment at the University of Ottawa as an organization that has done a great deal of work with Aboriginal communities and the INAC. The institute uses a traditional western medical model for studying FASD, as well as links to community-based phenomena to learn how communities understand the ways of dealing with FASD. There are different models of research, she said, but much guidance can come from the communities themselves.

Breakout Group 2: Revising the Research Agenda Based on Participant Input—Education and Employment Theme

The group continued the previous day’s discussion about planning a research agenda under the theme of education and employment.

Participants first noted that early recognition of FASD is important. There is no adult testing, and an FASD-affected individual cannot claim disability without a diagnosis. Moreover, workplace accommodations are linked to diagnosis and proper job training. A key next step, therefore, is improving linkage to the education and mental health care systems.

How to determine economic cost? A delegate said the education system can provide data on many costs, such as those related to assessment, suspensions, and staff time and salaries. First Nations students are the only students who receive additional funding, she said, but the funding does not go directly to the students. It may go to such things as computer equipment.

Another participant said there are inconsistencies across Canada in terms of self-identification. Identification can be mandatory or voluntary. Most provinces and territories attempt to collect Aboriginal data, but data based on cultural differences are needed as well. Thus the education system data may not be accurate, a delegate said.

The first participant suggested asking the education system whether the data is accurate and if not, then why. There are many other questions. For example, how many students are undiagnosed or inaccurately diagnosed? If they are suspended and miss school, then the cost associated with their lack of education needs to be accounted for. Another

question is how much support FASD-affected people need and whether the support increases or decreases over time. Data on the cost of intervention and to the school system do exist. Comparison among jurisdictions is needed.

A delegate emphasized the importance of highlighting the benefits of doing this research. The educational strategies for FASD in the school system actually benefit other special education students as well as regular students, she said, because they are “better-teaching.” The modifications have applications for all the other children, who improve along with the FASD-affected children. When pointing out the cost, it is necessary to highlight the improvements in the system as a whole.

Other participants said they agreed. There is, in fact, a cost to the other students if these interventions are not put in place, as disruptive children really influence other children. Moreover, there is a cost to siblings and other family members, because extra time and energy need to go to the children living with FASD.

Advocacy and support for parents is another issue. The group said it is the responsibility of the provincial and territorial authorities, as well as municipal authorities, through district school boards and school trustees.

A participant suggested that a logical next step is to establish a memorandum of understanding for data sharing, stipulating what kind of data could be shared under what circumstances, while respecting confidentiality and privacy issues.

On the topic of evaluation, a participant said a research agenda would automatically include evaluation, as it is a funding requirement. At the same time, one cannot say that every child diagnosed with FAS will need extensive occupational therapy, full-time assistants, or other specific support. The percentage of FASD-affected children who require this full range of support is also not known. Only minimum and maximum estimate values can be given.

Another delegate said it might be possible to provide statistics on this information. However, a big issue is that children may be denied access because no funding is available, not because they are not eligible. This is something that the Ministry of Education may not wish to admit. She also noted that there are different cut-off points for eligibility; diagnosis alone does not determine eligibility.

Preliminary studies indicate that classroom adaptations could make a difference, a delegate said, especially for alcohol-related effects. This is a huge area that warrants greater awareness and knowledge in the system.

Another participant added that it is necessary to focus on both the costs and the benefits for the individual children, especially if the costs are substantial.

The group next identified the people and organizations that need to be involved. They include provincial and territorial authorities, economists, FASD professionals, school boards, and parent teacher associations.

Taking the effort to the national level will facilitate the gathering of comparative data. Senior-level people should be involved. Moreover, there needs to be a working committee to deal with this issue, with economists assigned to it. One possible structure is a large, overall committee that involves the 13 jurisdictions and has many subcommittees.

Employment and education should be kept separate, a delegate said. Another participant added that social services are also an independent piece. There needs to be many working committees representing the different areas involved. Private and government insurance agencies are another key information source on the cost of care and intervention.

In particular, better linkages should be created with employment insurance providers. Moreover, it is important to distinguish between people who were fired and people who quit their job. If they quit and are not on employment assistance, they will have no income. Yet they may have needed to quit due to their disability, and later they could be penalized if they wish to return. In the North, some can only find casual work, and many cannot seem to advance or keep their jobs. It is important to study the major groups who are being left behind, participants said.

With so many groups involved, who should take the lead? A participant said the federal government is the natural lead to get people to the table and to facilitate conversations. Another said there needs to be a national focus for FASD. With the issue so diffused across Ministries, federal government presence is needed to take the lead by funding research and facilitating provincial/territorial collaborations.

In particular, the Ministry of Education may feel at risk for not being responsible to do more. To encourage its cooperation, the participant emphasized the importance of showing it how its cooperation would help people.

Another delegate said the western provinces already have Ministries and steering committees established, with Ministers assigned. The next step is for the other jurisdictions to move forward. There may be resistance, but there is a great deal of pressure from the ground.

As a starting point, a participant suggested setting up test cases within different jurisdictions and demonstrating positive results before moving across a full national strategy. This will lay a strong foundation and ease buy-in. Another suggestion was to find a champion to help push the issue forward.

Stressing the need for collaboration among jurisdictions, a participant referred to the Canada Northwest FASD Ministerial Partnership that is already in place. There are no

Ministers of Education involved, however, although not all the Ministers are of health portfolios. The Ministry responsible for children's services is involved, for example.

The real interest is cost-based, and it must be demonstrated to the jurisdictions that it is in their own interest to do the work. It would be useful to be able to present some models of positive gain in different provinces, including deriving a provincial value for each province.

Some provinces may focus on costing education, and others might work on employment-related costs. Provinces in the west that are more progressive may lead on more than one project, and the north may focus on needs that are strictly related to that region, such as chronic underemployment. In particular, delegates noted that the issue of underemployed adults with FASD is an area of huge interest. Additionally, this is the group that will turn to drink.

The key is to generate interest across the board. Moreover, intervention in one area may help other areas to also realize potentials and successes. Once people realize the interconnections, they will see the value of bringing all areas together. One of the roles of the funding facilitator should be to bring together the leads from different areas on an annual basis.

A participant talked about how easy or difficult it might be to obtain data from different Ministries and areas. Education is likely the easiest, she said, but mental health, addiction, and housing will be difficult and should be looked at separately. Other, easier areas are justice and basic social services.

Another delegate raised the issue of what education should be looking for. Is it being employable? Or is it quality of life? This definition also has a bearing on the direction of research.

The group discussed the outcomes of interventions in education and employment that can be linked to research parameters and targeted to quality of life. Some of the outcomes are better teaching, reduced dropout rates, and diplomas and job training that lead to jobs.

How long would it take? One participant suggested indicating short-, medium-, and long-term until a conceptual model is developed. Others added that it depends on whether there is national facilitation and funding, as well as collaboration among jurisdictions. The federal government must provide direction and facilitation to the provinces and territories to help them identify the problems and do costing. It must also provide extra funding to do targeted studies in the jurisdictions.

An interprovincial ministerial group is needed to act as the lead agency to help each jurisdiction take leadership in specific areas.

Delegates also noted that it would be helpful to demonstrate how different jurisdictions can take action even without additional funds in the short term. This can help bring

people on board, especially the federal government. In fact, some provinces and territories would work on different projects out of their own interest and needs regardless of whether there is additional funding. In particular, there is already high interest in western Canada.

Besides the Canada Northwest FASD Ministerial Partnership, the participants said they would each help identify any interministerial committees they knew of in their respective jurisdictions. This can be a starting point for the next step of collaborating across Canada.

Breakout Group 3: Defining Model Components—Criminal Justice System Theme

This group discussed the indicators for and the economic value of measuring the cost of FASD on the criminal justice system.

The group's first step was to define cost. One group member suggested that anything that uses resources in the criminal justice system or any event, program, or intervention that causes resources to be used is a cost. This would include apprehension, the training of officers and school personnel, juvenile detention or incarceration, physical injuries, property damage, rehabilitating and compensating victims, and self-inflicted injuries. Costs may also include lawyers' fees, special schooling, interventions, courts, and the criminal justice system.

This would capture more than just time in jail or legal fees; it would help show all the costs that interventions can prevent.

“How many in the criminal justice system have FASD?” asked one member. “And what's the difference between those with FASD and those without, in terms of their impact on the criminal justice system?”

Another member asked whether the costs of intervention and of preventing crime are two separate questions.

There are costs associated with every stage in an offender's contact with the criminal justice system, from committing an offence to release on parole. These costs may go to victims, to property, to the offender, or to courts, lawyers, and corrections.

A cost-benefit analysis determines the rate of incarceration of people with FASD, as well as a measure of the effectiveness of programs and whether they have an impact on recidivism or other characteristics.

Some participants said costs should be organized chronologically; however, one member pointed out that most people with FASD are not diagnosed in jail, but usually long after

they have been convicted several times. Therefore, some kind of screening of all offenders to identify those with FASD is necessary. A screening process at intake into the criminal justice system could lead to a measure, but the group said that mandatory screening is not desirable. (Not every person with FASD has all these problems or characteristics.)

The group then debated two approaches: measuring the total number of people with FASD in the criminal justice system first and taking a sample from those already identified.

The advantage of the sample approach is that no baseline exists for FASD in Canada. A sample population can help associate costs with FASD and can help put interventions in place, but it is harder to evaluate success unless those being tracked have histories of behavioural problems. People with FASD tend to be role models in jails—they respond well to the structure of the prison system.

One report showed that 91% of people with FASD had been involved with the law. However, changes in the way people deal with problems could be driving up those numbers. Foster parents and other home staff are more likely to call police for any problems, rather than intervene themselves. Zero tolerance policies in schools force principals to call police for all incidents.

Ironically, while children with FASD have more encounters with the law, most of them are relatively minor, such as failure to appear before probation officers. On the other hand, people with FASD are more likely to get into trouble at the federal, as opposed to the provincial, level. They are more frequently put into maximum-security institutions and isolation units within prison, and they are more frequently abused.

Because an FASD diagnosis is not necessarily included in police or court records, judges, police, and others need training to identify FASD. British Columbia is starting to implement this training, as is the RCMP in Manitoba, but this information and these modules need to become more broadly known.

Given the cutbacks in spending, convincing government to fund training requires showing the number of people affected. Therefore, surveillance is the starting point.

Diagnosis of FASD affects life insurance and parole likelihood: boards are less likely to grant parole to offenders with FASD because of their higher likelihood to re-offend. This means longer jail terms and higher costs. Educating the National Parole Board will save costs. At Stony Mountain Institution, liaison with prison officials and parole boards has had significant effects.

The group identified several components that need to be measured:

- The number of people with FASD, through surveillance, and the incidence of “generational” FASD (children with FASD who grow up to have children who also have FASD)
- The available community support

- Costs to the system, such as training prosecutors, lawyers, judges, and parole and probation officers, which are easy to measure. Costs also include the evaluation of training; interventions; courts, lawyers, and judges; and the youth justice system. Crime also incurs costs, such as surveillance, depending on the type of crime and the amount of damage to property and individuals
- The FASD-affected offenders' history within the system, including the number of their encounters with police; their prosecution and victimization history; their sentences; and their provincial, federal probation, parole, mandatory addictions treatment, and interventions (if any). Women have different experiences from men within the system.

The PHAC, which tests HIV anonymously in every region, stands as a possible model for measuring FASD. The reporting of numbers is mandatory, and the PHAC collects statistics.

Breakout Group 3: Planning a Research Agenda—Criminal Justice System Theme

The group returned to select highlights of its discussion to help plan a research agenda.

Existing data is scanty. Because there is no reliable measure of the total number of people in Canada with FASD, we cannot reliably measure the proportion of them who are in prison. Streissguth found that 60% of people with FASD in the US had had some involvement with the criminal justice system, but Canadian data is needed.

We can, however, measure the number of people in prison with FASD.

Better surveillance is required to determine the prevalence of FASD. To get that, the population needs to be broken into groups: youth, adults, those in federal prisons, those in provincial systems, and those never incarcerated. The last group is challenging. Could the information be found through the courts?

One suggestion was to take a cohort of people with FASD, follow them through the criminal justice system, and then measure costs. Getting funding for this kind of research project probably would require a feasibility study to establish the protocols on conducting research on youth.

The basic question would be of those in the criminal system, what characteristics are different between those with FASD and those without it?

Some data would be easier to collect than others. For example, Children's Aid societies can give data for youth; however, for many adults, the diagnosis may have been lost.

The challenge in working with youth is in getting proper consents in place to conduct research. If a study were to use non-identifying information and just such points as

gender, age, and history of involvement with the criminal justice system, data could be obtained from Children's Aid. However, following a person through time in a longitudinal cohort study would require individual identification.

One group member suggested using police records—identifying a person using a number. Police services use a unique number for each person they have contact with; the same number follows the person throughout his or her career with the criminal justice system. This model would avoid using a person's name, but would provide an individual identifier.

Privacy laws prevent using social insurance numbers. Health card numbers are not captured in the criminal justice files.

In addition to a feasibility study, a cohort study would require research protocols to measure regional differences and ethnic identification of offenders. It also would require collaboration or partnership with ethnic communities.

Another protocol to establish is which prison community or cohort should be measured or studied. Who decides? This may require the agreement of or cooperation with First Nations or Aboriginal communities and with provincial bodies as well.

One member advised the group to use caution in identifying First Nations or Aboriginal groups or members. A study may find that 66% of the FASD-affected prison population is Aboriginal, which can be used to look at convictions and determine whether there is a bias in the system. However, "there's no real value in publishing that 66% of people in prison are Aboriginal."

Regarding existing data, some provincial youth justice systems are starting to track disabilities, including FASD. Two British Columbia studies specific to FASD focused on youth, which may provide some initial data.

FASD is not characterized as a disability or a diagnosis in the DSM-IV manual, which can hamper data collection.

Tax records could be a source of FASD, if the tax systems recognize FASD as a criterion for pension, disability allowances or deductions.

The criminal justice system has a census, a database on every offender that includes community and institutions; comprehensive data on each offender, but not on FASD incidence; the history of functioning within the community; substance abuse; marital or family abuse; and mental health.

One questionable source is a study by Larry Bird of North Dakota: he sent a mail survey to the heads of all correctional facilities in Canada, asking whether they knew about the prevalence of FASD, and found 13 diagnosed cases in all of Canada. This is neither

useful for the development of further research or a model. Nor is it useful for supporting the seriousness of FASD in terms of funding in Canada.

Some basic questions about research need to be asked:

- Are there substantial differences between those with FASD and those with non-FASD cognitive disorders (e.g., those due to brain trauma, drug abuse, and other causes) in the criminal justice system?
 - Are there differences in their history with the criminal justice system?
 - Are there differences in their patterns of behaviour?
- Do people with different cognitive differences commit different kinds of crimes?
- How does the criminal justice system treat people with other disabilities, such as autism?
- Based on cognitive abilities, do offenders with cognitive disabilities deserve to be in jail? Many do not understand why they are in jail—although they are adults, their thinking is at a Grade 2 or a Grade 3 level, or at an age eight–ten level.

Finding these differences may lead to a way of flagging individuals for possible identification or diagnosis with FASD.

New data is needed as well. The group said a criminal justice profile for people with FASD is needed, which looks at the offender's history and identifies costs for each event or interaction with the criminal justice system and totals them. The profile would determine whether the basket of consequences faced by people with FASD is different from others' experience.

Focusing on people with FASD who are in the criminal justice or corrections system, the group said that developing a neuropsychological profile of offenders with FASD is needed. Questions in this area include

- What is the typology of offenders with FASD?
- What is the profile of offenders with FASD by age, gender, and access to services?
- What is the incidence of additions among individuals and their families?
- What are the impacts of intervention that occur within the criminal justice system when the offenders get out?
- How do offenders with FASD function in their communities?
- What mistakes or problems do they have? Many people with FASD do not know they have it and are abused; they often do not understand when they do something wrong, or they admit to doing something they really did not do because of the way questions were worded.
- What is the age of onset of contact with the criminal justice system? Are children with FASD getting involved with the criminal justice system at an earlier age now than before? This should also look into contact with other services besides the criminal justice system and red flag identifying behaviours.

- How are children learning violent behaviours—from video games, TV, or elsewhere? Disentangling social versus physical or health drivers of behaviour can help develop effective interventions.
- What other special indicators related to gender and age can identify risk?

A cost-benefit analysis of interventions is necessary.

Members of the group also said they felt strongly about educating the criminal justice system itself: the police, the courts, and probation and parole boards. Thus research is needed to determine exactly what the criminal justice system needs to do to be better equipped to understand and deal with people with FASD.

The cost of generating new data includes the money it takes to develop a screening tool. Because it will be a national model, the cost will be huge, because research will have to be done in many different places.

Costs include those at federal, provincial, territorial levels and depend on what kind of data is gathered. There are administrative costs, survey costs, costs for basic research, and costs for specific kinds of research.

How and what kind of research is being done dictates the cost. A cohort study is expensive, but it will show the cost to incarcerate a person, and it will predict the probability that a population with FASD will be likely to commit offences.

If the kind of offences committed by people with FASD and the reasons for the offences are statistically distinct from those committed by the general offender population, research can help determine interventions that can prevent crimes.

Researching FASD in the criminal justice system is a project that crosses several disciplines: health, mental health, and criminology. The group said funding should, similarly, be interdisciplinary.

There are few sources of funding however. The Social Sciences and Humanities Research Council (SSHRC) funds research on the social data of deviants. The CIHR funds research on a variety of health issues, and the RCMP also has a research unit that may cooperate or perhaps fund research. Other provincial funding foundations or agencies may provide funding, depending on the kind of data collected.

Control of the study would require participation from both university- and government-based people and agencies.

However, even though funding should have multiple sources, the question remains: where does one start asking for funding—health or justice? Research must go through an institution, so it is important to find the right place to start.

Before starting the research, one must look at who has funded this kind of research in the past, for example, research into recidivism rates. Who funds general research in penal institutions?

Key questions include

- What is the prevalence of FASD among those in the criminal justice system? And what is the distribution of youth, adults, ethnic groups, and gender?
- What is the difference in the criminal justice profiles between those with FASD and those without FASD? What is the difference in the types of crimes committed, in the reasons for committing them, and in the age of entry or the first offence and in identification with FASD?
- What does the criminal justice system need to learn about FASD?
- Next steps: what will the criminal system do with the information? What will it do about training and about developing new interventions?

Breakout Group 3: Revising the Research Agenda Based on Participant Input—Criminal Justice System Theme

Participants discussed the wide range of costs and justice-related issues connected with the effects of FASD, from federal and provincial criminal justice systems to the family law system, and the links between the two. Justice Canada has a section that deals with family law at the provincial level.

A participant suggested conducting a very broad research project, and the group discussed the possibilities and specifics of such a project. One participant said, “We need to identify simple and measurable program costs and program outcomes,” which “may be simply keeping these kids out of the criminal justice system.” He suggested a second stream of research for those who are already in jail, starting “with programs that have achievable outcomes that can be measured” before trying to capture all the costs related to the criminal justice system.

The participant recommended a basic intervention for those who end up in jail “because they made a silly mistake or got involved with the wrong people.” The intervention would have a measurable outcome, perhaps as simple as keeping those individuals from going back to jail.

Other participants said that keeping it simple would assist in providing results sooner. Some suggested keeping the program focused only on youth involved in the youth justice system, as there are already models in place, such as the Asante Centre. Although start-up costs may not be traceable (since the program is already running), it is possible to track operating costs and any measurable outcomes the program may have. The participants discussed the need for a control group and whether the program was keeping individuals from returning to jail or merely delaying their inevitable return.

Participants said they agreed on the need to involve corrections and justice personnel to provide information on the costs to both the provincial and federal systems. Many of the individuals who enter the court system remain at the provincial level, and data is needed to know how many do or do not “graduate to the federal system.” One participant said there must be a FPT group that could assign someone to this issue. Although they need not be involved in this stage of the discussion, “I think we need them to know that this process is going on” and to provide information on costs at some future point.

Other participants suggested involving organizations such as the Elizabeth Fry Society, the John Howard Society, or the Salvation Army. One said it is universities and academics who must take the lead, with input from governmental and other groups. Local police and the RCMP were recommended as other sectors to involve, in particular because there are many issues relating to the inappropriate charging of individuals who are caught in the wrong place at the wrong time. These are people who “should never be in the system in the first place.”

How long would this reasonably take? What are the key next steps? One participant said these processes often take two or three times as long as originally thought.

The group decided to address the questions of time and next steps by category: surveillance, training, treatment, and profiling.

Unless there are plans for a longitudinal cohort study for surveillance, any study sample should be just large enough to indicate incidence rates for some areas. People as well as money are needed to move forward with a study.

A participant spoke of a full diagnostic assessment study conducted through her department that was based on 165 eligible men from the intake population of a correctional facility. Involvement was voluntary, and 106 men agreed to participate. Each received a full medical assessment. The results showed that some of the men did not have FASD and others had issues that were unrelated to alcohol.

A similar, single-facility study at the provincial level would not yield enough eligible candidates. Ideally, the participant said she would prefer to conduct studies in every province, in all facilities for men and women, adults and youth. Another participant suggested four years to complete such a study with multiple provinces and facilities.

Funding is needed to conduct consultations and get the project off the ground, particularly with so many people and communities involved.

A participant said she had recommended that her department hire a coordinator for the consultation phase of a Labrador project. Another participant, speaking of involvement in research networks, suggested that diagnostic clinics are well organized to collect information from people participating in a study.

The participants discussed a horizontal approach with different Ministries and different justice groups. One mentioned Ontario’s provincial FASD working group for stakeholders. The National Association of Friendship Centres also has groups relating to both criminal and family justice.

An economic model of the current costs related to FASD must first be defined. Then research must be funded to provide more information. Without an economic model, “how do we know what the research questions are?” For that reason, one participant said the first step should be to create a schema of existing programs and invite representatives of various departments and organizations to meet and determine how the pieces work together.

Some participants said this process must have been done for other organizations and issues, and a health economist might be in a position to assemble the information from the sources. Others suggested having thematic workshops to bring specific groups (e.g. justice) together to create a model. Those groups then could be refined into a combined working group and rolled up into one model.

A participant asked whether these questions were intended to relate to the cost to an individual or to the system itself. Another noted that someone had developed an economic model for FASD in the US.

Developing a Canadian economic model is an attempt to “satisfy the hunger for knowing what kind of problem this is in Canada.” Determining the actual number of people in Canada who have FASD is still in the early stages, now that there are finally diagnostic guidelines. Every study must use the same diagnostic guidelines to get relevant results, and extra caution is needed when screening adults, because so many other factors can contribute to brain injury. Even identification at birth provides limited data. Some participants said some provincial programs identified mothers who drank. Another participant’s research study found instances of confirmed prenatal alcohol exposure and no related neurological issues.

A participant said his concern was that “we need a national strategy, not pocketed provincial strategies.” He also questioned the range of data sought for the costs model, whether it should be from prenatal to end of life, and which range would provide the data the government needs to make decisions.

“Governments want to know what it costs to do nothing, versus the cost benefit of intervening,” said the participant. “I think you need to know with fair certainty that an individual has FASD, or the numbers will be skewed.” This led the group into a discussion of testing at birth, the ages at which eye movement testing is effective, and the challenge of distinguishing FASD and ADHD in a study when they so often occur together.

Breakout Group 4: Defining Model Components—Health, Mental Health, and Addiction Theme

The participants applied a life history approach to the issue, starting with the neonatal phase and progressing through the various stages to late adulthood.

Discussion ensued with respect to the problems associated with assigning costs during the neonatal period. Because diagnosis is usually not made immediately, costs therefore are not recorded as relating to FASD. For example, in the area of congenital malformations, not all abnormalities are caused by FASD, but they do have an impact on health care costs.

Other potential indicators are cleft palate, heart defects, growth parameters, and premature births. There is a need for more surveillance with respect to those indications that are not recognized until later in development. Although information about costs is not readily available, costs can be determined by checking records for individuals who have been subsequently diagnosed with FASD.

Many of the same concerns are relevant to infancy. Problems with hearing, vision, and development are more apparent with age. For babies in remote communities requiring hospital stays, there are travel costs and medical foster care. During this period, medical practitioners may identify FASD, or they may not. Personnel must be trained to recognize FASD and to provide appropriate treatments. This aspect also involves the cost of improving the screening process and developing diagnostic guidelines. Participants recommended calculating the cost of not identifying FASD as compared to the cost of early diagnosis and intervention.

Children with FASD are more susceptible to illness and suffer a higher rate of injury than other children, often requiring numerous visits to emergency rooms. Dental anomalies exist, as well as sleep disturbances and problems with speech and fine motor skills. As a result of these conditions, costs associated with specialists, medication, and child development occur. If the child lives in a remote community, there are additional travel and living expenses, child welfare, and the possibility of a language barrier requiring the use of an interpreter.

For youth or adolescents with FASD, several more complications must be added. There are possible addictions, teen pregnancies, sexuality, and sexually transmitted diseases (STDs). Risk-taking is a factor, resulting in more hospital visits or violence. Teenagers suffer more self-esteem issues, depression, and suicides, which seem more prevalent in residential treatment facilities, probably because the youth are away from their community and culture. Misdiagnosis may result in failed yet expensive treatments. It is necessary to consider the costs of these treatments and their effect on the person with FASD, as well as the costs of proper FASD treatments. Costs related to emotional issues are more difficult to assess.

There is insufficient data to determine the costs of adults with FASD, and in some areas costs are difficult to measure. Adults with FASD may feel isolated. They may have poor quality of life, and they may be homeless, which causes further deterioration in health. “Addictions become a natural path,” resulting in increased health care costs. There are also costs associated with the lack of employment, chronic mental illness, and the potential loss of wages.

For senior adults, problems with poverty are intensified. Alcohol kills brain cells, which has an effect on aging and leads to higher mortality. There is also the intergenerational issue: adults with FASD cannot participate in community activities. Because information with respect to the effect of FASD on adults is scarce, more long-term studies and follow-up are needed.

The group considered other related costs, such as whether conventional medications used to treat certain conditions have a different effect on people with FASD, resulting in increased medical costs. Although mental illness in itself is expensive, the addition of FASD greatly increases costs. Mental health treatment is based upon cognitive processes; there may be co-occurring disorders that have a negative impact on treatment.

Because so little information exists about adults with FASD, participants discussed the possibility of conducting biological research on animals to determine answers to some of the above issues and to point the way in others.

Breakout Group 4: Planning a Research Agenda—Health, Mental Health, and Addiction Theme

Once again, the group tasked with considering the issue from a health perspective followed a life history approach, looking at what information is available, what is required, and the cost of generating new data.

With respect to the neonatal period, the group identified the need for reliable data on the incidence of FASD and congenital anomalies. The Canadian Perinatal Surveillance Systems (CPSS) conducted a maternal experiences study on a range of topics associated with pregnancy and childbirth, which provided information on consumption and exposure during pregnancy. A participant referred to the great deal of work that went into developing the survey and indicated that its detail would be helpful.

Also, new mothers complete prenatal sheets in hospital. Although there is not yet a national form, many hospitals require the completion of a questionnaire. Another participant raised the issue of privacy/confidentiality with regard to information sharing, informed consent, and linking records. In response to a question about the cost of physical anomalies that are seen in FASD, a participant said the information exists, but it is linked to prematurity.

Participants recognized the need for more reliable data. The presence of congenital anomalies is not necessarily an indication of FASD. Nor is their absence a sign that

FASD is not a concern. Some may be genetically predisposed toward having a congenital abnormality, but exposure to alcohol prior to birth may tip the balance. One must consider the attributable risk when examining any congenital anomaly. The intersection of alcohol with the congenital anomaly is the determining factor in diagnosing FASD.

Data on consumption and exposure is available. The problem, due to confidentiality issues, is accessing the database. A participant suggested checking the Canadian Institute for Health Information (CIHI), a government agency that is the repository of much health-related information.

Another referred to a study conducted on meconium and asked the cost of funding a biomarker. There are “small pockets” of information out there, but it would be necessary to locate them, access them, and then pull the information together.

Participants identified a problem with some data, stating that the costs between provinces may be different or, where they are the same, it may be an issue of who pays. They discussed the existence of expert, specialized teams in some areas, which would increase costs. Participants also stressed the need for a good developmental screen that would provide access, availability, and accuracy—recognizing that confidentiality and informed consent likely would be a problem.

With respect to childhood, there are questions concerning costing different data on various procedures and facilities, such as children’s hospitals and specialty clinics. In Manitoba, for example, a geneticist cannot access the genetic information on charts for research purposes without a protocol by a research ethics board.. Nursing stations and public health do studies related to screening with the appropriate consents.

Work must be done with communities to obtain information regarding the availability of services and professionals, as well as the costing of those items. Further, one could research what conditions influence the age at which a child is diagnosed with FASD, such as the lack of services in isolated communities or gaps in service. It would be beneficial to have reliable measurements of the incidence of illness in children with FASD as opposed to children without FASD.

More information is needed with respect to tracking children with FASD, which seems to be a provincial jurisdiction. Although it is difficult to isolate the effects of alcohol, drugs, and nutrition, information on the impact of multiple exposures would be helpful. Given the number of variables with children and their environment, animal studies would be more reliable, because it would be possible to control all factors.

Information about costs could be borrowed from other developmental disabilities and then applied to children with FASD. Further, sleep disorder studies could provide some of the required data. A participant referred to a study of sleep disturbances and FASD done in San Diego. There is also the specificity of the behaviour profile for persons with FASD.

Several general health surveys have been done with Aboriginal adolescents with FASD. One participant cautioned that potential respondents boycotted the surveys, to the extent that the results may not be valid. As individuals age, it becomes even more difficult to collect data, because adolescents drop out of school or are unwilling to buy into processes anymore. New models of research or a new interactive study are needed to reach out to these people.

Several participants identified “burning issues,” such as homeless youth and youth in facilities, whether they be justice, detention, or other types of institutions. People with FASD who are severely addicted may fall into criminal behaviours. There is also a need to consider the impact of socio-economic status on how an individual is diagnosed. To participate in treatment, it is necessary to provide informed consent. People with FASD may refuse treatment while not really understanding the consequences of their refusal.

Participants said research is needed with respect to the number of individuals diagnosed, the types and availability of facilities, the health services, and their utilization. In addition, there is the issue of adolescents who take the appropriate medication and those who do not. Some people with FASD resist taking medication, because they do not understand why it is necessary. The emphasis of most of the research is on ill health, with none being conducted on what keeps people with FASD healthy and what helps protect them from other illnesses.

With adults, prenatal and preconception counselling is very important, and it would be beneficial to quantify that effect. It is a common belief among Aboriginal peoples that one treatment is sufficient to cure an illness and continued treatment is unnecessary. One participant gave the example of an Aboriginal woman whose first child was born with a birth defect. For her second pregnancy, the mother followed a treatment process and was delivered of a healthy baby. However, her third child was born with a birth defect. When asked why she had not followed the course of treatment prescribed for her second pregnancy, the woman replied that because the second child was healthy, the problem was cured. She believed that the treatment was no longer necessary. It is a “big jump” to accept that the treatment must be ongoing.

The problem is that the knowledge base is there, but there is no behaviour modification. One participant referred to an exercise she was involved with in which pre- and post-surveys were conducted. Results indicated that the awareness levels were high; the problem was in the follow-through. Education must take place at the elementary school level about FASD and the harmful effects of consuming alcohol during pregnancy. It is hoped that this also would have the effect of reducing unplanned pregnancies.

Participants expressed concern about the lack of information on the intergenerational effect of FASD.

In older individuals with FASD, the outcomes are usually related to health. When they hit a certain age, they do not seem very different from everybody else at that age. In fact, people with FASD in long-term care facilities blend in quite well, especially if there is

cognitive impairment among the other residents. There are fewer data sources, because there has not been time for sufficient research on this population and because there is a feeling that a diagnosis at this time of life is no longer important. Many older adults with FASD are particularly vulnerable because their support network has been taken away, usually through the death of their parents. Further, these individuals have “aged out” of government programs.

A participant said the general feeling among some parents of children with FASD is that the army or prison is the best thing they can hope for. Long-term incarceration is safe, but persons with FASD model the behaviour of other prisoners. One part of sentences for white-collar crimes could be to act as mentors to other inmates on a one-to-one basis.

The whole question of the intergenerational effect of FASD has been understudied. One means of research in this area would be to ask adults with FASD who or what helped them.

Participants identified lotteries as a source of funding, in the sense that lottery commissions use some earnings to fund various causes, such as research into illnesses. However, this may present an element of ethical dilemma. Funding can come from all three levels: federal, provincial/territorial, and municipal.

Because many of the costs are borne by the federal government, it would be in its best interest to fund research in this area. Funding for research can be sought from the PHAC, the CIHR, the Canadian Perinatal Surveillance Systems/Canadian Congenital Anomalies Surveillance Network (CPSS/CCASN), and the Canadian Mental Health Commissions. At the provincial level, funding comes from education and health sectors, as well as various foundations. There are also team grants, standard grants, research conducted by universities, and graduate students.

Because of the stigma attached to FASD, it is difficult to have a fundraising capability such as that enjoyed by juvenile diabetes, and much of the fundraising is family-driven. There is a need to coordinate research activities and to seek publicity of the results from local media. “We have to make research in these areas ‘catchy’,” said one participant. It also would be important to convince others of the worthiness of the cause.

Participants concluded that information is available from other sources, but that information becomes less reliable and less accessible with age. Also, problems with access, due to confidentiality and consent issues, exist with this vulnerable population. There are biases in the data that must be overcome, and it is imperative that the data sets be linked.

Breakout Group 4: Revising the Research Agenda Based on Participant Input—Health, Mental Health, and Addiction Theme

Group members said it is important to identify the direct costs to treatment and prevention that are difficult to measure, including those emotional costs such as self-esteem. Because the Health Utilities Index (HUI) does not deal with the social interaction aspect, one participant recommended considering the FASD health survey questionnaire developed by a student to see if it captured what was missing.

One of the first steps is identifying costs. Although there is data regarding issues that are seen with FASD, such as congenital anomalies, injuries, and mental health, it is necessary to obtain the costs for the different health outcomes. Once that has been completed, the next step is to compare the costs of the average number of additional treatments with the cost of help at the outset.

A participant recommended looking at the data that exists for everyone and extrapolating what is relevant to people with FASD. To determine what health information is out there, another participant suggested an environmental scan. There was general agreement with this approach. Many studies in existence have not been publicized. There is a lot of literature from the US, but given the different system and different costs for services in the US, participants questioned its relevance to the Canadian situation. Some of the health studies related to indigenous peoples might be more relevant to Canada.

Participants identified the two main issues as costs and outcomes. With respect to costs, there was concern that there is still no accurate information about those people with FASD who are accessing the system. There is also a need to compare the difference in the system's costs for people who were diagnosed early and received the necessary supports and those who were not diagnosed until later and therefore did not receive proper early interventions.

Given the sheer volume of necessary information, one participant asked whether it would be possible to do small studies rather than global ones. She gave the example of optimum services for a neonate with FASD compared to a healthy child. The situation would be too unwieldy if an attempt was made to conduct a cross-Canada survey, but would be possible if one confined the study to a community. It would be a smaller, short-term study rather than a larger, long-term one. Participants rejected characterizing this as a pilot study, preferring the term “prototype.”

With respect to the next steps of the exercise, participants stated that the identification of costs was of prime importance. One participant recommended contacting the various Ministries of Health across the country to determine what data is available. Another commented that the information is likely available for the average child, but not necessarily for the child with FASD. Presuming that there is no database with respect to the incidence of FASD, it might be possible to look at other databases to determine those costs related to probable/possible FASD patients.

One possible piece would concern exposure information, such as the number of exposure episodes. There are gross inequities in this area regarding the release of information. For example, a group in Ontario attempted to obtain information about incidence but was

frustrated by the amount of resistance to its efforts. Given the major nature of this issue, cooperation among jurisdictions is essential.

A participant identified the need for more national surveillance. Several suggested a groundswell from this type of forum that national surveillance should be the focus. Another participant asked whether there were any engaged stakeholder groups that might be willing to take on this effort. Unfortunately, most of the advocacy in this area falls upon the shoulders of parents. It is difficult to obtain widespread public support, because there are no poster children for FASD.

One participant identified the International Classification of Disease (ICD), which has a code for pregnancy complicated by alcohol exposure that is underutilized, as a next step. Because it deals with exposure to noxious substances, information obtained from the code would be inaccurate. The codes cannot be changed to capture FASD more clearly.

Regarding incidence issues, one participant said the best studies involve active surveillance. Most surveillance is passive—looking at records, for example—while active surveillance studies a particular group, such as first graders, and diagnoses FASD from that examination. As examples of this, the participant referred to recent studies in Seattle and Italy. The Italian study found that 20–40 out of 1000 first graders presented with FASD. It is expected that the incidence rate is much higher, because only about 50% of the parents consented to their child taking part in the study. As well, in some cases where the evidence was strong, the diagnosis could not be verified, because the family refused to confirm exposure to alcohol.

A participant recommended the school readiness testing that teachers do when children first enter school. Another said there had been many cases where the accuracy of the test had been questioned, citing an example of a child being assessed as ready for school when clearly she was not. The Understanding the Early Years research initiative was recommended as a better indicator. It is important to have the province at the table in the planning, because the federal government will not tell the provinces what to do.

Participants identified groups that could provide information, such as the CIHI, for the national component. They also mentioned FASD clinics, where they exist, with Aboriginal representation from the National Indian and Inuit Community Health Representatives Organization (NIICHR) or the NAHO, for example. There should be representation from a national organization for FASD. However, another participant said the creation of a national organization needed drivers and resources, and these were difficult to obtain because of the stigma associated with FASD.

One participant said it would be prudent at the outset to bring to the table people against surveillance, on the grounds that it is a violation of their rights to get their cooperation. There is a need to integrate this group to get the objections up front. Another noted that part of the problem with data collection is that the workload of social services is so huge that there is resistance to additional tasks. Funding should be tied to research; it cannot be done without resources.

Participants suggested numerous organizations that could be approached for information, such as Motherisk (through the Fetal Alcohol Canadian Expertise) and the

- Centre for Addiction and Mental Health
- Canadian Centre on Substance Abuse
- FASD Centre for Excellence in the US
- Homeless Individuals and Families Information Service (HIFIS)
- CIHR
- Canadian Mental Health Association
- Canadian Paediatric Society
- Perinatal Network.

To ascertain the prevalence of FASD, someone should be tasked with contacting these groups. Stakeholders were phoning hospitals to determine where the data is kept and what is available.

Participants recommended that a small group look at the quality of life of people with FASD. Waiting for data collection could take years.

Feedback on Day 1 Small Group Work

Hammond invited the delegates to give feedback on the newsletter summaries of Day 1's small group work around planning a research agenda.

On the social services theme, a participant from that group said there also had been a great deal of discussion about social services and what it covers. This discussion took place during the small group work on defining model components.

On the education and employment theme, group participants added that the spectrum of education was covered, from preschool to employment. Also, there was emphasis on using a strength-based approach and identifying the best ways of working with FASD-affected children through the system. These ideas were discussed during the small group work on defining model components. Moreover, the suggestion to identify the factors that lead expectant mothers to drink was related to a discussion on cultural differences.

There were no comments on the summary of the criminal justice discussion.

On the health, mental health, and addiction theme, the group discussed the different variables that contribute to positive outcomes, from the perspective of those affected with FASD. In terms of funding sources, a group member said the group did not necessarily recommend that revenue from a tax on alcohol be used to fund research in FASD. Moreover, to address crime prevention, Public Safety Canada can be a possible funding source.

Report Back on Day 2 Breakout Groups

Hammond invited a representative from each of the four main groups to present the highlights of their group's discussion, with particular emphasis on the next steps and who should be involved.

From the social services perspective, future modeling exercises should recruit a large number of participants, including independent researchers, stakeholders, organizations, and representatives from each of the three levels of government. The speaker identified the importance of establishing parallel linkages between Aboriginal and non-Aboriginal organizations to develop a common research design.

Members of the social services group recognized the need to involve academics in development and the need for training an advisory body. Following the discussion, the group decided that the initiative should come from the top down, as long as the advisory body was engaged.

As for immediate steps, the group recommended that the government establish a lead organization and set the parameters "around which an advisory body could be created." There should be broad participation in the advisory board from all levels. Following consultations, the advisory group would then determine a research conduct model.

The education and employment group stated that the federal government should provide the funding, with the PHAC taking a leading role to facilitate the process.

Financial input would be necessary to identify costs. Where provinces already have information, it would be a question of accessing it. With respect to who should be involved, the group identified economists, representatives with funding authority from all levels of government, subcommittees at the provincial level, a broader range of disability groups, and insurance groups. Education and employment are separate issues and would have to be addressed separately.

A national approach with provincial support and involvement is required for employment programs. Employment insurance should be re-examined to ensure that it provides programs that are effective for people with FASD.

Under next steps, it is important to get research on the agenda for the next federal Ministers' conference. The issue of FASD is huge, and it would be a good idea to set up case studies as an effective vehicle for making the case to government. Provinces could be asked to conduct research on specific issues, followed by cross-comparisons to show positive gains and best practices. One approach would be to identify major issues and have each province focus on one issue. With all provinces engaged in research, there would be a "stronger buzz" across the country. A protocol for data sharing from province to province would help offset the privacy issue. Any research agenda should automatically include an evaluation piece that would "work on results-based management."

The criminal justice system group said it is impossible to separate criminal law from family law in the issue of FASD and that both would have to be improved. Given the enormity of the task, there is a need for more direction and more clarity with respect to the overall objective. Rather than re-inventing the wheel, a cost-benefit analysis might look at programs already in place to determine which ones capture the information. This would be helpful in developing future models.

Initially, the people to involve would be health economists, who could design a template, and program personnel. There also would have to be representatives from the FPT governments, as well as any other group involved in criminal justice.

The process would take much longer than people would like it to. It would be necessary to estimate the prevalence of FASD, leading to a basic cost estimate. If everything were started at the same time, the project would take approximately four years. The initial stages of the project would be directed by researchers in all fields, with professionals brought in for checks and balances.

The health, mental health, and addiction group discussed the research agenda and the information that was already available, such as the costs for different therapies and research into FASD cohorts. Some international research relevant to the Canadian situation would be very valuable. The group proposed an environmental scan to determine what information is available and useful.

Players should include funding partners, such as the CIHR, Aboriginal networks, national networks for addiction, and special provincial organizations. Although the push would be national, it would be imperative to have the involvement of both the provinces and the territories.

In terms of survey data, it first would be necessary for groups, such as the appropriate housing authority, to see what data they have on FASD. Participants also recommended the establishment of a national stakeholder organization for FASD, to ensure that everyone is on the same page. It would be possible to find mechanisms to fund prototype studies that could be focused on smaller areas, to move the research agenda forward to eventually encompass broader, longer-term studies.

Hammond asked participants to listen to the specific ideas that had been put forward and consider what work had to be done in each subject area. He reminded everyone that the ideas were not the final product, but represented the “best thinking in the day and a half.”

Hammond thanked the representatives for their presentations. He asked everyone their general impressions from the next steps identified and whether there were any big gaps or themes.

Plenary: Strategy for Moving Forward

A participant said one thing had been overlooked: moving something forward would involve getting it on the political agenda. He identified the need for a champion to bring the cause to the attention of government and to lobby for funds.

Hammond asked the participants to look at how to move the agenda forward. He gave the example of the need to determine the economic impact of FASD.

Stone said her group had talked about the economic impact model and how it would need all participants to be involved, as well as additional people on all levels. There is a need to be creative in finding these people.

With respect to the economic impact, there is a need to determine which interventions and preventions are working, how to determine whether they are working, and what the cost is. The PHAC had been trying to move forward to a concrete outcome, and there is a need to know the cost-benefit analysis of prevention.

Regarding evaluation, more work is required to identify what is working and how, to know why it is working, and to know how to replicate the process. There are many components involved, and there are very large chunks of material to be studied. Stone said the establishment of a steering committee would be helpful.

This two-day meeting was not the end, Stone said, but the beginning. The PHAC had at least one scheduled meeting in the coming fiscal year.

There is a need to understand the cost and the time needed to conduct the research. It must be a sustained procedure across the country. It is a creative approach, and the PHAC is happy to be part of the process.

In response to a question about whether the study on diagnosis would be retrospective, Stone said it did not need to be specifically retrospective or prospective. There is a rich data source “that is as yet to be tapped,” but the information needs to be synthesized, and a protocol for its use needs to be developed.

Regarding use, both types of research are needed. As well, the participants must identify a steering committee.

Hammond asked the assembly what needed to be in place to realize the desire to move forward. A participant said the goal is to develop an economic model, and the next step would be to establish a set of objectives. MacKay said the PHAC and Aboriginal peoples could not do this alone.

One participant commented that the initial step would be to get the economists who have been working in this area to provide information regarding the work entailed in developing a model. He indicated that a small group of experts in the field could look at

the costs of providing the service versus the costs of not providing it. In response to a question from MacKay, the participant said he agreed that the discussion paper from that group could come first to those in attendance and then to the policy-makers who could provide funding.

A participant said one model alone would not be enough, because the topic is so broad and encompasses so many issues. The result would be a broad model, which would be insufficient; it needs to be nuanced. She recommended that the issue be broken into workable pieces.

When MacKay said there would be a number of discussion papers, the participant asked whether it would be necessary to wait until that time to get started. The participant gave the example of a “clean” research project that she was contemplating, involving infants. MacKay said waiting for the discussion paper would be helpful, because the knowledge uptake of what is out there is missing. She recommended fleshing out the study and bringing it forward. To the participant’s comment that she would be asking for partners from across the country, MacKay replied that the request for partners could be an action item.

With respect to the idea of overarching concepts, one participant asked for particulars about the environmental scan. Another stated that it could be done with a developmental approach, but that participants had been looking at the issue from a systems basis. All the information should be brought together. Reference was made to the need to involve the intergovernmental, interministerial committee at the beginning of the project. MacKay mentioned the groups of partners that exist in the provinces and the need to continue to work with those coalitions.

In response to Hammond’s request for strategic ideas, one participant said that she had no conclusions, but that she questioned whether research would be at the jurisdictional level or whether there would be a non-governmental body of research. She said she worked with Aboriginal peoples and children in an FASD program. Aboriginal people have expressed strong concern that any research about their conditions be done by Aboriginal researchers. The participant asked whether there could be counterpart, arm’s-length research bodies to establish commonalities of research study and an advisory body of experts with long track records.

MacKay described the CIHR as a key partner, referring to specific application dates for submitting proposals for funding.

Another participant recommended that a small group be tasked with looking at the quality of life and the emotional burden of FASD. She referred to a research study conducted by a graduate student and said she would like to send it out for input. It would be possible to do an economic analysis of the quality of life.

MacKay said there was a four-year time frame for the project, and this was the first of what would probably be many meetings.

This was the first step along the way, said Hammond, and the ideas that the group had presented would be helpful in moving the agenda forward. The roundtable report would be available in mid-April, accompanied by an evaluation form.

Concluding Remarks

MacKay expressed her pleasure at the opportunity to talk with so many people and thanked everyone for making the roundtable such a lively and productive event. The process had begun several months previously, she said, with a recurring theme of the importance of early intervention. There needed to be a mechanism to give concrete shape to what had been discussed. There is a need to find common ground and forge a consensus.

Several immediate issues or themes had arisen over the roundtable period, including the importance of prevention and evaluation—having prevention programs versus not having them. In addition, it is essential to improve the models for data collection, discuss the economic impact of previous data, secure adequate funding, and involve Aboriginal communities. The various systems must be costed, the price of providing service versus the ultimate costs of not providing it should be evaluated.

MacKay proposed the establishment of a working group, with members drawn from roundtable attendees and those who had not attended, so that all views are incorporated. Discussions with Aboriginal peoples were underway, and a meeting with the interdepartmental working group would determine possible initiatives among federal partners. She recommended at least one other meeting to help move the issue forward.

MacKay expressed an intention to continue to engage new partners, and she encouraged all participants to recruit everyone who needed to be engaged, when they got home.

Analysis

This national roundtable was the first activity to discuss the process of developing a model for measuring the economic impact of FASD in Canada. The importance of having an economic impact estimate for FASD is crucial to show the magnitude of the problem in a language that policy developers and decision-makers can act on.

This work will evolve simultaneously with other ongoing efforts that aim to strengthen the evidence base for FASD in Canada. For example, incidence and prevalence data is essential to a complete economic impact model and activities to obtain that data will continue in parallel. The next steps include a wider discussion with stakeholders around the costs to be included in each of the component areas of the model. This analysis will provide an overview of the overarching themes that emerged from the presentations as well as from the discussions among participants. It will also explore next steps.

Throughout the breakout sessions, the intervention needs of people with FASD and their family dominated discussions. Although it is very probable that offering certain interventions could avoid higher costs and that discussions are bound to arise in this context, the purpose of the exercise was to focus on the elements of an economic model. Therefore interventions will not be discussed as part of this analysis.

In addition, participants emphasized the need for cost benefit analyses for interventions regarding FASD affected individuals. Yet, such an analysis is premature in the absence of actual cost of FASD including the costs for the various systems encountered by affected individuals, comparison data as well as evaluations of FASD interventions. At this stage, agreement must be reached on a comprehensive model for calculating the economic impact of FASD. Subsequently, the actual cost data must be gathered to determine the overall economic impact of FASD. As was expressed by various participants, efforts should concentrate first on finding the data that is available, build on current research, and develop the model despite the gaps in data.

Conceptual issues

Conceptual issues concerning the economic impact model arose as major concerns in the Roundtable discussions. The first issue pertains to the need to clarify the use of the final product to give direction to the development of a model. In fact, the overall goals will tend to shape the model's design. The general purpose of this exercise is to inform policy and decision-makers, program design and delivery as well as practices. In an effort to simplify future discussions, a definition of key terms, such as costs, should be on the agenda for next steps.

An ongoing debate among participants was the level at which the model should be developed. On one hand, some argued that the appropriate approach is to develop a broad model that includes all the elements of the model focusing on the minimum information required. The macro-level of analysis would look at costs on a national scale. This approach has the advantage of allowing for better comparability in the data that is gathered from the various sources across the country. It is also easier conceptually and might include costs that cannot be captured at the micro or meso level of analysis. It would also permit a better integration of general costs such as those sums invested by governments in the FASD Initiatives. The drawback of the macro approach is that without actual national prevalence and incidence data, measuring the economic impact at the macro level is not possible.

On the other hand, some claim that starting at the individual level (micro) allows work to start on the model for economic impact in the absence of complete national prevalence data. The proposed solution is to use a sample from those already identified with FASD. To ensure that the data is comparable, the proponents of micro-level research suggest that the models for each of the components should be developed in coordination with each other. In addition, consensus on basic guidelines to secure comparable data would be necessary for a micro research to be successful. Events and conditions at the level of individuals as well as at the level of communities are strongly influenced by political, economic and other dynamics at the regional, national, and international levels (macro). Therefore a weakness of micro-level analyses is that while macro-level features are implicitly captured by some micro-level data by reflecting their impact on individuals and families, the difficulty of a micro level analysis lies in systematically linking these levels of analysis. Another problem is that it is unlikely that researchers in the field will want to change the level or scope of their research. Despite its drawbacks, micro level research is the more practicable option.

Research at a meso-level of analysis would situate itself at mid-point between the macro and micro approaches. As an example, a meso-level research project could evaluate costs of FASD to the health or education system in a particular province. The disadvantage of this approach is that extrapolation and comparison of the gathered data may not be possible.

Some of the elements that gained much consensus include the necessity to organize costs chronologically. In fact there was general agreement that the model should follow costs as the child ages and moves into adulthood. It is also important to note that most participants agreed that the model should give consideration to less tangible effects of FASD. For instance, some elements such as stress in families, although difficult to quantify, still have an economic impact. There are direct costs to the person with FASD and direct costs to the systems but the indirect costs to the caregivers also represent a significant burden. Many studies have already been done on the high costs of care giving

for chronic diseases and conditions that, to some degree, mirror those of FASD. Examples include studies and models that determine costs to the caregivers of Alzheimer's or autism patients. These could be good starting points to build on to assess the cost impact for FASD on care givers and to society.

This issue raises questions about the model itself. Should the model show both direct and indirect costs? How will the model distinguish between direct and indirect costs? In the case of caregiver costs, one solution could be to create a separate element of the model. Given that FASD has physical, mental, financial effects on caregivers that are difficult to associate with any one element already identified at the roundtable, factors such as loss of productivity, lost opportunities for promotions, loss incurred by death are not easily inserted under any one category.

Also arising from discussions is the need to differentiate between the costs encountered by the individual and the family and the costs to the systems themselves. These are very separate costs in terms of data collection but are important parts of the development of the model.

Among the gaps in the exchange at the roundtable is the lack of attention given to gender issues. Gender-based analysis would allow an assessment of the differential economic impact of FASD on women and men. In fact, any socio-economic analysis should take into account gender as it is a factor in all social and economic relations (CIDA). According to the WHO, women are often statistically “invisible” in data and, as a result, priority-setting approaches can easily ignore women.¹ In fact, since women take on so many roles that go unnoticed in standard economic analysis, it is argued that

¹ World Health Organization website: <http://www.who.int/trade/glossary/story032/en/index.html>
Neo-liberalism: a label for economic liberalism that describes government policies aiming to promote free competition among business firms within market, notably liberalization and monetarism. While it is often assumed that these policies and theories are gender neutral feminist economists and scholars have clearly demonstrated their inherent bias (see Elson & Catay 1999/2000; Women's Edge 2002). One example of this is the standard use of economic conceptualizations of the household as the smallest unit of measurement. The literature shows how claims based on household measures are misleading and inherently gender bias because they fail to take into account well-documented gender differences in access to resources and decision-making within the home (see Apps 2002; Women's EDGE 2002; World Bank 2001).

women are often the “shock absorbers” for the neo-liberal economic policies.² Therefore, if the goal of the economic impact model for FASD is to inform sound policy that takes women’s realities into account then its design should encompass Gender Based Analysis if it is to yield expected results.

Ethical issues

As people’s demands are increasing in terms of information, so are concerns for the amount of their information being gathered and stored. As such, confidentiality and privacy issues with regard to data collection for an economic impact model for FASD were recurring concerns for participants. Therefore, strong measures will need to be taken to ensure that the confidentiality and security of data provided by individuals, businesses and organizations are carefully protected. As part of the development of guidelines for data collection, precautions should be taken to prevent disclosure of information.

Aboriginal Research Agenda

Parallel Aboriginal research in this area was also identified as an important element of the development of the model. Participants emphasized that the availability of data for Aboriginal people presented a sizeable challenge and that part of the solution lies in communities having a strong sense of leadership and ownership over the process. The need for specific data with respect to Aboriginal peoples was also stressed as most participants agreed that the model should reflect the diversity of Aboriginal communities. In addition to addressing aboriginal specificity, the model should be culturally appropriate as Canada is made out of many different cultural communities. The data collection tools should also reflect this diversity. To facilitate that process, First Nations, Inuit and Métis communities have developed OCAP principles for research (Ownership, Control, Access and Possession). Therefore, the communities should be involved as this work progresses.

² Id.

Working group

In order to oversee the development of the economic impact model for FASD, participants recommended the creation of a Working Group (WG). With regard to the WG membership, the goal is to have a balanced and representative group of people at the table who are committed to taking this agenda forward. Among WG members, there should be federal and provincial representatives, researchers as well as member of key networks. Subcommittees could also be formed for every jurisdiction or leads at the area level could be identified in order to ensure participation across Canada. At this point, membership will be formed on a voluntary basis but to ensure that the WG is representative, the FASD unit in PHAC may contact specific people.

Several different purposes were envisioned for the WG. Thus, the first step should be to determine the role and responsibility of the WG as well as some terms of reference. Tasks of the WG could include clarifying the goals of developing this model as well as coming up with a definition of basic terms to establish common grounds. This document could take the form of a short discussion paper and would be a useful tool in making a strong business case for this endeavour whenever it may be needed. The WG could oversee other activities such as:

- Priority setting
- Resolving conceptual issues.
- Taking precautions to prevent disclosure of information
- Establishing and maintaining partnerships
- Identify researchers who could potentially carry out some of the work that is required for the development of the model
- Develop principles and terms of reference for whatever research is required
- Privacy Assessment

Partnerships

It was strongly advocated that some solid partnerships should be established in order to sustain the efforts required to carry this work through. In fact, an important level of commitment and collaboration are necessary considering the jurisdictional issues that arise. Getting all jurisdictions to participate could be secured by presenting them with some models of positive gain. Although the WG could be in charge of establishing and maintaining partnerships, a formal mechanism would be more desirable.

The question of how the model would cross over jurisdictions to take into account the P/T systems was a concern for most participants. Many were of the opinion the model should show a regional breakdown of the costs but were still puzzled with resolving jurisdictional sensitivities (access to data). A suggested solution for data sharing would be to establish a Memorandum of Understanding (MOU) between the concerned P/T authorities. A MOU for data sharing would stipulate the type and circumstances under which data could be shared.

A potential solution to the lack of comparability of provincial data is to have different provinces working on different aspects of the model. Of course, in terms of extrapolating the data this option is not ideal but it would allow for work to begin on all components and for best practices to be developed.

Participants identified other organizations that should be involved in this process. Among them:

- Canadian Centre on Substance Abuse
- Canadian College of Family Physicians
- Canadian Institute for Health Information
- Canadian Institutes of Health Research
- Canadian Medical Association
- Canadian Mental Health Association
- Canadian Paediatric Society
- Community Health Representatives Organizations

- FASD Centre for Excellence in the US
- Homeless Individuals and Families Information Service
- Motherisk (through the Fetal Alcohol Canadian Expertise)
- National Aboriginal Health Organizations
- National Indian & Inuit Community Health Representatives Organization
- Parents
- Perinatal Networks:
 - Canadian Perinatal Surveillance System
 - Canadian Congenital Anomalies Surveillance Network
- Provincial and Territorial Addictions Agencies (AADAC, AFM, CAMH, etc..)
- Society of Obstetricians and Gynaecologists of Canada

Environmental Scan

Participants generally agreed that a large scale review of the literature was needed in order to evaluate the models and data that are available for measuring FASD in various systems. Although little is available on FASD, a possibility is to look into the literature for other disabilities. Also, the environmental scan could show existing data, where it can be found and what is available in terms of research.

Furthermore, an analysis should assess the utility of the information that is gathered and whether it is reliable, quality data. As an example, participants mentioned that provincial databases have many blank fields, making data comparison difficult. Because of this inability to use historical data, new data will need to be collected for a baseline to be established in the future. It should determine what information is missing, assess the feasibility of the work and determine who can do the work. Finally, the environmental scan should develop principles to ensure the cultural appropriateness of the process.

Sources of funding

With respect to funding, participants identified CIHR as a potential source of grants for future research. Next steps should include the drafting an RFP for the development of the environmental scan. Subsequently, organizations or researchers who could do the work should be identified.

Action plan

Year One:

- Getting FASD on the political agenda (long term goal)
- Establishing a working group
 - Membership
 - Terms of Reference
- Setting priorities with regards to next roundtable themes
- Developing discussion papers:
 - Definitions and conceptual issues
 - Specific themes
 - Guiding principles for research
- Co-hosting 2 Meetings
- Developing a Workbook for consultation process

Year two to four:

- Meetings of WG representatives
- Reporting results of preceding year
- Setting priorities (roundtable themes)
- Developing discussion papers
- Continue thematic meetings