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Fetal Alcohol Spectrum Disorder and the Criminal Justice System
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Purpose:

The purpose of this gathering was to explore Fetal Alcohol Spectrum Disorder (FASD) in relation to the criminal justice system in Canada.

Goals:

1. To provide an opportunity for workshop participants to share thoughts and experiences around the issue of FASD and the criminal justice system.
2. To share strategies for FASD and incarceration.

Objectives:

1. To obtain specific information from participants on their experiences working with FASD-affected individuals;
2. To determine the supports necessary to work with FASD-affected individuals;
3. To learn if local resources had been trained to effectively assist persons affected with FASD;
4. To determine what resources are required to effectively support affected individuals; and,
5. To identify strategies for addressing the needs of persons affected with FASD who are incarcerated.
Introduction

The gathering was hosted by Ma Mawi Wi Chi Itata Centre in Winnipeg, Manitoba. This centre was established in 1984 to provide Aboriginal solutions to support and rebuild families through the provision of culturally relevant prevention and support programs and services to the Aboriginal community. In doing so, they work with families to better care for their children, create meaningful opportunities for family and community involvement and place a strong emphasis on positives and individual strengths. Their philosophy is rooted in the belief that the entire community is responsible for the development of future generations.

The Aboriginal Corrections Policy Unit of Public Safety Canada collaborated with Ma Mawi Wi Chi Itata Centre in the facilitation of the workshop and provided the funding. This unit works with Aboriginal people, governments and organizations to develop unique and innovative solutions to the challenges that Aboriginal people encounter within community corrections and the criminal justice systems. In doing so, pilot projects that use holistic and restorative approaches, emphasizing methods that have not yet been tried, are supported. The unit further meets its objectives through training and capacity building, project development, communications and policy development and support.

Both Ma Mawi Wi Chi Itata and the Aboriginal Corrections Unit are keenly aware of the over-representation of Aboriginal people in the mainstream justice system and the fact that the numbers continue to rise. There are many reasons for this, a number of which can be directly linked to colonization and its inter-generational effects. As a result, today we see generations of Aboriginal families shrouded in apathy, hopelessness and despair. Often, as a manner of coping, families turn to alcohol or other substances resulting in additional debilitating conditions such as addictions, violence, homelessness and involvement in the mainstream justice system. Specifically in relation to alcohol use, the Aboriginal community is concerned about its use and the prevalence of FASD in this community. Although FASD has not been documented in the Aboriginal community to have a greater incidence rate than that of other peoples, the fact remains that alcohol abuse in Aboriginal communities is a serious issue. Furthermore, the children and youth population of Aboriginal peoples is growing at a rate that exceeds non-Aboriginal population of Canada. It is fair to make an assumption that increasing numbers of young Aboriginal people are at greater risk of being born with FASD. Without the necessary prevention and interventions, diagnosis and treatment, it is also safe to assume that the secondary characteristics of FASD will be pronounced, including involvement in the mainstream criminal justice system.
Gathering Overview:

The gathering included 18 participants from across Canada, representing a number of different nations and vocations. Some work directly in communities, both urban and on-reserve, while others work in correctional facilities. In addition, three federal government employees were in attendance representing Public Safety as well as the Public Health Agency of Canada.

The format for this event provided an open forum circle for participants to freely provide input. The facilitation structure was relatively amorphous allowing participants to address many of the questions within one response, or providing information beyond the identified subject.

The questions used to guide this gathering included:

1. Do you currently work with individuals with FASD? How many participants in your program? Who refers individuals with FASD to your program? What services are you able to provide? What has worked in assisting community members with FASD understand the consequences of getting involved with the justice system?

2. Have any community members with FASD been incarcerated? What supports did they receive while in the system? Did they understand why they were incarcerated? Did they reoffend?

3. Has there been training for members of your staff, community or participant group on the effects, risks and prevention of FASD?

4. Have police and members of the justice system in your community received training to assist identifying members of the community affected by FASD who have come in contact with the law? What tools, training and resources would your program need to affectively assist members of the community that have been diagnosed with FASD and have been in conflict with the law?

5. What resources are available in your program, community, region or province for assistance for community members with FASD? Who is available in your region or community to provide this type of support? What training and resources would be needed to provide adequate information and support for community members in your area?

6. What are the gaps in providing adequate support and prevention in your community for FASD?

7. What needs to be done for FASD-affected members to improve their outcomes when involved with the justice system, alternative measures or support programs?
What needs to be done for FASD-affected individuals to have better outcomes that what they are doing?

8. How should communities be supported to assist in caring for community members affected with FASD?

Once the topic of the gathering was introduced, participants introduced themselves and shared information about who they were and the work they did. The questions were provided to the participants, in the format shown above, and the participants provided answers as were relevant to their own professional and community experiences. This gathering was recorded, with a verbatim transcript produced upon conclusion. It was with the aid of the transcript that this report was written.

Of interest to the reader, included within this document is a comprehensive annotated bibliography at the conclusion of the report. The purpose of this bibliography is to provide sources of research and documentation that focus on justice and medical related issues as they pertain to FASD. The sources included are primarily Canadian and effort has been made to include information published by Inuit, Métis and First Nations organizations.
FASD Quick Facts

- The term Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that refers to the full range of prenatal alcohol-induced impairments. The possible diagnoses within the range of FASD include:
  1. Fetal Alcohol Syndrome (FAS)
  2. Partial FAS (pFAS)
  3. Alcohol-Related Neuro-developmental Disorder (ARND)
  4. Alcohol-Related Birth Defects (ARBD)

- Fetal Alcohol Spectrum Disorder (FASD) is the most common non-hereditary cause of cognitive disabilities world-wide.

- Fetal Alcohol Syndrome was first described in scientific and medical literature in 1973.

- In the past, diagnosis of FAS was based on documented prenatal alcohol exposure in conjunction with a triad of characteristics including growth retardation, central nervous system (CNS) dysfunction and craniofacial anomalies such as small eye slits, flat midface, and/or a thin upper lip. Medical professionals now know that cognitive deficits can occur independently of morphological anomalies.

- FASD is a lifelong disability that cannot be reversed or cured.

- The effects of FASD can manifest through primary and secondary disabilities.

  **Primary Disabilities**: Primary disabilities are those that are a direct result of alcohol damage to the brain and brain function. They manifest themselves in ways such as impulsive behaviours, slow thinking, poor memory, money and time management problems, failure to understand, excessive talking and so on.

  1. Infants with FASD may be affected by the following primary disabilities: irritability, jitteriness, tremors, weak suck, problems with sleeping and eating, failure to thrive, delayed development, poor motor control and poor habituation.
  2. Pre-school children may be affected by primary disabilities such as hyperactivity, attention problems, perceptual difficulties, language problems and poor motor coordination.
  3. School-age children at the primary level may exhibit hyperactivity, attention deficits, learning disabilities, arithmetic difficulties, cognitive deficits, language problems and poor impulse control.
  4. The primary disabilities for adolescents and adults with FASD include memory impairments, problems with judgment and abstract reasoning, and poor adaptive functioning.
Secondary Disabilities: Secondary disabilities are those that develop over time as a result of FASD needs not being met. One such example could relate to substance abuse. If an FASD-affected individual is constantly told in a straightforward manner that they are not to drink alcohol, they are less likely to drink and to develop a substance abuse problem.

- Adolescents and adults with FASD may be affected by secondary disabilities that include substance abuse, inappropriate sexual behaviours, mental health problems, and trouble with the law. As well, they may have difficulties remaining focused and are easily distracted, have difficulty managing money and difficulty learning from experience, have trouble understanding consequences and perceiving social cues, and experience low tolerance and high frustration.

- According to the Public Health Agency of Canada, as of 2005 FASD affects approximately 1% of people living in this country. This means that there may be about 300,000 living in Canada today with FASD.

- Diagnosing FASD is a difficult process. Many physicians are not trained in this area, and diagnostic facilities are lacking in Canada. Most provincial health care plans do not cover the cost of a full assessment. Assessments are ideally conducted by a geneticist or pediatrician experienced with FASD in collaboration with a clinical psychologist, speech-language pathologist, and a social worker. Furthermore, diagnosis of FASD becomes more challenging as an individual’s age increases.

1. Do you currently work with individuals with FASD? How many participants in your program? Who refers individuals with FASD to your program? What services are you able to provide? What has worked in assisting community members with FASD understand the consequences of getting involved with the justice system?

Eighty nine percent of the participants who answered this question indicated that they did work directly with FASD-affected individuals. The participants worked in a variety of fields including Aboriginal and mainstream justice, corrections, and social services with target audiences of adults and youth, both in custody and within the community. Referrals to their various programs were provided by Aboriginal Court Workers, lawyers, social workers and other court personnel.

Workshop participants were not specific as to the types of services provided to clients; rather they emphasized practices that are effective in working directly with Aboriginal people affected with FASD as well as a best practice model from a programmatic perspective1. As well, they discussed the challenges in providing services, mostly from a programmatic perspective with some reference to overall policy.

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1 Ka:nen, an Ontario-based Aboriginal organization that administers the Canada Prenatal Action Plan (CPNP) and the Community Action Plan for Children (CAPC) at approximately 90 off-reserve
It was identified that the incorporation of cultural programming is vital to their client groups and the particular characteristics of FASD. In doing so, it is important to recognize that the teachings and cultures of the many different Aboriginal nations in Canada are unique and varied and that a cookie cutter approach to programming is not effective. Furthermore, the participants emphasized the importance of a holistic approach. In particular, by incorporating a holistic approach at the intervention and prevention stages of pregnancy, opportunity is provided for clients to address all aspects of pregnancy, including proper nutrition.

Cultural oversight by the Aboriginal community is effective and necessary. The model cited was the Ontario-based Aboriginal Community Action Plan for Children (CAPC) which has a strong FASD component and targets new mothers and their children. In this case, Ka:nen – Our Children Our Future (based out of Thunder Bay) administers the overall program which is then delivered at a variety of Aboriginal social service provider sites (such as Friendship Centres) and is provided oversight by a joint management committee of Aboriginal community organizations and government stakeholders.

Early diagnosis is very important and provides opportunity to work with clients from a young age to establish necessary supports and to work with the whole family. In effect, children and families that are provided early intervention and support anecdotally report the decrease in the prevalence of the secondary characteristics of FASD (such as mental health issues, school drop out, employment difficulties and trouble with the law). In the same vein, clients who are aware of their diagnosis are aware of their limitations and know what strategies and practices are best suited to their needs and challenges. With this knowledge, they are better able to communicate this information to the people they interact with to further inform appropriate responses (for example, a child telling their teacher of their diagnosis to improve information retention or to mitigate disruptive behaviour).

Some programs allow the parents to tell service providers what they need – a truly client need driven process. They ask the client group what their needs are and collectively identify solutions within the overall program mandate.

Programs that are open to all ages of the life cycle and both males and females are also identified as appropriate and culturally relevant, as they are more holistic in approach and responsive to community needs. Programs in the Aboriginal community that are mandated to work only with women of childbearing years and their children will often bring in grandmothers and fathers who benefit individually from participation, but in the bigger picture, benefit the whole family unit. Ultimately, this kind of benefit is of value to the whole community.
Finally, broad understanding of FASD by front line service personnel is necessary. The knowledge base must include an understanding that persons affected with FASD require lifelong support and that that support will have to come from a variety of different sources throughout the lifespan. With this knowledge, front-line service providers are better able to adopt comprehensive case management approaches and can develop a community safety net for an individual or family. This too nurtures a holistic approach in service delivery, promotes community mobilization and results in a cohesive and collaborative approach in working with FASD-affected individuals and families.

Numerous challenges to the provision of services were expressed by the gathering participants. Among these were: lack of long-term sustainable funding, program restrictions, lack of diagnostic services, misdiagnosis, cookie cutter approaches to programming, and stigma, to name but a few.

One of the primary challenges expressed were programmatic restrictions, i.e. for a client to participate in an FASD program they must have an FASD diagnosis. This is problematic for many programs across the country since diagnostic services are greatly lacking. An FASD diagnosis involves a multi-disciplinary approach with input from a psychologist, a doctor, an occupational therapist and speech therapist. For some areas of Canada where provincial/territorial FASD strategies are in place (British Columbia, Alberta, Saskatchewan and Manitoba), there are some diagnostic services available; more so than provinces/territories without such a strategy (Ontario, Quebec, New Brunswick, Nova Scotia, Newfoundland and Labrador and Nunavut). Couple this with other issues that hinder diagnosis (poverty, lack of transportation, stigma, and lack of awareness) the overwhelming majority of persons affected with FASD likely never receives a diagnosis, let alone supportive services. Furthermore, where diagnostic services do exist, they often target specific populations, such as children or youth. Very few diagnostic sites work with adults. For persons who are in custody, obtaining a diagnosis is virtually impossible.

In the same vein as lack of diagnostic opportunity, another recurrent challenge is misdiagnosis. Despite the fact that FASD awareness in the health care field is increasing, the majority of health care providers do not recognize that the cause for which a patient presents with may be maternal alcohol consumption during pregnancy. It is reported that doctors either lack awareness of the issue and, as a result, it is not at the forefront of their consciousness to inquire about maternal alcohol consumption. As well, it may be that the doctor is fearful of asking sensitive questions. As a result, FASD-affected individuals are repeatedly misdiagnosed, in particular with mental illnesses, a strong secondary characteristic to FASD. Without accurate diagnosis, affected individuals do not receive the necessary supports and treatments they need, further compounding their negative circumstances.

Without policies and long-term sustainable funding to support FASD strategies, including diagnosis, the Aboriginal community cannot document the prevalence rates of FASD, consequently leaving extensive gaps in programs, services, supports and resources.
One of the major gaps identified relates to both programmatic restrictions and lack of mid/long term funding. FASD is a lifelong disability and although the needs of an affected person will change from infancy, to childhood, to adolescence and adulthood, the affected person will always experience complex needs requiring multi-disciplinary responses and supports throughout the lifecycle. Most programs, as noted previously, target specific age groups, sexes, circumstances and are time limited. This is counter-productive in serving the needs of FASD-affected individuals and their families.

The stigma attached to FASD also poses a major challenge in the provision of service to FASD-affected individuals. Communities are sometimes reluctant to acknowledge the presence of FASD. The shame associated with FASD cannot be discounted. Programs and communities often react negatively to mothers who drank during pregnancy and will often project great blame upon them, thereby increasing the odds that a mother might not seek assistance for herself or her child(ren). Culturally appropriate responses that are blameless in their approach and holistic in manner appear to be effective in addressing FASD. One example provided described programs that do not identify as FASD specific programs; in this manner opportunities are increased to reach their target audience.

FASD policies and models that are framed on mainstream Canadian notions of prevention, intervention, support, health and wellness are ineffective in reaching an Aboriginal audience. Numerous gathering participants reiterated this problem throughout the gathering, emphasizing that effective responses must be designed, developed and delivered by the Aboriginal community and that such responses be culturally appropriate.

Despite the challenges in providing services to FASD-affected individuals and families, Aboriginal community services have been creative in their responses and have developed some best practices within programs, some of which have been referenced above.

Programs that are flexible and adaptable to client needs are highly effective. In addition to determining client need before a program commences (as mentioned previously) programs that have the ability to change midway through a cycle are also identified as successful. By having this flexibility, it ensures that the needs of the client group are still met and the program can still remain within their mandate.

Front-line personnel trained in FASD are aware of the disorder’s characteristics and are better able to identify clients who may have FASD. Without a confirmed diagnosis however, it can often take months, if not years in some cases, of working with a client before a full picture of their challenges and characteristics are presented indicating that FASD may be an issue. Once the worker has completed an informal assessment of the situation, they are better able to respond and refer the client for a diagnosis (if the facilities and opportunity exist). They can also seek additional information from the client, family, other social service providers, and community to learn if maternal alcohol consumption during pregnancy was present. Even in the absence of an official FASD diagnosis, if front line service provider can recognize the symptoms, they are better able to respond to the client’s needs and change how they work with them.
As mentioned previously, in Canada the multi-disciplinary approach is utilized in diagnosis. Aboriginal communities undertake a similar approach which is referred to as holistic. This approach involves variety of community members – each bearing particular gifts and skills, who may be involved in working with an FASD-affected person at specific times and for specific purposes. As well, individuals are attended to in a manner that addresses their physical, mental, emotional and spiritual aspects of a being. This type of approach is culturally meaningful to the affected person, their family and the community. This, coupled with the strong safety net of supports built around a person, ensures greater chances of success for all who are involved.

In addition to these important elements, Aboriginal teachings provide a strong understanding that regardless of a persons place in the life cycle – whether infant or Elder, everyone has individual responsibilities with ultimate responsibility to the overall well-being of the community. As such, addressing the needs of a community is seen as a community responsibility, with each person having a role to play. In addressing the issue of FASD, it is not only the affected person who will need support, but this also extends to their family; the needs will be lifelong and will change over the years. As a result, a continuum of holistic care is the best practice in responding to FASD. This model is also preventative in nature – affected persons will be less likely to become entrapped in the revolving doors of the justice system and will experience lesser degrees of challenges with mental health issues, housing and employment challenges etc.

2. Have any community members with FASD been incarcerated? What supports did they receive while in the system? Did they understand why they were incarcerated? Did they reoffend?

One hundred percent of the gathering participants indicated that Aboriginal community members with FASD had experienced incarceration. Prevalence of FASD within institutions is not known, however anecdotal participant reports estimate that 50% of the Aboriginal inmate population has FASD. In custody, few programs are available for Aboriginal inmates with FASD and where they do exist, programming can often be problematic.

Aboriginal offenders present themselves to the mainstream justice and correctional systems with a multitude of complex issues and needs. As well, it is believed that a large percentage of Aboriginal people with FASD enter correctional facilities and are ill-equipped to deal with this chronic condition. Training for correctional services staff is minimal and inconsistent, offenders rarely have an accurate diagnosis which results in lack of appropriate response from correctional institutions, and programs that specifically address FASD are virtually non-existent. Of the programs that do exist, there are serious challenges for FASD-affected individuals to participate in them.

Aboriginal offenders are also over-classified once incarcerated and many end up with a maximum security classification, which proves to be a significant barrier to
programming. Secondly, of the programming that does exist, much of it is based on mainstream approaches and is not culturally appropriate. An additional barrier to programming is the fact that programming is often targeted towards higher functioning offenders, excluding those who may have trouble with reading, writing, memory and comprehension. Finally, persons with FASD often experience great frustration, they are easily led, and they do not understand consequence, have trouble concentrating, confabulate, perform poorly in overwhelming environments and consequently may be disruptive to the program. This poor performance leads to expulsion from programs and could serve as a barrier to participation in additional programs. The result, the FASD-affected Aboriginal offender is further marginalized and does not obtain necessary supportive programming.

Upon leaving a correctional facility, affected individuals are again left without proper resources and supports. Discharge planners are not aware of the fact that an offender has FASD which results in inappropriate referrals and a lack of community support to aid in reintegration. Lack of community support and effective programming can be a contributor to reoffending and it is often reported that FASD-affected individuals seem unable to learn from previous experiences and are rearrested, often for crimes that appear completely illogical.

With regard to the level of understanding, FASD-affected Aboriginal people may have of their offence and conviction, it was identified that offenders may understand that they are in custody for breaking the law but comprehensive understanding is lacking. Lack of awareness of consequence is a common characteristic of FASD as is the inability for abstract reasoning. A workshop participant provided a classic example of this nature:

A young girl used to set fires to bales of hay, which she quite enjoyed. Once, she set fire to a trailer while somebody was still inside and this person died. The young girl did not understand that setting fire to a trailer could lead to the loss of life. In her mind, it was fun to set fires, regardless of the consequence or the destruction that would ensue.

Gathering participants also expressed that superficial questioning as to the level of appreciation for an offence often resulted in seemingly positive responses. However, upon further questioning, it could be readily determined that the FASD-affected offender did not truly appreciate their crime and in fact, an offender’s only memory of an offence might be that which was shared with him/her by the police and courts.

There was acknowledgement that the Aboriginal community is starting to understand the breadth of FASD in the community still, there is a ‘strong river of denial running in the communities, in families, in individuals and in offenders’ themselves’. In spite of these barriers, there is growing momentum to addressing FASD and there is now growing community acknowledgement that the problem does exist.
3. Has there been training for members of your staff, community or participant group on the effects, risks and prevention of FASD?

There was a broad range of responses from workshop participants as to whether or not there was training and where applicable, the level of training. For the most part, responses seemed to indicate that although some training was available, it was insufficient, sporadic, time limited and narrow in focus of target audiences. The interesting fact that came to light for this question however, was the fair amount of collaboration in pooling training resources, which was encouraging.

Training examples that gathering participants had been directly involved in included:

- Collaboration with other agencies (i.e. the Canadian Centre for Substance Abuse) and developing training resources for FASD to be offered locally;

- Some workers, in particular those that work at Friendship Centres in Ontario, receive FASD training from the Ontario Federation of Indian Friendship Centres. In turn, this training is shared with a broad range of community members. As well, on a national level, the Aboriginal Court Worker training has offered FASD training sessions;

- On-line courses at Lethbridge Community College;

- The University of British Columbia’s Inter-professional Education Department hosts a bi-annual FASD training event. This conference was spoken highly of for its ability to attract a broad range of participants and speakers with direct interest and expertise in FASD; and,

- Agencies that have an FASD position provide training locally. The example provided related to an agency with an FASD worker who provided training to local doctors in an effort to foster stronger diagnostic capacity.

Many challenges to training were discussed. In particular, gathering participants identified specific institutions (corrections and child welfare) that would benefit from further training and additionally identified that training is only one piece to the overall strategy of addressing FASD. The training that is offered seems to provide enough information for front-line workers to identify that a person has FASD, yet institutions are challenged in providing appropriate referrals. In the example provided, corrections workers who suspect FASD refer offenders to alcohol awareness programs or mental health services – neither of which is specifically geared to, or capable of providing FASD support.

Other participants report sporadic one-day workshops in their community and anecdotally report that they believed that people involved in the social services or health care field
received more training. The challenge with isolated one-day workshops is that the information gained from these training initiatives does not trickle down to the community members and, with the high level of burn-out and turnover of front line service providers, there is on-going need for training.

In relation to staff turnover, it was identified that training on FASD is not necessarily standard to the process of orientation for new employees at community organizations. As such, new employees enter an organization and must wait until the opportunity for FASD training presents itself, which could be years. As well, because the training is community based (i.e. it takes place in the community and/or is paid for by community agency budgets) it may not be considered a priority in light of other areas of priority, interest, or crisis.

Often excluded from culturally appropriate FASD training are local Elders. Gathering participants indicated that Elders are available to engage with all members of the Aboriginal community – locally and regionally and sometimes provincially/territorially and nationally. However, they are often overlooked as a target audience who might benefit from training specifically on FASD. Not only would knowledge of this issue aid in the direct work they do with individuals or agencies, it would also prove beneficial in guiding the overall direction of the community in its setting of priorities and community development. This is a gap that must be addressed as they are an important population with an ability to reach a greater audience and will provide the all-important traditional teachings that should accompany FASD training.

Overall, it was expressed that current levels of FASD training are insufficient for community need and demand. Existing training is far from comprehensive and given the breadth of the subject it is not realistic to expect that one FASD training session is sufficient.

To close this section on a positive note, where FASD is deemed a priority by even one community agency, there can be great success. One gathering participant told of a local agency that had made FASD a priority. In doing so, they became members of local training institutions, have staff that have taken extensive FASD training, serve on FASD networks, access the training and resources of other organizations with an interest in FASD, attend conferences, recruited staff who are able to serve on FASD speaker’s bureaus, have staff that are skilled in the area of providing training and workshops, monitor other FASD initiatives, and respond to requests for training and resources from other communities. The effect of this agency’s efforts has resulted in a ripple effect within the community, has increased community collaboration in regard to FASD and can be considered a best practice.

4. **Have police and members of the justice system in your community received training to assist identifying members of the community affected by FASD who have come in contact with the law? What tools, training and resources would your program need to effectively assist members of the community**
that have been diagnosed with FASD and have been in conflict with the law?

Gathering participants provided two examples involved police or justice system personnel training on FASD – one example specifically cited training and the other referenced amenability to training. In the first example, participants who worked with correctional officers indicated that the training that the CO’s receive is minimal – only one half day. The implication for FASD-affected inmates is that corrections staff are ill-equipped to respond appropriately to affected inmates and the characteristics they display as a result of their condition. For example, those with little impulse control, anger management problems and who do not appreciate the consequences of their actions are more likely to act out in a physically aggressive manner and, as a result, be placed in segregation or classified at a higher level of risk. It was expressed that should CO’s be trained on FASD and appropriate responses, they would minimize the negative outcomes experienced by inmates as well as staff and the offenders would likely have greater access to necessary programming.

Another participant indicated that a local Chief of Police and their member officers were amenable to taking suggested training. This draws attention to the need for local leadership to be understanding of the need for FASD training and a willingness to commit time and resources to such an endeavour. Without the support of local leadership, important FASD work will be inhibited.

Aside from the two contributions just mentioned, there appears to be a lack of FASD training available for justice system personnel. Gathering participants discussed this challenge and offered several points for consideration in planning FASD training for justice personnel. It was noted that, in addition to formal training on FASD, justice system personnel require comprehensive understanding of Aboriginal issues, and an understanding of local Aboriginal concerns. As well, it is equally important that justice personnel understand that Aboriginal communities wish to address FASD from a holistic perspective that includes the physical, mental, emotional and spiritual aspects of a being and community.

Prior to providing justice system personnel FASD training, it is important to examine the current levels of knowledge and understanding of the condition and how it impacts on the work of justice personnel. One gathering participant spoke of a local psychologist who completed a survey of justice personnel on their level of understanding and attitudes towards FASD2. With the knowledge gained from this survey, a training manual for judges and lawyers was developed.

Many FASD initiatives across Canada are targeted primarily towards children and sometimes youth, however there is a scarcity of information and resources available to

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respond to adults with FASD. More awareness for justice personnel is needed, particularly in the area of assessments for adults.

One participant indicated that they did not believe that the local police service had FASD training. As a default to lack of knowledge about FASD, the local restorative justice worker did have such training, and it was felt that the identification of an FASD-affected individual would fall to that person. The gap exposed in this process however comes to the forefront when consideration is given to the fact that most restorative justice programs deal with relatively minor offences committed by offenders with little or no criminal records. Given the fact that many Aboriginal people are charged with more serious offences and are more likely to have a criminal record, most Aboriginal offenders do not qualify for restorative justice programs.

With respect to tools and resources needed in communities to address FASD, a variety of points were identified, ranging from staffing issues to individual and community characteristics. Some of these included:

- Less turn over of police personnel at local police stations; and,

- An interest on the part of all community members to learn about FASD. It was observed that, in some circumstances, there is a level of denial or shame that hinders the delivery of knowledge.

Additionally, gathering participants noted that FASD must be taught in schools and that in particular, there is a need to teach about it in law school. It is important that law students understand how FASD will impact their work.

In addition to training justice personnel, there is also a need for diagnostic services for people proceeding through the justice system, along with resources and proper follow-up supports. This was reiterated by several participants as a strong need. It was suggested that regional correctional reception centres would serve as appropriate locations to complete FASD diagnoses as all offenders are processed through these centres. The assessment would have an impact on the case management plan designed for the offender. As well, an important consideration to completing a diagnosis is the need to consider and respond to the family, should a positive diagnosis be made. There could be a great deal of shame and guilt associated with a positive diagnosis and it is important that supportive resources be made available to families as well.

Interestingly, it was identified that FASD awareness is not simply about having access to tools and resources; it also involves a degree of assertiveness on the part of the community. Communities themselves, both individuals and organizations, must insist on receiving training, but equally so, it is important that assertiveness be used in telling justice system personnel that they too need to be trained in order to more effectively respond to FASD. The final point concerning assertiveness was expressed by one gathering participant who indicated that it was important for those with the knowledge of FASD to tell people that they have this knowledge and be willing to share it.
5. What resources are available in your program, community, region or province for assistance for community members with FASD? Who is available in your region or community to provide this type of support? What training and resources would be needed to provide adequate information and support for community members in your area?

Gathering participants identified the following resources available specific to their communities and more broadly available services. Community specific resources included:

- In Winnipeg there is the Ma Mawi Wi Chi Itata Centre, Aboriginal services at two local hospitals, resources from Health Canada and the shelters;
- One participant reported an FASD diagnostic team, prevention services, home visiting for pregnant and new mothers who have addictions to alcohol, school support programs, the Eastern Door Centre in Elsipogtog First Nation (coordinators, family advocates, teachers);
- Another participant identified Friendship Centres, the Prince Albert Grand Council, Saskatoon Health, social services, mental health services, a psychologist that does FASD assessments, and that the courts have been made aware of FASD and the needs of people affected by FASD;
- One participant described the material resources within their FASD program that they use – a non-affected doll, an FASD-affected doll and a doll affected by maternal drug use, videos for all target groups, including those in the correctional system, and photocopies of handouts that are broadly disseminated in the community; and,
- The Prevention Institute – human and material resources, the Saskatchewan FASD Support Network, a house for people with FASD in Saskatoon, a local FASD committee, website resources;

Other FASD resources identified included:

- Web resources (parenting guidelines, ‘Let’s Talk FASD’ by the VON, PHAC);
- Community health centres that do FASD diagnosis;
- Canada’s Prenatal Nutrition Program;
- Pathways;
- The Early Years program;
Despite the wide range of entities responding to FASD, availability of resources is not consistent across Canada and there are numerous challenges in obtaining supportive services. Examples of such hindrances include high turnover of staff, limited numbers of staff versus large caseloads, lack of FASD specific resources once a diagnosis is made (such as housing), and lack of funding to develop FASD specific programs. It was also identified that community leadership and government stakeholders will target other health care issues for children as a main concern (such as obesity and diabetes) resulting in priority development at the expense of FASD-affected children.

Of interest in the responses to this question, gathering participants were able to easily identify specific as well as general FASD resources for children. Very little mention was made regarding services for adults, and in particular adult Aboriginal offenders. As such, it is reasonable to assume that an extensive deficiency of FASD specific resources exist for this particular demographic.

6. What are the gaps in providing adequate support and prevention in your community for FASD?

Gathering participants provided an extensive list of gaps relating to FASD support and prevention within their communities. These gaps can best be categorized as: community, government, service, attitudinal, and other.

Broadly, it was acknowledged that there is a general lack of knowledge about FASD within the criminal justice system as well as within the child welfare and family law systems. Without adequate levels of awareness of an issue, it is problematic to formulate appropriate responses at local levels.

On a broader scale, the lack of long-term funding at provincial/territorial and federal government levels ultimately impacts the ability of Aboriginal communities to develop and implement appropriate responses. As well, because of the general lack of awareness of FASD, efforts at encouraging governments to make it a priority have been frustrated and as a result, the policies necessary to address FASD are minimal and not comprehensive.
Locally, Aboriginal communities must develop a long-term vision and supportive policies to support community healing, inclusive of FASD. To do this, there must be leadership and buy-in from the local leaders. Without this, there will be a lack of unity and collaboration not only within the overall context of a community but also on the part of local social service providers.

Those in the front lines of service provision suffer a great many challenges in addressing FASD. Not only is accessibility to service problematic across Canada, but programming is often inconsistent and sporadic. Social service providers, whether they are Aboriginal or non-Aboriginal, operate many programs on an intermittent basis and many do not have continuous intake policies. As a result, many people who would otherwise access services are forced to wait for the next intake cycle, are placed on waiting lists, or short term funding is not renewed and the program vanishes.

Best practice guidelines or processes are a necessary, albeit tricky, concept. What is defined as a best practice in one specific Aboriginal community may be best for that particular community, but may not be appropriate for another community. As important as it is to not apply a cookie-cutter approach in programming, it is equally important that communities have the opportunity to develop and enhance the best practices that suit their local needs.

One such best practice that bears close scrutiny in FASD resource development is cradle-to-grave programming. Policies must reflect the fact that the needs of FASD-affected individuals are present throughout the life cycle (i.e. from birth until death). The needs of FASD-affected individuals do not lessen throughout a person’s lifespan; rather, they change and different responses will be required at different stages of a person’s life cycle.

A very significant gap in the delivery of service to adults is the inability to obtain an FASD diagnosis. This challenge exists as a result of lack of policy and resources and results in the following deficiencies:

- A lack of professionals trained in FASD diagnosis;
- FASD diagnosis requires multi-disciplinary teams consisting of a doctor, a speech pathologist, a psychologist and an occupational therapist. The combination of these services are often unavailable in many communities across Canada, and where they do exist, their specialty or area of awareness/expertise, may not include FASD;
- Lack of resources to pay for a diagnosis (i.e. some provinces have provincial health care plans that will cover the full diagnosis and others may only cover part of it);
- Logistical challenges – one such example includes in-custody diagnosis. Arranging to have the four members of a multi-disciplinary team enter a correctional facility can be problematic without the full cooperation of the
correctional facility, the facility’s schedule and security needs, court dates etc.; and,

- Most diagnostic services target children and youth.

Ultimately, if the person is an adult Aboriginal offender there are even less opportunities for diagnosis.

In the same vein, many FASD programs target one group while excluding others. For example, programs might target young mothers, or mothers-to-be, while excluding their partners. They also might target young children with FASD and their mothers, but not the fathers. Or, they work with youth up to the age of 18 but do not provide service to those who are 19 or older – despite the fact that one of the characteristics of FASD is that affected individuals may suffer from delayed development – i.e. they may be twenty-five years old but possess the maturity level of a twelve year old. In keeping with this theme, targeted service provision may not necessarily be in keeping with the concept of holistic healing approaches, unless there is another local service that can meet the need of different groups. All of this is not to say that local service providers are to blame for targeted service provision rather, funding criteria often restricts the target audience as well as programming criteria. Other obstacles that feed programming may also include attitudes towards FASD, which will be addressed shortly.

Gathering participants indicated that FASD programs must build in components that will empower affected individuals as well as families and communities as a whole. In doing so, a more holistic approach will develop and will include indirect needs such as housing, prevention and the emergence of FASD advocates helping affected individuals and families’ access necessary supportive services.

The recruitment, retention and maintenance of personnel to work in the field of FASD is problematic. As noted previously, there is a lack of FASD-specific services which results in untrained staff providing services. There is considerable need to provide dedicated training on FASD to FASD program staff as well as to provide training to other stakeholders, such as ancillary staff and local resources such as Elders.

It is fair to state that most front line staff at Aboriginal social service agencies are poorly compensated, overworked and undertrained, yet there is a significant expectation, on the part of funders, an organization, and the staff person themselves, that they provide extensive service. From an organizational and staff perspective, front line staffs endeavour to provide holistic services and often compensate for programming deficiencies by working beyond their mandate because ‘somebody needs to do the job’. Aboriginal clients rarely present to a social service agency with just one problem and as such, a worker may find themselves also dealing with mental health issues, domestic violence, poverty, child welfare matters, substance abuse and so on. This feeds into excessive and draining case loads which often result in burnout at local levels, which ultimately feeds into high staff turnover rates.
The final gap identified by gathering participants related to attitudes – those of the Aboriginal social service providers, birth mothers, families and communities. A brief overview of some examples includes:

- Corporate culture of local Aboriginal agencies often sees the placement of priority on the current community crisis. That is, community leadership is reactionary rather than strategic in its planning and responses;

- FASD is also a highly stigmatized disorder – birth mothers are often blamed for giving the disorder to their child(ren) with little regard to the circumstances of her substance abuse;

- Persons with FASD may have lower IQ’s and a variety of other developmental disorders which lead to secondary characteristics such as disrupted educational experiences. As a result, persons with FASD may be identified as unintelligent or unmotivated;

- Community perceptions of Aboriginal agencies are often an inhibiting barrier to service. For example, Aboriginal community members may fear a lack of confidentiality within an agency and may leave their problems unaddressed;

- Families of FASD-affected individuals often express the legitimate fear about acknowledging that FASD may be a problem, particularly when young children are involved, for fear of child apprehensions by the local child welfare authority;

- And finally, families may be in denial about an FASD diagnosis and may refer to the disorder as something more socially acceptable (ADHD, bi-polar).

7. What needs to be done for FASD-affected members to improve their outcomes when involved with the justice system, alternative measures or support programs? What needs to be done for FASD-affected individuals to have better outcomes that what they are doing?

Gathering participants provided a number of options to improve outcomes of FASD-affected individuals relating mostly to the mainstream justice system but also within the community, where most alternative justice programs reside. In addition to concrete options, participants also reflected upon important cultural considerations, such as those found in the Seven Grandfather and Grandmother teachings of wisdom, respect, humility, love, honesty, bravery and truth.

Before looking at what improvements need to happen in the justice system, it is important to reflect upon traditional ways. Children are considered to be gifts from the Creator and each child has gifts that need to be discovered and nurtured. It is not known what a child’s role in life will be, but ultimately it is the responsibility of the whole community
to ensure the health and well-being of that child. This teaching does not come into effect when the child is born, but ideally is in effect when the parents are planning to have a child and throughout the pregnancy.

Historically, when an Aboriginal community faced threat it was the responsibility of the whole community to respond and intervene appropriately as any threat could ultimately be a threat to the safety and security of the whole community. This concept also applies to FASD in that this disorder is not simply one that affects just the individual, but also has impacts on immediate and extended family, the community, social service providers, the education system as well as the justice system. For example, an affected individual that does not understand the concept of consequence might set a fire in the forest which could threaten to burn down a whole community and result in loss of life and injury. Also, a fire in the community could also impact the local economy, education system, housing, social structures, infrastructure as well as other community resources. As such, in relation to FASD, a community also has responsibility. When a woman is pregnant, it is the community’s responsibility to be supportive; when she is pregnant and drinking they are also responsible to provide appropriate interventions. As such, in contemporary times, the community shares in the responsibility of future generations and it is important, and necessary, that they possess the willingness to respond as well as the financial and policy support required to fulfill this task.

One participant reflected upon the importance of dealing with FASD-affected individuals with respect. Despite the circumstances of the individual, persons with FASD should be treated kindly and have equal and appropriate access to necessary services, such as housing and health care.

One manner in which kindness can be expressed is by the willingness of those in the community – whether it is the justice community or the whole of the community – to have a level of understanding of the disability and recognition that FASD is irreparable brain damage. The mainstream justice system in Canada has placed strong emphasis on the deterrent and denunciative effects of punishment, yet increasingly it is recognized that these concepts are largely ineffectual for all offenders. Furthermore, when dealing with an FASD-affected individual who may have poor memory, the inability to conduct abstract reasoning and be unable to understand consequence, these concepts hold even less value.

To address these challenges, it is important that mainstream justice personnel be educated about FASD, whether this be police, judges, crown and defence counsel, corrections personnel or persons employed within alternative justice. With adequate awareness of this permanent, lifelong spectrum disability, the justice system will be better able to respond to the unique needs of affected individuals. Currently the justice system is set up to fail FASD-affected individuals – poor memory functions results in missed court appearances resulting in fail to appear charges. Many bail conditions (such as curfews, reporting conditions, and abstinence conditions) are inappropriate and impossible to achieve, especially if the affected individual does not have a circle of support with an understanding of the limitations imposed by FASD.
The courts in Canada increasingly have developed a number of specialized courts – youth court, mental health court, community wellness courts, drug treatment courts, domestic violence courts etc. Given the high incidence of FASD-affected individuals involved in the justice system, one of the additional specialized courts that should be developed is an FASD court. But again, this is problematic when no one knows exactly what the prevalence of FASD is in the mainstream justice system. As such, it would be necessary for the court system to build-in processes to have diagnoses completed.

Following court processes, Aboriginal offenders are disproportionately sentenced to custody. A broad range of additional challenges arise at this point as correctional services are ill-equipped to respond to FASD. While serving sentences, affected individuals who may have attention deficits, anger management problems, and inappropriate reactions to events, are at higher risk to negatively act out resulting in increased classification which inhibits participation remedial programs. As well, the correctional system programs largely provide cognitive behavioural programming, which are ineffectual for FASD-affected persons. So, not only is the justice system largely designed to be an inappropriate response to affected individuals, it is fraught with systemic barriers resulting in enhanced negative outcomes for FASD-affected individuals.

This is also true of alternative justice programs, whether they be Aboriginal or mainstream. Without understanding of the disorder, it is difficult for alternative programs to provide adequate community responses. However, where both mainstream justice systems and alternatives have developed an enhanced understanding of the issue, more meaningful and appropriate responses have been undertaken with great success. As such, it is important that efforts are made to ensure that FASD training is standard for all personnel in the justice system and that policies be developed to provide appropriate response. This should be accomplished by first completing a comprehensive review of the justice system spectrum to determine need, which will ultimately inform policy changes.

One of the most noticeable gaps in justice responses to FASD is the lack of involvement of local Aboriginal resources. This occurs for a variety of reasons including: lack of awareness by justice personnel as to the availability of such resources and local Aboriginal resources being aware of their ability to assist in justice processes. Regardless of the reason, in addition to increasing awareness about FASD, it is equally important to respond to the issue in a more holistic manner, which would necessitate the involvement of local Aboriginal resources. One of the most under-utilized resources in this regard is Aboriginal Court Workers. Court Workers are often familiar with the accused or their family and are well-familiar with local community supports that could help the FASD-affected individual. Also under-appreciated are local Elders. A number of courts across

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3 One such example is the Community Justice Program in Lethbridge, Alberta which offers a diversion program for youthful offenders affected with FASD. They make recommendations to the courts for assessments, alternative measures or sentencing, and develop case management plans and/or pre-sentence reports. As well, they offer advocacy for youths, their families, the school and community. They have ongoing support from the Lethbridge Police Service, agency partners and community groups.
Canada have increased their use of Elders, often in the form of sentencing circles, however this has proven problematic as these circles are time consuming and have often resulted in an appeal by the crown. As well, sanctions imposed by the courts often still rest within the mainstream justice system and do not adequately address the unique needs of FASD-affected individuals.

A successful alternative to the justice system are restorative justice types of programs. However, this option is not widely available across Canada because of lack of acceptance of the process, lack of policy, and lack of funding. But where they do exist, they have proven themselves to be highly culturally appropriate responses; they significantly reduce recidivism and are most cost effective.

One of the main challenges to responding to FASD in the justice system rests with the inability to obtain diagnosis. Because the incidence and prevalence rates of FASD in Aboriginal communities (reserve or urban) are not known, there is reluctance to invest resources in the issue. Because diagnostic standards in Canada are comprehensive and require the involvement of at least four different medical professionals (which are largely unavailable) there is a need to develop an FASD assessment tool that can be utilized by professionals within the justice system or Aboriginal community. With assessment, early interventions, supports and alternatives can be delivered, ultimately aiding in better outcomes which could also serve as a strong crime prevention tool.

However, as noted previously in Canada there are inconsistent responses to FASD from province to province and as a result, there are insufficient resources available. Strategies must be developed nationally, provincially, regionally and locally to involve a broad range of community resources. Many of these resources have not historically been directly involved in justice responses to FASD yet they are vital and necessary. Such resources would include those involved in the education and health sectors, as well as other social services. Ideally, when dealing with Aboriginal people affected with FASD, culturally appropriate services should be included such as Elders, drug and alcohol workers, parenting programs, family workers and so-on. As noted previously, FASD is a spectrum disorder and a lifelong disorder, which necessitates a multi-disciplinary response.

For a plethora of reasons, parents and families of FASD-affected individuals are often excluded from justice responses to FASD-affected individuals. Sometimes it is out of sheer frustration and inability to cope with an FASD-affected person that family will become unresponsive. Other times it is because the over-extended justice system fails to request their involvement. There are a number of additional reasons why parents and families may not be involved, some of which include poverty (i.e. they cannot afford the bus fare to court, they do not have childcare to look after the other children while they are at court) or an affected individual might have been adopted and be disconnected from their biological and adopted family (adoption breakdowns are common with FASD-affected persons). Despite these reasons, parents and families are an important sector of appropriate response. In working with FASD-affected individuals it is necessary to
develop a safety net of many supportive services and families are vital to this kind of response.

A strong safety net of services is considered to be a best practice in FASD response, yet they are difficult to organize due to lack of awareness, lack of policy and lack of funding among other things. But where utilized, they have proven beneficial to not only the affected individual, but in all aspects of the justice system – from arrest to the courts, to corrections and to eventual release back in to the community.

One area of particular FASD-affected offender need is for those released from correctional facilities. But this again is problematic without the ability to undertake diagnosis of affected individuals – if it is not identified that a certain percentage of the population has a disorder it remains challenging to justify appropriate responses. It has been reported that offenders are often released from institutions without having the benefit of programming and are frequently in the same or worse condition than they were when they first entered an institution. As well, upon release, many offenders spend time in the city or town where they were released yet have no established supports available. This highlights the importance of involving the Aboriginal community in the justice system, and in this case in corrections, so that comprehensive release planning can be undertaken in an effort to ensure successful release and reintegration. In particular, an area of great need, from a correctional perspective, is the need to address female Aboriginal offenders. It is well documented that Aboriginal services within provincial and federal facilities are lacking, yet little attention has been afforded Aboriginal female inmates. This population is growing within corrections and the majority of female offenders are of childbearing years. Given the high rate of substance abuse within that particular population, it is necessary that programs be developed that can offer support and assistance that will address the environment and circumstances that contributed to their involvement in the mainstream justice system in the first place.

Other interventions and supports necessary to facilitate successful reintegration include housing. Many people with FASD suffer the inability to acquire and maintain adequate housing – not only is this a result of the range of deficits which they may possess (i.e. the inability to manage time and money, memory problems, inability to understand consequence), but they are likely without the necessary community supports that would help them remain housed. As well, there is a great resource gap in supportive housing directed at FASD-affected individuals.

There needs to be compassion and empathy from persons working in the justice system towards persons with FASD. There cannot be high expectations of success with the affected persons that are processed through the justice system, there must be a level of understanding as well as discretion that the FASD-affected person may take longer to accomplish their goals and that they might not always succeed during the first few attempts. All people deserve to be treated with respect and understanding and kindness.
8. How should communities be supported to assist in caring for community members affected with FASD?

All too often decisions affecting Aboriginal communities are made at leadership levels without adequate or meaningful consultation. It is vitally important that when developing strategies and responses to FASD that local Aboriginal communities are first asked how they wish to be supported in the development of responses. It was reiterated by gathering participants that every Aboriginal community is unique, and as such, the responses will be unique. Aboriginal communities in Canada are representative of different nations, different traditions, and different languages and possess a range of capacity. As well, many Aboriginal communities, particularly reserve communities, face a variety of crises on a continual basis. These realities require great consideration and it is important that consultation processes are conducted with respect and be truly collaborative.

By involving Aboriginal communities in a meaningful manner, communities will be empowered to respond to FASD. In keeping with Aboriginal traditions, the responses will be holistic in nature and meet a variety of needs. One gathering participants shared an idea of a holistic response that had many benefits, was holistic in nature and involved comprehensive local collaboration. The idea involved a proposal to build a home for FASD-affected individuals, but to have these individuals work on the home as well. They would be paid, learn new skills, have a home when it was completed and have a sense of pride in their accomplishment. This type of initiative could be community based involving many facets of the local Aboriginal community and would also empower the broader community.

Communities will be supported in addressing FASD with the increase of awareness of FASD as well as Aboriginal culture and circumstance. Not only will the justice system be better able to be effective in response, but local Aboriginal communities will also take more responsibility and come together on this issue, reflecting back to how communities used to mobilize on matters of importance;

Communities can be supported if they have leadership support at the local level – whether they be elected leaders or the traditional leaders, as long as they are people familiar with the local culture and community;

It is important to have an understanding of the incidence and prevalence levels of FASD in the community. To do so, more research is required. Once research and assessment is available, increased and targeted training should follow. As well, assessment should include the identification of service needs and available resources in order to develop comprehensive community plans to address the issue.

Some gathering participants identified more specific program requirements to assist in caring for and supporting FASD-affected individuals. Many of these items have been previously identified, but bear repeating. These include:
• The provision of FASD advocates supporting affected individuals and families. The advocates should not be restricted to paid personnel, but could also include Elders and existing social service providers who are well placed to respond;

• In relation to Elders and traditional teachers, they are often the most under-utilized and under-appreciated resources. This group possesses a wealth of information and teachings that can aid in FASD responses yet they are not compensated for their efforts nor are they supported in other ways to do this work (i.e. they are not targeted for training); and,

• Finally, as mentioned previously, Aboriginal community justice circles are well placed to respond to FASD and it is well documented that they are effective, meaningful, and cost effective and reduce recidivism. It is necessary that policies be developed and enhanced to support their use and that these measures be supported by leadership in their implementation.
Conclusion

The overarching purpose of this gathering was to draw together persons from across Canada that work with FASD-affected individuals involved in the criminal justice system. Its goal was to hear the thoughts and experiences around the issue of FASD in the criminal justice system as well as to share strategies for FASD and incarceration.

The gathering participants came with a variety of backgrounds and experiences and were able to contribute substantially to the gathering. Although no specific strategies for FASD and incarceration were identified, the deficiencies in the Canadian criminal justice system were highlighted and a number of specific recommendations were made, mostly from a programmatic perspective.

Upon analysis of the deficiencies, overarching themes emerged pointing to areas that require strategic direction. These include:

1. The need for strategic policies based on holistic approaches, i.e. any strategic or policy development aimed at FASD responses for Aboriginal communities (whether they be urban or reserve based) must be grounded in holistic approaches, be culturally relevant, and provide recognition for the unique needs of each Aboriginal community;

2. Best practices need to be evaluated and analyzed to aid in the determination of best approaches and challenges. It is important that best practices not translate to a cookie cutter approach to policy and program development, rather Aboriginal communities have opportunity to take elements of best practices and adapt responses relevant to local Aboriginal cultures and community needs;

3. Addressing the overwhelming lack of FASD responses for adults;

4. The need to support the development of accessible diagnostic services across Canada, in particular for adults, inclusive of diagnostic services for those who are incarcerated (whether it be provincial or federal and for offenders who are on both remand and sentence); and,

5. Ensure that all personnel working within the mainstream justice, or those collaborating with the system, are provided with standard and on-going training on FASD.
Introduction

This bibliography is intended to provide an introduction for readers to some existing literature on Fetal Alcohol Spectrum Disorder. It is divided into two sections - a brief bibliography followed by a comprehensive annotated bibliography.

The sources in this bibliography are primarily drawn from Canadian-based research and writings that focus on medical and justice-related issues pertaining to FASD\(^4\). This bibliography also aims to highlight the impact that FASD has on Aboriginal communities and includes information published by Inuit, Métis, and First Nation organizations in Canada. Unfortunately, there is not a substantial scientific material on Aboriginal-specific issues related to FASD, in Canada and otherwise, but the compilers of this bibliography have endeavoured to highlight as many sources in this area as possible.

Bibliography


The Asante Centre for Fetal Alcohol Syndrome. (2002-2004). Fetal Alcohol Syndrome and the Criminal Justice System- Understanding the Offender with FAS. (Video Series).


\(^4\) Please note the use of FASD terminology throughout this bibliography. Although some authors utilize specific terms such as FAS or ARND, readers should be aware that the terms utilized may specifically be in relation to a particular disorder within the FASD spectrum or the author may have utilized a term to describe the range of disorders (i.e. utilizing the term FAS when they may be referring to the whole FASD spectrum). As such, it is recommended that readers investigate each of the references individually to determine if the particular reference meets their needs. For the purposes of this bibliography, the compilers utilized the terminology of the particular reference.


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Annotated Bibliography


- The Ajunnginiq Centre is a part of the National Aboriginal Health Organization, which is based in Ottawa. The Ajunnginiq Centre partnered with the Inuit Tapiriit Kanatami to participate in activities related to creating a Memorandum of Understanding (MOU) between Indian Health Services in the United States and Health Canada. FASD was identified as a key area of activity for the MOU to address, and a working group was formed to initiate activities to address evidence-based practice models in Aboriginal communities.
- In order to get this project underway an environmental scan of practices addressing FASD at the national, regional and community levels was required. The report provides a snapshot of available services and gaps in services in Inuit communities in 2004. The results indicated that there is a lack of funding and human resources to deal with pressing FASD related issues in Inuit communities, and that there is a need for Inuit-specific research and strategies on this issue.

The Asante Centre for Fetal Alcohol Syndrome. (2002-2004). Fetal Alcohol Syndrome and the Criminal Justice System- Understanding the Offender with FAS. (Video Series).

- This 3-part video series deals with FASD and the criminal justice system. It is split into three videos, each part told from a different perspective within the system. The first video features interviews with an offender with FASD, the second a judge, and the third a defence attorney. The videos are entitled:
  1. Video 1 - "Talking with Victor" (43 min)
  2. Video 2 - "A Judge's Perspective - with Judge Cunliffe Barnett" (56 min)
  3. Video 3 - "Mistakes I Have Made - with lawyer David Boulding" (28 min)
- To order the videos by visiting the Asante Centre website store at: http://www.asantecentre.org/store.html


- This is a study prepared for CSC that sets out to identify the needs of Aboriginal women incarcerated in federal correctional facilities and serving time in the community, with the more specific goal of examining the substance abuse and family related needs of this offender population.
• This research also focused on the impact of Fetal Alcohol Spectrum Disorder (FASD) on Aboriginal women offenders and their families.
• This article records observations and profiling information on the incarcerated population of Aboriginal women in Canada in order to offer readers background information on some of the people who are affected by FASD in some way or another.
• This article makes a number of recommendations in relation to FASD and the incarcerated female Aboriginal population in Canada.


• This is a report prepared for CSC that reflects their organization’s growing awareness of FASD and its attendant challenges in the late 1990s. The main focus of this report describes the primary need for correctional institutions to identify individuals with FASD as they enter the system.
• The executive summary of this report reads as follows:

This report reviews the literature on Fetal Alcohol Syndrome from the perspective of the implications this condition might have for the criminal justice system and for Correctional Service Canada. The report is presented in three parts. Part I provides a basic background about the disorder. Part II traces the course and consequences of this condition, including the connection to delinquency and crime. Part III considers the possibility of identifying fetal alcohol syndrome and related effects in individuals who come in contact with the criminal justice system, and how institutional and post-release programs might best fit their needs.


• This is a study that set out to gauge the availability of services for the diagnosis and management of people with Fetal Alcohol Syndrome (FAS), Alcohol Related Neuro-developmental Disorder (ARND), or Fetal Alcohol Effect (FAE) in the Canadian correctional system. In order to derive this information the researchers asked all of the provinces and territories’ correctional systems to complete a questionnaire on the demographics of the population and services related to FAS. Responses were obtained from eleven of the thirteen provinces or territories invited to participate.
The basic numbers of this research reads as follows: The provinces and territories reported a total population of offenders of 148,797. In the eleven responding entities, the mean rate of substance abuse was 50.5%. Of the total population, 13 inmates had a reported diagnosis of FAS for a prevalence rate of 0.087 per 1,000 population. In the Yukon Territory the correction system estimated that 2.6% of offenders had FAS. None of the entities reported having a screening program for FAS in the correctional systems. Three out of eleven entities (27.3%) reported having access to diagnostic services for FAS.

After assessing the data, the authors of this study offer some of the following observations and recommendations:

1. The information in this survey suggests that CSC’s infrastructure capacity, staff awareness, access to screening, and diagnostic services are insufficient.
2. The number of affected inmates currently identified in the Canadian corrections system by this study is well below expected rates. The authors conclude that these numbers are likely very conservative estimates that likely reflect CSC’s inadequate screening and treatment programs for FASD as of 2003.
3. The study also indicated that the majority of the correctional systems that they questioned expressed a need for better staff education about basic recognition and management of persons with FAS.
4. This article’s final conclusion is that a thorough completion of prevalence studies of FAS and ARND in the correctional system is essential. CSC would benefit from a clearer picture of the prevalence of FASD in its incarcerated population. Using more accurate data could help Canada’s correctional system develop better awareness programs for staff, which would then help to improve management strategies for this population.


This article provides a chronology of the history of FASD and development as an official medical diagnosis.

The article’s abstract reads as follows:

Fetal Alcohol Syndrome (FAS), the most severe manifestation of the adverse effects of alcohol on foetal development, was first described in the French medical literature by Lemoine et al. in the 1968 article “Les Enfants des parents alcooliques: anomalies observes a propos de 127 cas” (The children of alcoholic parents: anomalies observed in 127 cases). Five years later, Jones et al. were the first to delineate systematically the association between maternal alcohol abuse and a specific pattern of
birth defects and to provide diagnostic criteria for this condition. Several diagnostic systems have since been developed with a view to capturing the wide spectrum of physical and behavioural anomalies resulting from prenatal alcohol exposure. The purpose of the current paper is to outline the evolution of FAS as a medical diagnosis.

Canadian Journal of Clinical Pharmacology- Incorporating Fetal Alcohol Research

- The Canadian Journal of Clinical Pharmacology is a valuable source of information on FASD. This is because in the fall of 2007 The Journal of Fetal Alcohol Syndrome International was amalgamated with The Canadian Journal of Clinical Pharmacology. The Journal of Fetal Alcohol Syndrome International is now entitled Fetal Alcohol Research within the Canadian Journal of Clinical Pharmacology.
- Fetal Alcohol Canadian Expertise (FACE), under the leadership of Dr. Gideon Koren, is the expert organization that mainly writes and submits articles to Fetal Alcohol Research. This journal is published three times a year, and each issue features a number of articles reflecting medical and scientific research in this field, along with occasional articles that address the sociological, legal, and policy issues related to FASD.
- The amalgamated CJCP/FAR is a web-based journal and is freely available to clinicians, researchers, and teachers, individuals affected by FASD (including parents, partners, and siblings), program providers, community leaders and the public at large. The most recent issues and archives can be found by visiting the CJCP website at http://www.cjcp.ca/.


- This website features the work of researchers from British Columbia, Alberta, Saskatchewan, Manitoba, Northwest Territories, Yukon, and Nunavut. Members of the Prairie Northern Pacific FAS Partnership learn from one another, as well as share expertise, resource materials, and "best practices" through their network.
- The official goals of the Canadian Northwest FASD Partnership include:
  1. Acting as an alliance of partners in the development and promotion of an inter-provincial/territorial approach on the prevention, intervention, care and support of individuals affected by FASD.
2. Working collaboratively in the prevention of FASD through education and information dissemination; and
3. Sharing expertise, best practices and materials among members, thereby aiding effective and efficient use of resources.


- In the early 2000’s, the CDC worked with a group of experts and organizations to review research on FASD in order to develop guidelines for diagnosis. The resulting diagnostic system was published in 2004. This diagnostic system only covers Fetal Alcohol Syndrome however. The CDC and its partners are currently working to put together diagnostic criteria for the other conditions that fall under the FASD umbrella.
- The FAS diagnostic guidelines outlined by the CDC have been incorporated into the Canadian FASD diagnostic guidelines as well, and thus may be of interest to individuals wishing to understand FASD related issues in Canada.


- This thesis was prepared by Jennifer Chapman as an MA project for the School of Criminology at Simon Fraser University, British Columbia. The thesis can be read by visiting Simon Fraser’s library website at http://ir.lib.sfu.ca/handle/1892/10127.
- The thesis’ abstract reads as follows:

Fetal Alcohol Spectrum Disorder (FASD) is widespread amongst inmates within the Canadian correctional system. Although research suggests that up to half of the prison population is plagued by an alcohol-related birth defect, little has been done within corrections to address this problem. Diagnosis is rare and treatment is ineffective. Research pertaining to the treatment of FASD-impacted adult offenders is limited; however, interventions can be derived from work done with children and youth affected by FASD. To date, Canada only has one community residential facility working with FASD-impacted male
offenders on parole [Genesis House, in New Westminster B.C.]. Although an innovative project, it has been faced with many challenges. In order to assist with the successful reintegration of FASD offenders, many changes need to take place within our correctional system.


- This paper examines jurisprudence as it relates to FASD in Canada in 2003. The analysis concludes that traditional sentencing principles are inappropriate for offenders with FASD and should be rejected in favour of a sentencing approach that is sensitive to the unique circumstances of these individuals.
- The paper opens with an overview of the nature of FAS/ARND and its prevalence in the criminal justice system, and then proceeds to examine the case law involving the sentencing of offenders with this condition in order to identify emerging sentencing trends and other issues of concern.
- The article pays particular attention to the problem of judges who are prevented from being able to tailor appropriate sentences for offenders afflicted with FAS/ARND.
- The authors of this article also discuss some of the problems with the initial assessment of FAS/ARND and the failure of the existing correctional system to provide appropriate programming options for offenders with FAS/ARND, which has given rise to various challenges based on Charter and potential human rights violations.


- This article describes the official guidelines for diagnosing FASD that were adopted in Canada in 2005. Canada’s guidelines for FASD diagnosis harmonize most of the differences between the U.S. Institute of Medicine and the University of Washington's diagnostic systems, which are both commonly used in the United States.
- The abstract of this article reads as follows:

The diagnosis of Fetal Alcohol Spectrum Disorder (FASD) is complex and guidelines are warranted. A subcommittee of the Public Health Agency of Canada's National Advisory Committee on Fetal Alcohol Spectrum Disorder reviewed, analysed and integrated current approaches to diagnosis to reach agreement on a standard in Canada. The purpose of this paper is to review and clarify the use of current
diagnostic systems and make recommendations on their application for diagnosis of FASD-related disabilities in people of all ages. The guidelines are based on widespread consultation of expert practitioners and partners in the field. The guidelines have been organized into 7 categories: screening and referral; the physical examination and differential diagnosis; the neurobehavioural assessment; and treatment and follow-up; maternal alcohol history in pregnancy; diagnostic criteria for fetal alcohol syndrome (FAS), partial FAS and alcohol-related neurodevelopmental disorder; and harmonization of Institute of Medicine and 4-Digit Diagnostic Code approaches. The diagnosis requires a comprehensive history and physical and neurobehavioural assessments; a multidisciplinary approach is necessary. These are the first Canadian guidelines for the diagnosis of FAS and its related disabilities, developed by broad-based consultation among experts in diagnosis.


- This book was written to provide information about Fetal Alcohol Syndrome and Fetal Alcohol Effects for legal professionals in Canada. The authors wrote the guide with judges and lawyers in mind, but they argue that other legal professionals such as police officers, probation officers, and correctional workers can also benefit from increased knowledge of this subject. The main focus of this guide is on criminal justice issues such as sentencing considerations, incarceration, and alternative measures for handling offenders with FASD.


- This report summarizes The Path to Justice: Access to Justice for Individuals with Fetal Alcohol Spectrum Disorder (FASD) Conference that was held September 17-19, 2008 in Whitehorse, Yukon. The organizers of the conference believe that improving awareness of the issue is the most important step in addressing access to justice for individuals with FASD. Thus the main goal of the conference was to raise awareness at a national level on the impact that this disorder has on the lives of the people who live with FASD, as well as those who provide justice related services and the system as a whole.
The Broken Cord is an autobiographical account of Michael Dorris’ struggles with parenting a child with FAS, and can provide readers with a moving first-hand account of the devastating effects of this condition on children and their families.

This article briefly describes in a brief manner some of the major issues relating to individuals with FASD and the legal system.

One of the main problems that individuals with FASD face is that their condition is often unrecognized and undiagnosed when they enter the legal system. Wider education and understanding among legal professionals is the essential first step in accommodating the unique and challenging needs of individuals with FASD who come in contact with the criminal justice system. Enhanced recognition of this disability may also reduce the over-representation of this group in the criminal justice system in the long run.

This article focuses heavily on the principles of sentencing, which are based on cognitive functioning and reasoning abilities that may not be present in a person with FASD. The article argues that a progressive legal system must recognize that the most effective sentence for people with FASD may be one that aims to change their living or social situation, rather than their behaviour.

One of the other major legal issues relating to people with FASD is that they often require particularly intense levels of support when on conditional release in order to successfully complete the community-based portion of a sentence because of their difficulty with understanding rules and abstract concepts.

This article also draws attention to the special consideration that in-custody prisoners with FASD require. Without it, these individuals face major obstacles such as being misunderstood by correctional staff, to becoming disproportionately victimized by other prisoners who can exploit their cognitive limitations.

Located in downtown core of Maple Ridge, BC, Canada, the Asante Centre is a North American leader in diagnosing and treating FASD. The Asante Centre is governed by the Fetal Alcohol Spectrum Disorder (FASD) Society for British Columbia. The centre offers diagnostic, assessment and family support services,
based on a multidisciplinary team approach, for children, youth and adults affected by FASD.

- The core services offered by the Asante Centre include:
  1. Diagnostic and Assessment Services
  2. Outreach services
  3. Coordinated Care Plans
  4. Support Services Before, During and After Diagnosis
  5. Family Centered Intervention Groups
  6. Speech and Language Intervention Services
  7. Educational activities
  8. Consultation services, and;
  9. Research

- The Asante Centre web site also features an FASD glossary.


- In 2005, the First Nations Child and Family Caring Society of Canada and the Pauktuutit Inuit Women of Canada worked together to conduct a study to better understand FASD services and non-academic FASD training in First Nations and Inuit communities across Canada. Their study also set out to ascertain the extent of FASD training opportunities available to First Nations and Inuit service providers and community members.

- The findings of this report describe how both the First Nations and Inuit respondents to the study universally called for a greater breath and depth of ongoing training in the areas of prevention, intervention skills/supports, diagnostics and assessments for individuals with FASD.

- This report also offers a number of policy recommendations to help prevent FASD in Aboriginal communities across Canada.


- This article was prepared by the Research and Statistics Division of the Department of Justice in order to provide a review of the issues related to FASD and criminal justice issues, with specific emphasis on victims of crime.

- This article describes how the impact of FASD on the Canadian justice system has received considerable attention in recent years. Unfortunately though, there is still limited empirical evidence available on the prevalence or outcomes for those with FASD.
This article cites a growing body of evidence that suggests that individuals with FASD are at a high risk of coming into repeated contact with the criminal justice system both as victims and offenders.

This article laments the fact that there is no consistent standard treatment of victims, witnesses, or offenders with FASD in the Canadian justice system.

This article also features a reference section that lists examples of how the cognitive and behavioural characteristics of FASD apply to victims and/or witnesses in the following areas:

1. Intellect
2. Academic performance
3. Attention
4. Memory
5. Executive function
6. Adaptive behaviour
7. Language
8. Social communication
9. Neurological hard and soft signs


This is a Department of Justice publication that examines the subject of FASD and the criminal justice system, but from the point of view of victims of crime who have FASD. Information for this report was gathered by conducting interviews with victim services workers in jurisdictions across Canada who have experience working with clients who have FASD.

Some of the findings based on these interviews include:

1. Observations that individuals with FASD are often at higher risk of becoming victims of crime. In addition, like people with other types of disabilities, victims of crime who have FASD are at increased risk of being repeatedly victimized compared to the general population. The interviewees explain that victims of crime who have FASD are in particular danger of being denied justice when they come in contact with the justice system because their condition is often unrecognized by themselves and the courts.

2. Victim services workers often point out that individuals with FASD require the same amount of care and guidance when navigating the legal system as do those with other cognitive disabilities.

3. The interviewees also argued that providing a basic level of FASD education (pamphlets, DVDs, etc.) to families of individuals with FASD and professionals who work with them would be relatively inexpensive.

- This article critically reviews and evaluates 5 current FASD assessment tools in Canada. The following five methods were reviewed: screening fatty acid ethyl esters in neonatal meconium, the modified Child Behaviour Checklist, the Medicine Wheel, Asante Centre Probation Officer Tool, and maternal history of drinking and drug use. The different screening tools were measured on factors such as ease of use, accessibility, cost, required expertise, opportunities and barriers to implementation, and cultural appropriateness.


- In response to the growing recognition of FASD and calls for action, the Government of Alberta established the Fetal Alcohol Spectrum Disorder Cross-Ministry Committee (FASDCMC) to provide a coordinated approach for a unique Alberta-specific framework for addressing FASD. The result of their work is the FASD 10-Year Strategic Plan.
- Alberta’s strategic plan includes a vision, mission statement, guiding principles and a broad framework for the coordination, planning and delivery of FASD services across Alberta in the areas of:
  1. Awareness and prevention
  2. Assessment and diagnosis
  3. Supports for individuals and caregivers
  4. Research and evaluation
  5. Strategic planning
  6. Training and education, and
  7. Stakeholder engagement
- Like its BC counterpart, the Alberta strategic plan also aims to identify the needs of Aboriginal communities and develop strategies that are culturally relevant for these individuals, families, and communities.


- British Columbia was one of the earliest jurisdictions in Canada and North America to take official action on FASD. Their provincial action plan was the first of its kind. British Columbia’s strategic plan on FASD was written to provide policy makers, service providers, community groups, and researchers a map of the complex and multifaceted work involved in the prevention and intervention and support for FASD.
• B.C.’s strategic plan on FASD also addresses some of the unique FASD-related needs of the Aboriginal communities in that province.
• British Columbia’s strategic plan lists its core components and goals as follows:
  1. Community development, health promotion and public awareness strategies to raise awareness of FASD as a life-long disability and the risks associated with alcohol and substance use during pregnancy;
  2. Early identification and intervention/support for all pregnant women who use alcohol and their partners/support systems;
  3. Focused intervention with high risk pregnant and parenting women and their partners/support systems;
  4. Timely diagnosis, assessment and planning for children, youth and adults affected by FASD;
  5. Comprehensive and lifelong intervention and support for children, youth and adults affected by FASD and their families/support systems;
  6. Leadership and co-ordination of FASD initiatives at the community, regional, provincial and national levels.


• British Columbia’s 2008-2018 strategic plans on FASD builds on and renews the goals of the 2003 plan. The first portion of this report reviews the progress on the goals set out in the 2003 report, and the second half sets out the goals for the next ten years. Most of the goals reflect a continuation of the aims of the earlier plan. Some of these goals include:
  1. Increasing access to support and information on having healthy pregnancies for women of childbearing age;
  2. Reducing the incidence of infants born with FASD;
  3. Ensuring that individuals and families dealing with FASD have the support they need to thrive.


• In 2007, the Government of Manitoba set out to create a coordinated Fetal Alcohol Spectrum Disorder Strategy through an interdepartmental committee in consultation with experts and community stakeholders. The strategy builds upon existing multi-departmental, multi-million dollar prevention activities and service supports available for individuals with FASD. The final draft of Manitoba’s ambitious FASD strategy set out to:
  1. To create a mobile support team that helps people living with FASD to navigate issues around housing, finances, work, health care, mental health and addictions;
2. Appoint FASD specialists at each of Manitoba’s four child and family services authorities to support agencies to provide services to families impacted by FASD;
3. Increase support to develop diagnostic services for adolescents and in rural and northern regions;
4. Create a new FASD Research Scientist Award to stimulate and facilitate more research in the area of FASD;
5. Create new investments to co-ordinate and improve services for women with addictions;
6. Increase funds to enhance public education initiatives;
7. Create a training strategy to improve existing service delivery systems for individuals with FASD;
8. Invest in more training supports for school divisions to implement best practice approaches to educating students with FASD.


- The government of Saskatchewan commissioned an inter-departmental group to create Saskatchewan’s Action Plan for Citizens with Cognitive Disabilities in 2003. This framework outlines the strategy for supporting individuals in Saskatchewan with cognitive disabilities who have significant behavioural and developmental challenges, including those with FASD. The action plan was formed by information gathered from a number of sources, including Saskatchewan’s Fetal Alcohol Spectrum Disorder Community Discussions in 2003. Some of the goals of Saskatchewan’s action plan include:
  1. Strengthening direct supports for individuals with cognitive disabilities based on need;
  2. Improving access to assessments; and
  3. Investing in more prevention and intervention of FASD specifically.


- This manual is meant as a resource for educational workers working with children and youth with FASD. The manual breaks down its instruction into 12 chapters, or “elements,” such as observing and understanding the behaviour of students with FASD, understanding their limits and abilities, how to create the kind of structured lesson plans that suit the learning style of students with FASD, creating suitable learning environments, using concrete language, and more.

• Prevention of Fetal Alcohol Damage in Northern Native Communities: FASD in Lab Mice- A Practical School-Based Approach was presented at the 3rd International Conference on Fetal Alcohol Spectrum Disorder, which was held in Victoria B.C. on March 11-14, 2009. This presentation was put together by Steven Jacquier, David Gilliam, and Judith Kleinfeld. In this presentation, Jacquier et al. describe an innovative educational program that has been used to inform children and youth in northern Aboriginal communities about the dangers of FASD and alcohol consumption. This lesson was imparted on students by having them take a science class where they gained an in-depth education on biology and the effects of pre-natal exposure to alcohol. The most striking portion of their lesson plan is the inclusion of real mice in long term experimentation. The mice provide the students with direct, first hand visual evidence of the devastating effects of fetal alcohol exposure. The authors report that these classes seem to have had a profound effect on the at–risk youth who participated because of the tangible nature of their lessons, and that participants also benefited from a rigorous science program at the same time.


• ‘Fetal Alcohol Syndrome’ was first named in 1973 by two dysmorphologists, Drs. Kenneth Lyons Jones and David Weyhe Smith of the University of Washington Medical School in Seattle, Washington. This article has historical value for being the first English language publication to apply the term ‘Fetal Alcohol Syndrome’ to this condition that at the time was only beginning to be systematically understood by medical researchers. Jones and Smith applied the name after observing a constellation of features in children born to mothers who drank alcohol in pregnancy. The features that Jones and Smith described here remain the core physical traits that are identifiable aspects of FAS to this day.


• FASD and the Justice System is a Canadian web-based resource for information on FASD. This website focuses primarily on justice and legal issues as they relate to FASD, and includes a section for justice system personnel that give advice for addressing FASD throughout the criminal justice process. As well, there is an information/contact reference list and a glossary.
• This website also has a section on Aboriginal specific issues dealing with subjects such as the incidence and prevalence of FASD among Aboriginal people, Aboriginal cultural needs, information on biology and culture that disputes myths and stereotypes, and a legal section for workers dealing with Aboriginal issues in the legal system.

• This website has a section that reviews Canadian case law dealing with FASD related issues.


• This article has historical value for recording the first official recognition of a variety of birth defects and developmental disabilities in offspring born to alcoholic parents. These findings were uncovered by Dr. Paul Lemoine and his colleagues in Nantes, France.


• FASD Connections is a Canadian-based website that was created to offer help and information to adolescents and adults with FASD as well as the families and frontline caregivers who work with them. This website has links to various papers and reports divided under various subject categories (i.e. justice and legal issues, homelessness, prevalence, etc.); included is a section that is devoted to Aboriginal peoples and FASD related issues.


• Primary care offices can be the main venues for FASD interventions. This article argues that there is a cultural gap between urban-based primary care physicians and Aboriginal women that limits the potential of this area of intervention among this vulnerable population. Bridging this gap could help to improve physician-patient relationships and facilitate effective FASD interventions, and so the authors argue for the development culturally appropriate environments and care givers who are culturally aware to ease this process.
• Rae Mitten’s contribution to the *The First Nations and Métis Justice Reform Commission* was a chapter on FASD in Canada’s criminal justice system. The thrust of her analysis is that for offenders with FASD, holistic, community-based treatment is preferable as a sentencing option to incarceration because of their unique needs and inability to adjust to, or learn from a prison experience. Mitten backs this point up by conducting an economic and social cost-benefit analysis in her chapter to demonstrate that society and state are better served when offenders with FASD are properly diagnosed and treated rather than receiving traditional prison sentences.

• Mitten primarily writes about Aboriginal offenders with FASD in this chapter. But the author also points out that fetal alcohol issues are not solely or largely an Aboriginal phenomenon. FASD is a problem that affects people across the globe. Mitten argues that these kinds of social problems are especially endemic in areas where populations have been subjected to the damaging effects of colonization or globalization, and resultant poverty. Mitten examines the historical context of the Aboriginal peoples in Canada in order to trace the roots the social problems like FASD that affects many of their communities and dispel myths and stereotypes.


• When faced with the challenges that Fetal Alcohol Spectrum Disorder present, how can individuals living with FASD, their parents, families, teachers, other professionals, communities, courts and governments best respond? The author of this article sees this challenge as a wake-up call and turning point for her community. Mitten uses this article to call for holistic and community driven efforts to overcome ignorance and stigma in order to initiate widespread efforts at combating the prevalence of FASD among Aboriginal peoples in Canada.

• This article examines the challenges that FASD presents to the criminal justice system as well as the particular difficulties that are faced by individuals with FASD when they enter the system.

• One of the main problems facing offenders with FASD is that they challenge the requirement that defendants understand the relationship between their actions, outcomes, intentions, and punishment. The varying levels of cognitive impairment that affects individuals with FASD should require that our legal system pay special attention to the individual responsibility of offenders with FASD, both at the guilt determining and sentencing stages of the adjudicative process.

• Some of the specific particular legal challenges raised by FASD include issues related to investigative procedures, witness advocacy, fitness to stand trial, diminished responsibility, pre-trial diversion, effective representation, the role of expert evidence, persistent recidivism, special supervision needs during probation and parole, testimonial capacity and reliability, false confessions and sentencing. The main body of this article focuses on an introduction to the last three issues, with a particular emphasis on young persons with FASD – both defendants and complainants.


• This report was written to explore how Aboriginal cultures and practices can help with the development and daily lives of Aboriginal people with FASD. All of the articles in this report were compiled with this theme in mind and were written from the point of view of Aboriginal parents, teachers, and community workers who have experience with FASD, as well as stories recounted by people who have FASD themselves.

• This publication also features an article that highlights the success of an Aboriginal community justice program that helped FASD-affected offenders.


• This tool kit was created to be a user-friendly resource for frontline workers who work with children, youth, adults, and families affected by FASD. This tool kit is unique in that it employs a medicine wheel model based on traditional Aboriginal practices to help frontline workers explore problems and find solutions. The wheel is divided into four sections that guide users to begin in the eastern portion of the wheel and move clockwise through the other three steps in order to address FASD issues holistically. The sections are entitled East (Vision), South (Relationship), West (Reason), and North (Movement).

- This manual was created to be a user-friendly resource for Aboriginal communities who need introductory information to start clinics for people with FASD. This guide offers information on assessing community needs, personnel requirements, space and equipment, diagnostic processes, and care provision methods that are needed to run an affective FASD clinic.


- This FASD fact sheet from a governmental source is meant to help readers quickly catch up on some of the basics of this subject. Some of the questions covered in this FAQ include:

1. What is Fetal Alcohol Spectrum Disorder?
2. How do you get FASD?
3. Can FASD be cured?
4. What's different about the way people with FASD may behave?
5. How much drinking by the biological mother can cause FASD?
6. How do you know if you have FASD?
7. How many people have FASD?
8. Can biological fathers cause FASD?
9. Does drinking during breastfeeding cause FASD?
10. Prevention of FASD
11. Where can I go for help?


- The Public Health Agency of Canada released this framework for action in 2003 to provide the public and governments with a structure and basic building blocks for comprehensive and consistent action on FASD prevention and support. The framework was designed to be adapted to the unique characteristics and opportunities of different communities, allowing each "owner" to tailor the ideas to suit local needs.
- The five broad goals of the framework of action include:
  1. To increase public and professional awareness and understanding of FASD and the impact of alcohol use during pregnancy;
  2. To develop and increase capacity;
3. To create effective national screening, diagnostic and data reporting tools and approaches for FASD;
4. To expand the knowledge base on FASD and facilitate information exchange; and,
5. To increase commitment and support for action on FASD.

- For each of the 5 goals outlined above, the Framework for Action also lists various strategies that can be adopted to accomplish these aims.
- The Framework for Action also offers specific information and advice to the various levels of government on how to pursue the 5 goals and implement the strategies.


- The Public Health Agency of Canada provides this website which offers an introduction to the subject of FASD along with numerous links to other resources and information. The homepage describes the FASD spectrum and breaks down its four possible diagnoses, including Fetal Alcohol Syndrome (FAS), Partial FAS (pFAS), Alcohol-related Neuro-developmental Disorder (ARND), and alcohol-related Birth Defects (ARBD). The homepage also describes the causes of FASD as well as some its characteristics, which fall under the two categories of primary and secondary disabilities.
- This website also contains a resource page that lists numerous links to FASD-related subjects and items such as fact sheets, general information, health and allied professionals information, policy and national reports, public awareness, training, and an archive or older items.


- This paper sets out to provide an overview of the issues that arise when someone with FASD encounters the justice system in Canada. The report examines Canadian jurisprudence dealing with FASD from the investigation of crime through to the sentencing process. The authors of this article conduct a survey of reported case law to determine how frequently judges have made reference to FASD and to chart the general trend in their decisions. In addition to this, the authors also examine how individuals with FASD fit into the trial process as witnesses.

- This report presents a comprehensive literature review on the best practices for the prevention, identification, and intervention of FAS/FAE. The review was conducted by the Canadian Centre on Substance Abuse on behalf of Health Canada. In addition to alcohol, this report also addresses the effects that other substances such as cannabis, opiates, and inhalants have on fetal development during pregnancy.


- This is a guide for physicians, psychologists, social workers, educators, advocates, and families of individuals of adults and children with FAS that touches on numerous facets of this condition including diagnosis, services for high-risk mothers, teratology and brain damage, employment and advocacy, physical and behavioural manifestations, education and public policy.
- This volume draws upon the career and life’s work of FAS and FASD researcher Ann Streissguth. Streissguth is the author of dozens of scientific papers on the same subject that are valuable FASD resources as well.


- This volume is a collection of twenty-two essays dealing with the prevention and treatment of secondary disabilities for people with FASD. The papers were written by experts working in the fields of human services, education, and criminal justice. Some of the essays in collections include “Primary and Secondary Disabilities in Fetal Alcohol Syndrome,” “Representing the FAS Client in a Criminal Case,” and “Legal Issues and FAS.”


- This report was prepared by Métis scholar Caroline L. Tait on behalf of the Aboriginal Healing Foundation in 2003. The Aboriginal Healing Foundation is a government sponsored organization that is devoted to facilitating the healing process for individual Aboriginal people and communities that were damaged by Canada’s residential school system.
This is a lengthy report that discusses FASD in the context of its effects on the various Aboriginal communities residing in Canada. The report draws a link between the negative effects of the colonial experience on Canada’s Aboriginal populations and the incidences of alcohol abuse and FASD in various communities.

Being an AHF publication, the main focus of the report is on the residential school system. The author concludes that the residential school system was a major contributor to high rates of alcohol abuse among many Aboriginal people who previously attended these institutions. The trauma of the residential school experience further contributed to alcohol abuse among subsequent generations of Aboriginal people, including women of child-bearing ages.

Following the investigation into the linkages between residential schools and FASD, the second portion of the report examines and evaluates the current research on best practices for the prevention and treatment of FASD in the context of their value and relevance for the Aboriginal peoples of Canada.


This web page summarizes and collects the material that was presented at the 3rd International Conference on Fetal Alcohol Spectrum Disorder, which was held in Victoria B.C. on March 11-14, 2009. The materials collected here offer the most current international and Canadian research on FASD.

On this web site readers will find web cast videos, PowerPoint presentations, and research papers on FASD from a number of angles.

One of the presentations that stood out at the conference was entitled “Prevention of Fetal Alcohol Damage in Northern Native Communities: FASD in Lab Mice- A Practical School-Based Approach.” The presentation was put together by Steven Jacquier, David Gilliam, and Judith Kleinfeld. In this presentation, Jacquier et al. describe an innovative educational program that has been used to inform children and youth in Northern Aboriginal communities about the dangers of FASD and alcohol consumption. This lesson was imparted on students by having them take a science class where they gain an in depth education on biology and the effects of pre-natal exposure to alcohol. The most striking portion of their lesson plan is the inclusion of real mice in long term experimentation. The mice provide the students with direct, first hand visual evidence of the devastating effects of fetal alcohol exposure. The authors report that these classes seem to have a profound effect on the at–risk youth who participated because of the tangible nature of their learning plan, and that participants also benefited from a rigorous science program at the same time.

This presentation can be found at:
http://www.interprofessional.ubc.ca/Brochures/March%202013_Jacquier_Prevention%20of%20FASD%20in%20Northern%20Native%20Communities.pdf

- This brochure provides a brief overview of FASD and Aboriginal peoples in the U.S. Some of the main aspects of the problem that are discussed in this pamphlet include the scope of FASD among Native American populations, why FASD is a problem in some Native American communities, and what is being done to address these problems. This page also features a short list of resources.


- This is a U.S. based website. Medline Plus’ FAS page has links to research, FAQs, directories, statistics, multimedia, and reference material. This page also covers many aspects of FAS such as diagnosis/symptoms, prevention/screening, coping, and children.


- This manual was written to be a culturally relevant resource for community-based prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects among Aboriginal communities in Canada.


- This discussion gives an overview of the Canadian legal system’s understanding of FASD and young offenders as of 2003.
- This paper examines a number of legal issues in regards to young offenders with FASD such as:
  1. The accused person’s fitness to stand trial.
  2. The question of criminal intent.
  3. The appropriate proportionality of legal responses to offenders with FASD.
  4. Sentencing young offenders with FASD.
  5. The role that social services should play when a young offender with FASD enters the criminal justice system.
This discussion paper’s abstract reads as follows:

Legal issues related to Fetal Alcohol Spectrum Disorder (FASD) have been explored recently by a number of authors. This discussion paper canvases issues specifically related to FASD and the youth criminal justice system. Where available, court decisions that have addressed these issues are reviewed. Issues are explored under six subject headings: (I) the FASD construct; (II) fitness to stand trial; (III) criminal intent; (IV) proportionality of youth court outcomes; (V) sentencing; and (VI) bridging with social services.


This article provides insight into the current state of awareness and concern over FASD among legal professionals in New Brunswick.

The abstract for this article reads as follows:

Results of a provincial survey of Judges and Crown Prosecutors to determine specifically, their attitudes, knowledge, behaviours and training needs related to Fetal Alcohol Spectrum Disorders. In general, the survey results suggest that while aware of some aspects of FASD, Judges and Prosecutors both desire and need more education and training to support them in their work with individuals with FASD who come into conflict with the law. The findings also suggest that access to accurate and timely assessment and diagnoses of FASD would be beneficial. Survey findings point to the need for specific action to improve the ability of Judges and Prosecutors to recognize and to work with people affected by FASD in the Criminal Justice System. The results further indicate the need for changes and improvements in several areas regarding legal policy issues, research, and professional education and practice.

This is a guide for legal workers on the frontline and in the courts who encounter individuals with FASD. The guide is divided into 7 chapters and numerous sections that address topics such as recognizing the signs of FASD in individuals and clients, how to refer people for assessment, the cognitive limitations brought on by FASD, and how these disabilities can affect confessions and testimony in court.


- The Medicine Wheel Difference Game Cards are an introductory and accessible tool that can be used as a way to introduce people to the FASD Medicine Wheel System.
- For information on how to access and use these cards, see www.hcip-bc.org


- The FASD Medicine Wheel diagnostic tools were originally developed to identify and meet the unique educational needs of First Nations students on the Elsipogtog First Nation in New Brunswick in a manner that was reflective of their cultural roots. This article describes the evolution and successful implementation of the early Medicine Wheel System on the Elsipogtog First Nation in New Brunswick.

The FASD Medicine Wheel Diagnostic Approach

- The FASD Medicine Wheel diagnostic approach is a holistic screening method that is based on the framework of traditional Aboriginal teachings. The Medicine Wheel approach consists of two tools: the Medicine Wheel Student Index and the Medicine Wheel Developmental History survey. This technique was developed to help assess and assist children and youth and is used for screening, referral, goal setting, and problem-solving.
- The author of Medicine Wheel Systems also designed and directed the Nogemag Initiative. This is a model of intervention based in traditional Aboriginal methodology for high-risk youth and their families, especially those impacted with FASD. The Nogemag website provides links to the Medicine Wheel diagnostic tools: http://www.nogemag.ca/resources.htm
- In 2008, the author submitted a presentation at the Canadian Association of Paediatric Health Centres annual meeting entitled “Medicine Wheel Tool Kit for Screening of FASD”. The following video chronicles the development of the Medicine Wheel, and can be found at http://video.google.ca/videoplay?docid=-5503098931558255100#
The Westcoast Genesis Society runs Genesis House, a 24-bed Community Residential Facility (CRF) and Programs Centre in New Westminster, British Columbia. Genesis House provides secure transitional housing for adult male offenders (federal and provincial) on various forms of conditional release under contract to the Correctional Service of Canada (CSC). What makes Genesis House unique is that it was developed to deliver the first specialized residential program in Canada for offenders on conditional release who have Fetal Alcohol Spectrum Disorder (FASD).

The program uses an intervention model that accommodates the disabilities of their clients. Staff at Genesis House receives extensive training in FASD awareness and effective FASD intervention strategies. In addition, staff assists clients with substance abuse awareness, first aid, non-violent crisis intervention, conflict resolution, risk assessment/risk management, and other skills that can help to prepare inmates for a successful release.