

Alberta FASD Cross-Ministry Committee

FASD Adult Assessment and Diagnosis Discussion Paper



May 13, 2009

Acknowledgement

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Thank you.



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Summary

On November 18 and 19, 2008 approximately 70 key stakeholders with experience and expertise in assessment and diagnosis from across North America gathered in Edmonton to discuss the basic elements of a comprehensive and coordinated system for conducting assessments and developing diagnostic criteria of FASD among adult populations in Alberta. The first day of the forum included a presentation of the current evidence on leading practices in assessment and diagnosis of FASD among adult populations; strengths and limitations of current approaches utilized by leaders in Alberta's FASD service delivery system; and a facilitated discussion regarding potential improvements and priorities.

The discussions and presentations on November 18th formed the basis of this discussion paper. Participants were provided an opportunity to review the discussion paper and provide feedback, which has been incorporated into this final version. This document will serve to influence more detailed planning and actions for conducting FASD assessments and diagnoses among adult populations in Alberta and will hopefully be beneficial for jurisdictions elsewhere.

Table of Contents

1. Introduction 1

2. Adult Assessment and Diagnosis in Alberta 3

3. Challenges in Expanding Adult Assessment Services 5

4. An Emerging Model of Adult Assessment and Diagnosis in Alberta 7

5. Next Steps 11

Annex 1 – Participants List - November 18th & 19th Leading Practice Workshop 12

1. Introduction

Fetal Alcohol Spectrum Disorder (FASD) describes a cluster of birth defects caused by prenatal exposure to alcohol. Difficulties due to birth defects include health, speech and language problems, learning difficulties, and behavioural problems. Since 1996, various provincial government departments and agencies have been actively involved in the prevention of alcohol related birth defects and support of individuals affected by prenatal exposure to alcohol.

In 2003, the Alberta Fetal Alcohol Spectrum Disorder Cross-Ministry Committee (FASD-CMC) was formed with the mandate to act as the primary vehicle to support a collaborative approach to plan and deliver provincial government programs and services associated with FASD. The FASD-CMC developed a 10- Year FASD Strategic Plan (Plan) which was signed by the 10 partnering Ministers, and approved by the Standing Policy Committee on Health and Community Living in September 2006.

The Plan was designed as a “direction setting” document to provide a broad framework for the coordination, planning and delivery of relevant FASD services throughout the province. The Plan provides direction for service in the areas of:

- **Awareness and Prevention:** Defined as services that educate and inform about the risks of drinking alcohol while pregnant, the effects of FASD, and increase overall awareness about healthy pregnancy. Awareness and prevention services are for both the general and at-risk populations.
- **Assessment and Diagnosis:** Diagnostic services include medical, cognitive and behavioural assessments by a multidisciplinary team that involves: physicians; psychologists or neuropsychologists; and other developmental and/or behavioural specialists as required by the age or presentation of the client. Assessment services include appropriate screening and functional assessments to guide planning. Diagnosis and assessment services may or may not lead to a confirmed diagnosis under the spectrum of FASD, which includes full Fetal Alcohol Syndrome (FAS), partial FAS and Alcohol-Related Neurodevelopmental Disorder (ARND).
- **Supports for Individuals and Caregivers:** Supports include programs and services that enhance protective factors and enable individuals and families affected by FASD to reach their potential in the community. Supports promote the development and well-being of individuals and caregivers;

Vision

That Alberta has a comprehensive and coordinated provincial response to Fetal Alcohol Spectrum Disorder across the lifespan and continuum of services that is respectful of individual, family and community diversity

promote healthy communities; and improve safety for impacted individuals, caregivers and communities.

In addition to the three service areas, the Plan identifies action in the areas of:

- **Research and Evaluation:** Refers to basic scientific and applied research leading to increased understanding of FASD, its epidemiology, best practices and the development of standards in service areas identified above.
- **Training and Education:** Efforts in this area will support the development of technology and programs to support formal education, pre-service and in-service training programs.
- **Strategic Planning:** Refers to the range of activities performed by government that are aimed at recommending priority areas for government policy and action.
- **Stakeholder Engagement:** Refers to a wide range of activities that support information sharing among government, practitioners and the FASD client population to facilitate informed and balanced decisions regarding government priorities and actions.

In February 2007, Alberta Children and Youth Services, as the administrative lead for the Plan, received \$4 million on behalf of partnering Ministries to begin implementation of the Plan. In March 2007, partnering Deputy Ministers approved using the \$4 million to support an FASD Network model of service delivery through the establishment of seven FASD Service Networks (networks) across the province. These networks, each of which is comprised of numerous agencies and organizations, have been tasked with developing or expanding services to fill existing gaps across the lifespan and align with the strategic directions set out in the Plan. The FASD Service Network Program (Network Program) has been in operation since May 2007 under the leadership of the FASD-CMC and facilitated by the Provincial FASD Service Network Program Coordinator.

The province of Alberta established a goal of having the capacity to conduct 900 multi-disciplinary assessments annually for individuals suspected of prenatal alcohol exposure by 2016. The goal includes multi-disciplinary assessments for adults, youth and children; and is considered a fundamental component of a cross-ministerial approach to meeting the needs of individuals with FASD across the life span.

On November 18 and 19, 2008 approximately 70 key stakeholders with experience and expertise in assessment and diagnosis from across North America gathered in Edmonton to discuss the basic elements of a comprehensive and coordinated system for conducting assessments and developing diagnostic criteria of FASD among adult populations in Alberta. The first day of the forum included a presentation of the current evidence on leading practices in assessment and diagnosis of FASD among

adult populations; strengths and limitations of current approaches utilized by leaders in Alberta's FASD service delivery system; and a facilitated discussion regarding potential improvements and priorities.

The purpose of this discussion paper is to summarize the current situation for adult assessment and diagnosis in Alberta, identify key elements of existing programs that should be built upon in the future; and recommend next steps to build a comprehensive and coordinated system for adult assessment and diagnosis. The information outlined in the document will be used to focus future discussions and actions to improve the system.

2. Adult Assessment and Diagnosis in Alberta

Currently, the FASD-CMC is aware of 10 clinics located throughout the province providing assessment and diagnostic services, four of which provide services to adults. Among nine of the 10 clinics, it was estimated that 352 assessments are completed annually, with the majority of them completed in Edmonton and Calgary and approximately 50 focused on adults.¹ All of the programs in attendance at the workshop reported they use the *Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis* (Canadian Guidelines) and have multi-disciplinary teams which work to obtain clinical intake information, conduct a physical examination, and conduct the evaluation to obtain the data necessary to complete the 4-digit diagnostic code. Among the four programs completing assessments on adults, two have a psychiatrist on their team and one has a mental health worker.

Three of the four clinics providing services to adults spoke about their clinics; two of which have been providing services to adults for a number of years. Although all of the clinics follow a similar assessment process (i.e. intake, internal team planning, testing, integration of data leading to diagnosis and original support plan, discussion with individuals and adjustment of support plan, and implementation), literature suggests that a diagnostic framework for adults is not currently available, and that most clinical services provided to adults have been adapted from the best practices in completing assessments with children.² In light of these challenges, the clinics discussed a number of key features of assessment and diagnosis services for adults that are fundamental and required in all clinics working with adult populations.

- **Approach individuals from a strength-based model** that delivers a message of hope and support and aims to reduce the stigma of FASD for the individual and their family.
- **Offer a multi-disciplinary diagnostic team approach:** A multi-disciplinary diagnostic team approach is recommended in the Canadian Guidelines, due to the complexity and the range of

¹ Personal communication with Sterling Clarren and Sandy Clarren, December 1, 2008.

² Badry, D. (November 18, 2008). Testimony given at FASD Assessment and Diagnosis Leading Practices Workshop, Edmonton, Alberta.

expression of dysfunction related to prenatal alcohol exposure, and the need for accurate and comprehensive diagnosis and treatment recommendations.³ Multi-disciplinary teams for adult assessments may benefit from including a psychiatrist, a mental health therapist, a career counselor or a representative from justice.

- **Inclusion of a mental health assessment in the FASD assessment process:** Mental health problems seem to be a very common component of the presenting circumstances for most adults. This may be a primary or secondary phenomena of the condition or may be unrelated to FASD per se, but are part of the common social experiences that people with FASD suffer (such as abuse or deprivations) in early childhood that lead to long term post-traumatic stress defining itself in a number of different ways. Mental health assessment clearly needs to be an integral component of the assessment for its own sake and because it is hard to understand the results of cognitive testing without taking mood disorders into account, (i.e. depressed and psychotic patients may not be able to provide valid test results.) A mental health evaluation will also help a more coherent transition to mental health supports after the evaluation process.
- **Allow flexibility in approach to accommodate individual needs:** This may be in terms of the process and/or professionals involved. Clinics recognize that each individual and their circumstances are unique and that the process may need to be adapted to reflect these differences and ensure positive outcomes for the individual and their family. For example, a clinic may need to adjust their data collection process to assist individuals who may have challenges recalling their personal history, have no fixed address or limited information regarding their family history.

In addition, the approach is often tailored to the capacity of the community. For example, in the Lakeland Clinic the diagnostic team includes a physician, psychiatrist, neuropsychologist, worker from Persons with Developmental Disabilities, mental health therapist, addictions worker, career counselor, legal representative (such as crown prosecutor, probation officer, or RCMP), cultural liaison, outreach support worker, and team coordinator. Although there is always a multi-disciplinary diagnostic team involved in the process, the specific mix of team members varies according to the individual circumstances. Clinics conducting adult assessments and diagnoses have worked very hard to develop community capacity and to establish informal networks of professionals that help meet the diverse needs of the individuals accessing services.

³ Chudley, A.E., Conry, J., Cook, J.L., Looock, C., Rosales, T., LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal*, 172 (5 supplement):S1. Online: http://www.cmaj.ca/cgi/reprint/172/5_suppl/S1

- **Aid in the translation of a diagnosis into a management plan:** An FASD diagnosis alone does not provide an individual with the information necessary to make positive changes in their life or to support optimal functioning. Often individuals accessing diagnosis and assessment services are in need of support for housing, employment, parenting, or lifestyle counselling. Assessment and diagnostic clinics assist individuals in translating their positive diagnosis into the development and implementation of a management plan that ultimately provides individuals with the skills they need to reach their potential.

3. Challenges in Expanding Adult Assessment Services

There are a number of key challenges that impact the ability to increase the capacity in Alberta to conduct adult assessments, including:

- Human resource requirements throughout the system
- Need for consistent policy and framework for adult assessments
- Development of a data management infrastructure

This section outlines these challenges in more detail.

Availability of skilled professionals: One of the most significant challenges in building capacity to increase the number of assessments completed for adults in Alberta is availability of skilled professionals with expertise in FASD and experience working with adult populations. While there are at least 10 clinics providing assessment and diagnosis services across the province, there are a number of geographic gaps leading to issues of accessibility for many individuals. This challenge is inflated for individuals with FASD, as changes in routine and travel outside of their communities are often difficult. These geographic gaps in service result from a lack of local resources and professional expertise required to complete an assessment.

The complex nature of an accurate diagnosis requires a multi-disciplinary team approach. Multidisciplinary team members are a resource in low supply outside of major centres in Alberta. If these professionals currently practice in rural or remote communities, they often do not have expertise in FASD and require additional training. In addition to physicians, adult assessments require the involvement of a number of professionals or paraprofessionals who typically would not be involved in an assessment for a child, such as a career counsellor, legal representative and a mental health therapist. As a result, clinics that focus on children often do not have the capacity or the resources required to expand their services to accommodate adults.

Lack of policy and frameworks for adult assessments: In the systematic review of the literature conducted by Badry and Bradshaw⁴, some of the challenges identified in assessing FASD in adults include:

- The changes in defining physical characteristics such as distinctive facial features, which is compounded by additional head traumas experienced from violence or accidents to which individuals with FASD may be more susceptible.
- Lack of specificity for many of the behaviours associated with FASD and their potential overlap with other common learning and behavioural disorders.
- The need for information related to prenatal alcohol exposure.

These challenges suggest that diagnostic criteria and practices used for children may not be appropriate for adults. There is significant need for evidence-based practices and models for assessments and diagnosis in adults. While clinics have been very innovative in adapting their policies and practices that were initially intended for children, the resulting lack of consistent protocols and infrastructure may contribute to misdiagnoses or provide a disincentive for clinics to work with adult populations. This may in turn lead to missed opportunities to connect individuals affected by FASD with the programs and services that will provide the support needed to promote optimal functioning and provide a better quality of life. These challenges must be balanced with the urgent need to better serve this population.

Consistent data collection and reporting: The prevalence of FASD is not well known; in fact only estimates of European and American prevalence rates are found in the literature.^{5 6} To effectively develop and deliver systems to support individuals affected by FASD common data management, standards and practices are essential. Consistent data collection will enable research on leading practices and the development of frameworks and standards, as well as improve program delivery. From a strategic planning perspective the development of consistent data collection and reporting will assist in determining areas of higher prevalence of FASD throughout the province and provide the information necessary to direct funds to develop community capacity in relevant communities regardless of their size.

⁴ Badry, D., and Bradshaw., C. (2008). Assessment and Diagnosis of FASD among adults: A national and international systematic review. Prepared for the Public Health Agency of Canada.

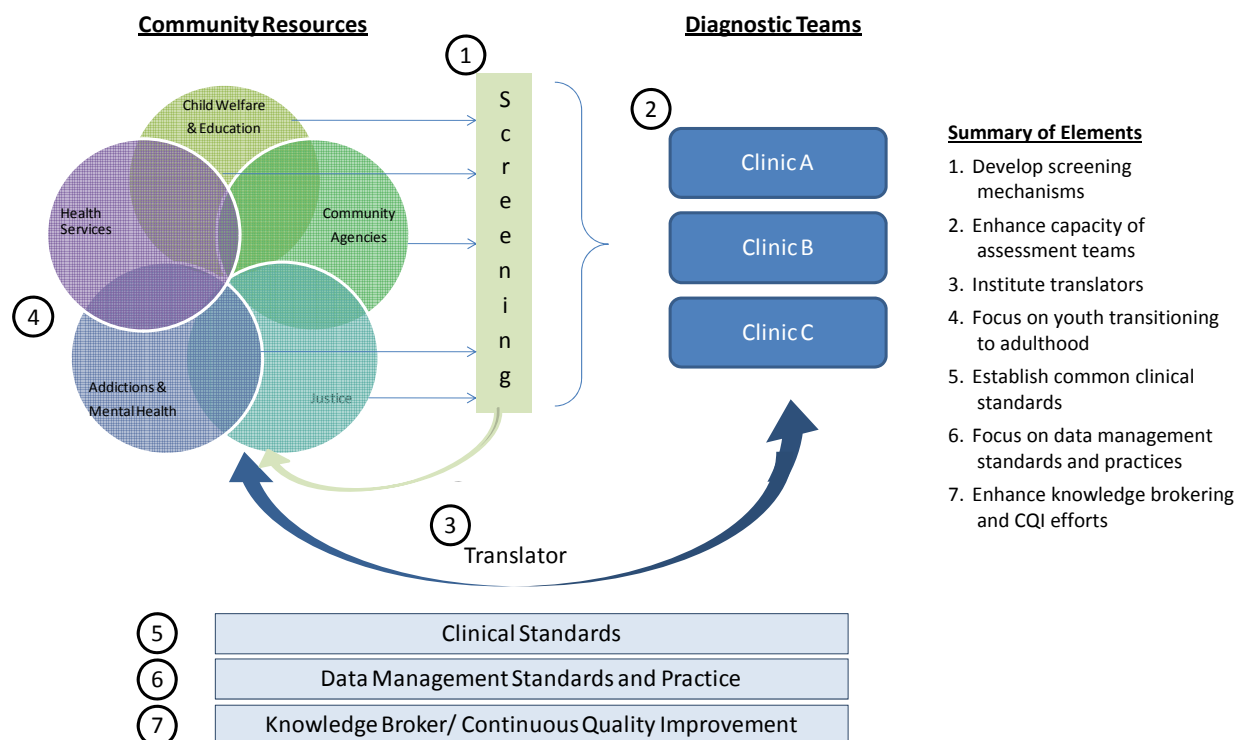
⁵ Badry, D., and Bradshaw., C. (2008). Assessment and Diagnosis of FASD among adults: A national and international systematic review. Prepared for the Public Health Agency of Canada.

⁶ Clarren, S.K., and Lutke., J. (2008). Building clinical capacity for fetal alcohol spectrum disorder diagnosis in western and northern Canada. *Canadian Journal of Clinical Pharmacology*, 15(2), pp 223-237.

4. An Emerging Model of Adult Assessment and Diagnosis in Alberta

Discussion among participants at the forum reinforced that FASD assessment and diagnosis among adult populations is complex, and that significant improvement opportunities exist at policy, practice and research levels. While no single model will likely be appropriate across the province, several fundamental elements of the system did emerge from the discussion. Figure 1 below summarizes important elements of a more coordinated system.

Figure 1: An Emerging Model for Adult FASD Assessment and Diagnosis in Alberta



The following recommendations are intended to build on the key features that exist in clinics currently providing services in Alberta, build on existing literature and leading practices, and address some of the challenges identified by key stakeholders who participated in the leading practices conference. Each recommendation is linked to one of the elements identified in Figure 1, and text boxes identify a specific action for the FASD-CMC to undertake to advance the recommendation.

- 1. Assist in the identification and or development of screening tools for adults:** Currently the demand for full assessments meets or exceeds the capacity of the system. The clinics currently providing assessment services have indicated that they are near full capacity. Developing one or more evidence-informed screening methods for adults will provide professionals from a variety of backgrounds (e.g. health, justice, employment, child welfare) with improved capability to determine if individuals should be referred to a full assessment. Most importantly, this would provide adults suspected of having FASD with an opportunity to connect with professionals who can assist them. The development of adult screening tools must be accompanied by efforts to build linkages with programs, systems and organizations that are typical points of entry for adults. Many professionals believe that the best screening tool is conducting a good history on the individual. This position also helps to limit the concern over screening tools inappropriately replacing a full multi-disciplinary assessment & diagnosis. Is there a need for both screening tools and individuals with the skill & knowledge to take a good history or does there need to be a choice? If a choice is needed, what criteria should be used to make this decision, and who should make this decision?

The FASD-CMC should partner with the Canada Northwest FASD Partnership, the Public Health Agency of Canada and Alberta stakeholders to identify one or more screening tools that can be used in Alberta. Screening tools should be accompanied with processes to facilitate referral from various professionals to diagnostic clinics.

- 2. Enhance assessment and diagnostic capacity across Alberta:** Ten of the clinics providing service in Alberta indicate they have the capacity to conduct approximately 350 assessments per year. While efficiencies may be found through improved clinical practices and optimized scope of practice for professionals on multi-disciplinary teams, there is a fundamental capacity issue that must be addressed if Alberta is to reach its goal of conducting 900 annual multi-disciplinary assessments. It is imperative that additional clinics be established and workers trained to participate in multi-disciplinary assessment team.

The FASD-CMC should invest in assessment capacity through pilot projects (e.g. Glenrose pilot) and by efforts to increase the size of and specialized training for FASD multi-disciplinary team members.

3. **Institute a translator function into Alberta's system of FASD**

supports and services: Through the discussion at the forum, two realities became very clear. First, it is unrealistic to believe that all major centres throughout the province will establish assessment clinics for adults. Second, a tangible connection between the assessment process and support resources in a person's community is critically important. A "translator" function is one option to help address both realities. Under one scenario, individuals would access assessment services in existing clinics throughout the province (which could be urban or rural) through a combination of telehealth, in-person visits to clinics and mobile services available in communities. A "translator" from the FASD Service Network that serves the individual's community would support the individual (and if appropriate members of their family) from initial screening and referral, through the assessment process, understanding the meaning of a positive diagnosis and into implementation of the individualized support plan. The translator function ensures valuable information is included as an input into the assessment process and that the appropriate support services are accessible to the individual, and provides a crucial support system. This translation function will assist support service providers (such as justice, employment or housing) in making services accessible to this population, by educating local resources about the results of the FASD assessment and diagnosis. In this manner, the FASD Service Network Program provides a platform to build community capacity for implementation of support plans that are developed during the assessment process. This type of a model would build on the infrastructure within the existing clinics and the community relationships that exist within the Networks.

The FASD-CMC should invest in development of translator functions by targeting funding toward the development of this role and, over time, requiring that translator be a core component of service delivery models.

4. **Build system capacity by focusing on youth transitioning to adulthood:** Anecdotal evidence from the field suggests that many individuals affected by FASD have difficulties as they transition from childhood to adulthood, as their daily lives lack the structure that school and family provided. While the focus of this document is adult assessment and diagnosis, there is an opportunity to ensure tomorrow's adults have appropriate support systems, including linkages between assessment and community-based supports and services. Where children have been diagnosed with FASD or are suspected as being affected by FASD, they should be reassessed before leaving the "child system", and their support plan should be updated accordingly to reflect

The FASD-CMC should ensure that supports are designed and implemented to assist FASD impacted youth in successfully transitioning to adulthood.

changing needs and life circumstances. A targeted effort in this regard would facilitate improved follow-up with these individuals to provide support and structure in terms of employment, physical health, mental health, independent living, housing, finances and addictions. This will not only improve the outcomes for the individual but will also provide a mechanism to begin to build community capacity to support adults with FASD in the implementation of their management plans.

5. Work towards the development of clinical standards across the lifespan for adult assessment and diagnosis:

Research evidence indicates there is no commonly accepted diagnostic framework for adults. The knowledge framework for how to approach assessment and diagnosis in adults has largely been built from experiences with child diagnosis processes and standards. As the system evolves to provide increased access for adults, there is a need to develop a common framework for assessment and diagnosis standards for adults. This will not only improve the process for individuals being assessed, it will also improve the information gathered and ultimately the outcomes for individuals.

Through linkages with the Canada Northwest FASD Partnership and the Public Health Agency of Canada, the FASD-CMC should work to develop adult assessment and diagnostic standards.

6. Develop data management standards and practices:

Dr. Sterling Clarren discussed the importance of adapting common forms for organizing historical materials and information; the results of the physical examination and the cognitive and performance evaluations; and the diagnosis and treatment recommendations. Standardized forms would significantly improve consistency of clinical documentation throughout the province, facilitate transfer of standardized data for evaluation of common client needs; provide a mechanism for quality improvement; and would serve as the basis for improved aggregation of data for program planning, policy development and performance reporting.

Through involvement with the Canada Northwest FASD Partnership and the Public Health Agency of Canada, the FASD-CMC should continue to support efforts for standardization of data and data management practices among FASD clinics.

7. **Enhance knowledge brokering and continuous quality improvement efforts regarding adult**

assessment and diagnosis: There is a need to develop processes and activities that help professionals and organizations to build relationships among peers, identify needs, and share ideas and evidence to support education and training, and research and development pertaining to adults with FASD. Brokering knowledge regarding FASD in adults will provide mechanisms to connect key stakeholders to maximize system efficiencies, share expertise and build the community of practice, as well as identify needs.

The FASD-CMC should build on the inaugural Assessment and Diagnosis Leading Practices Forum to ensure FASD professionals have future opportunities to learn and improve assessment and diagnosis practices.

5. Next Steps

On May 13th, 2009 the Alberta *Fetal Alcohol Spectrum Disorder Cross-Ministry Committee* accepted this discussion paper and recommendations. The FASD-CMC is striking a sub-committee who will develop an action plan for these recommendations.

Annex 1

Participants List - November 18th & 19th Leading Practice Workshop

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