

RURAL FASD DIAGNOSTIC SERVICES MODEL: LAKELAND CENTRE FOR FETAL ALCOHOL SPECTRUM DISORDER

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ABSTRACT

There are few FASD multi-disciplinary diagnostic teams in rural regions of Canada. Families often have difficulty accessing their services because of the lack of clinics available in Canada and the distance rural residents must travel to access one. Since its grass-roots beginning in 1995, the Lakeland Centre for FASD in north eastern Alberta has developed a community-based FASD diagnostic services model that utilizes the resources available in local communities and enhances the support to individuals and families living far away from urban centers. The article describes the history of the Lakeland Centre for FASD relative to the development of the model and diagnostic process used to diagnose children and adults. Rural adaptations to similar urban models are discussed. Critical elements to rural, in-kind services are also discussed along with ongoing challenges. Acknowledging the change in terminology over the years covered by this article, the term FASD (Fetal Alcohol Spectrum Disorder) is used throughout.

In response to the growing awareness of Fetal Alcohol Spectrum Disorder (FASD) and its likely affect on local residents and communities in the Lakeland region of north eastern Alberta. A group of concerned agency representatives joined together in 1994 to host the first FASD conference in this area. It was hosted by the Canadian Native Friendship Centre and held in Bonnyville (250 kilometres east of Edmonton). Following the conference, a core group began meeting regularly to develop prevention initiatives. As a result the Lakeland FASD Committee was formed in 1995. From this beginning, the group continued to learn about FASD, developed a variety of prevention campaigns and resources, prepared and delivered training presentations to both the general public and professionals as well as hosted numerous conferences.

The Committee knew that more needed to be done to support individuals and families dealing with FASD but that nothing could be put in place for them until they could receive an alcohol-related diagnosis. After hearing Drs. Sterling Clarren and Anne Streissguth from the FAS Diagnostic and Prevention Network (FAS DPN) at the University of Washington speak about the benefits of a multi-disciplinary team-based diagnosis, the Committee felt it was a model that could be used effectively in the local rural region.

In 2000 the Lakeland FASD Committee sent a team of local professionals recruited from committed agencies to Seattle to receive diagnostic training using Drs. Astley and Clarren's model. After adapting the model to meet local goals and realities, the team began providing diagnostic and assessment services in November 2000 with funding from an Alberta provincial government health innovation grant. The model is outlined in the Diagnostic Service Delivery Model section.

The Centre provides services to, and takes its name from, the Lakeland region which is an area in north eastern Alberta that includes one small city, 25 small towns/villages, seven First Nations communities, four Métis Settlements, and one military base, for a total population base of approximately 80,000. From Edmonton, the closest community is one hour and the farthest is 3.5 hours. All communities are accessible by road. The Centre is physically housed in Cold Lake, Alberta but provides its services to the region's communities through mobile diagnostic teams and follow-up support personnel.

The Lakeland FASD Committee became a legal entity in 2003 with the formation of the Lakeland FASD Society. Society status, while having no impact on diagnostic services, allowed the group to formalize funding and a more effective management structure. In addition to

diagnostic services for children and adults, it currently oversees a wide variety of training and prevention programs including mentorship programming for women at the highest risk of alcohol use during pregnancy.

The current Centre infrastructure funding is co-provided by the Alberta Ministry of Children Services as a demonstration project and the fundraising efforts of the Board of Directors of the Society. The model requires minimal sustainable funds for team coordination, infrastructure (office, etc), and clinic costs.

Diagnostic Service Delivery Model

The diagnosis of what is now called FASD was first recognized by Lemoine and colleagues¹ and subsequently elaborated on by Smith and Jones.² The diagnosis was a “gestalt” diagnosis based on the presence of physical abnormalities involving facial formation, growth patterns, and central nervous system or neurobehavioral disorders. In 1996, the Institute of Medicine (IOM)³ further delineated the spectrum of damage caused by alcohol to the growing fetus in their Diagnostic Criteria. The effects were further refined by Astley and Clarren leading to the introduction of the 4-Digit Code system of diagnostic management.⁴ The diagnostic criteria highlighted the need for a multidisciplinary team to be involved in the diagnostic process. These professionals, each with their individual expertise could provide a comprehensive assessment unique to the individual, providing the team the necessary information to support that individual in the full spectrum of identified disabilities.

The diagnostic service delivery model utilized by the Lakeland Centre was developed in 1996 and is based upon the FAS DPN model.⁴ The model adapted by the Centre fits well within the 2005 Canadian guidelines for diagnosis.⁵ The foundation of the service delivery model is the diagnostic team made up of agency service providers from throughout the area who come together on pre-determined clinic days to the community in closest proximity to the client’s home.

The Centre currently has two diagnostic teams operating throughout the service area to provide diagnosis for children under the age of 18 years. The Committee always envisioned

providing diagnostic services across the lifespan, so in 2002 an adult diagnostic team was launched. The children’s diagnostic teams generally includes of a pediatrician, neuro-psychologist, speech-language pathologist, occupational therapist, public health nurse, Aboriginal liaison, mental health therapist, social worker, addictions counsellor and a team coordinator. In addition to the core team members, secondary members may be added to meet specific client needs. If for example, a teenage client has been in trouble with the law, a probation officer or RCMP officer could be invited to assist the team. The adult team is comprised of a physician, psychologist, mental health therapist, career counsellor, addictions counsellor, Aboriginal liaison, disability services coordinator, and team coordinator. While a similar process is used by all three teams, which will be described later in this document, the adult and children’s teams differ primarily in make up as just described.

The two children’s teams diagnose four children per month in two clinic days. Each diagnosis takes four hours. Since November 2000, the teams have seen over 200 children. The adult team diagnoses only one adult per month as the volume of information needed for adult clients is very extensive and all the required assessments are completed in one day. Wait times for assessment are approximately 3–4 months.

The clinic process consists of six phases completed prior to, during, and following the clinic. Each phase involves many concrete tasks that are related to a variety of conceptual issues. The following is the process described in detail for the diagnosis of children. The adult version is virtually the same process over a longer period of time.

Clinic Process

Allowing for adaptations for individual needs, the diagnostic process for children with FASD consists of pre-clinic information gathering and five clinic phases as described as follows:

Phase 0: Pre-Clinic

Referrals are received by the team coordinator who completes the Initial Intake Form and determines eligibility. To be eligible for assessment a client must live in the service area

and the team must have confirmation of maternal alcohol consumption during pregnancy. The maternal consumption of alcohol is confirmed by the birth mother if she is still involved with the child. If not, information is collected from supporting documents such as birth records, Children's Service's documentation, or other reports as recommended in the Canadian Guidelines. An advocate from within the community is identified to assist the family to complete the application package. Most referrals come from schools, parents, and social workers. Once all the information is compiled, the family and referring agency are contacted to set a clinic day and team members informed of the case information and clinic date and location.

Phase 1: Assessments

The team arrives before the family and is provided with a verbal overview of the case and full documentation including application package, testing results, social history, medical history, birth records, etc. Information gaps are identified, and possible questions for the family are formulated to gain the knowledge necessary to make a comprehensive diagnosis.

The family arrives to the clinic location and is interviewed together by the physician, mental health therapist and one other team member (depending on the situation) to gather first hand information about the child. A checklist is used as a guide to the discussion.

At the same time as the family interview, the public health nurse completes the facial measurements of the child. This is followed by any other testing deemed necessary (i.e. speech-language or occupational therapy assessments, etc). Psychometric assessments for memory, academic ability, neuro-psychological functioning is often completed by the team psychologist prior to the clinic due to the length of time needed to conduct these tests. If current test results are available from other sources (i.e. school-based testing) these may be used instead.

The physician leaves the interview with the family at the half way point for the neurological and medical examination of the child, and to repeat the facial measurements completed by the nurse. Having both the physician and nurse take the measurements gives the team confidence

about their accuracy. The team uses the computer program provided by University of Washington DPN6 for assessing facial measurements accurately and objectively.

Interviews may also be occurring at this time with school or other program personnel by the team social worker to determine school programming needs, or life circumstances that might be important for recommendations. The social worker or addictions counsellor may also interview the child, depending on his/her age.

Phase 2: Discussion of Results

The team meets to review all the gathered information and to make a determination of diagnosis and recommendations. Input from all members has equal weight and each may contribute his/her ideas and thoughts to the process. Consensus must be reached in determining all four areas of the DPN 4 Digit Code by all members before concluding. Using the DPN 4 Digit Code and translating to IOM language, all diagnoses are listed, such as learning disabilities, language deficits, memory problems, etc. From this information, and taking into consideration the availability of services in the client's community, the team formulates the recommendations for follow-up services that will be given to the family that day.

When a teen is being assessed in clinic, the family determines how the diagnostic information is delivered (i.e. whether the teen participates in the case conference, meets one on one with a team member, or has the family discuss the results with him/her). Most often the physician, psychologist, coordinator and other relevant team members meet with the parent/caregiver in a case conference. The team coordinator determines which team members are appropriate to participate.

The physician takes the lead role during the case conference and begins by providing an overview of the diagnostic process. Each team member presents his/her own test results to the family and the physician reviews the diagnosis and recommendations. The family and/or their advocates or supports have an opportunity to ask the team questions and are given a number of resources to take home such as the "Simon Says"⁷ or "Polly Anna"⁸ books developed by the Lakeland Centre. During the case conference, if

the child is not participating, a team member stays with the child in another room.

Phase 3: Client Debriefing

The mental health therapist meets with the parent/caregiver privately to again review diagnostic and recommendation information and to emotionally debrief. It is important to provide clear closure for the parent/caregiver to ensure that they know where to seek emotional support if needed. If the client is a teen, the psychologist or addiction counsellor will meet with him/her and provide debriefing about the day, determine his/her understanding of the results and review team recommendations.

Phase 4: Write Up and Team Debriefing

The team waits for the mental health therapist and completes the necessary paper work including the writing of the final report which is completed by the physician and team members who conducted the testing. The report is a template that is completed on a notebook computer and printed on a portable printer. The report is signed by the physician. Upon return of the therapist the team debriefs the case and emotionally debriefs among themselves.

Phase 5: Post Clinic

The coordinator gathers the completed reports from the team members, forms one document and ensures that a copy is sent to the referring organization, family/caregiver, family physician, team physician, child's school and/or others as identified by the family.

The Centre believes that every family requires some form of additional support following a diagnosis. The Centre employs family support consultants to connect the family to the local community supports and assist with following through on recommendations. This family support is provided only short-term making it critical to assist the family in making local connections to access and implement suggested services. It was discovered that the adult clients had a great deal of difficulty accessing the services post-diagnosis that had been recommended by the team due to the lack of family or community supports needed to assist in making the connections to local services. Funding was secured to add an FASD adult support advocate to

assist clients break down the barriers that make participation so difficult.

Model Adaptations for Rural Diagnosis

After training in Seattle the FASD committee realized that a number of process adaptations were necessary for the model to be successful in rural areas. The specific adaptations are previously described in the clinic phases. In general, the adaptations include:

a) In-Kind Donation

The major adaptation made to the DPN model was the need for team member agencies to donate staff time on an in-kind basis. The Seattle team was made up of full-time professionals working for the clinic. Lack of resources made this approach impossible in a rural area, so a plan was formulated to fill the team positions with staff from existing organizations or departments. It was felt that these professionals would be able to make referrals from their own client base, know their communities better, provide some follow up support as part of their current roles, and would gain knowledge about FASD that could be used to benefit their own agencies. This in-kind agreement is in place for all but the physicians and psychologists on the team who are paid on a fee-for-service basis. To cover the costs of the operating on this basis, a diagnostic fee is charged for all clients. This fee is normally paid by the referring agency or cost-shared between agencies involved with the client. Typically the primary funding agencies have been Alberta Children's Services, local school divisions, First Nations communities, Alberta Human Resources and Employment, or Persons with Developmental Disabilities. In the rare cases where no obvious funder is available, anonymous private donations are utilized.

b) Follow-up Support

It was felt that to diagnose and then not provide follow-up support was a serious gap that would greatly diminish the potential benefit of receiving the diagnosis in the first place. Thus, a follow up support worker was a critical addition to the diagnostic team and the process. A core commitment to client care and respect is likely the largest contributing factor to the overwhelmingly positive client feedback the Centre receives.

c) Mobile Teams

While the Centre has an administrative office in Cold Lake, the Centre teams are mobile and meet the clients in their own or nearby communities, making it easier for clients on clinic day and more likely that they will follow through with recommendations to local services. In smaller communities, the issues surrounding confidentiality have required sensitivity and adaptation, but the benefits of taking the service to the client have far outweighed the potential concerns.

Factors Critical to Model Success

Several factors have been identified as critical to the Centre's success in the providing diagnostic services. Briefly these are:

a) Team Selection

The conscious development of an effective team is critical. Team members apply to be part of the team and are chosen (or not) based on specific criteria. (i.e. an interest and background in FASD, the ability to work effectively in a team and a good sense of humour).

b) Team Development and Management

Team members work well together and are dedicated professionals. Team dynamics are critical to the success of the work. Every team member's input is considered equally important and decisions are made by consensus. The work is serious but with as much fun inserted as appropriate. Passion for the cause is critical. Team professional development is critical to ongoing effectiveness and is either funded or provided by the Centre.

c) Team Coordination

All information flows to and through a team coordinator. She ensures that the information is collected, the families and site prepared, she controls the flow of the clinic day, engages and delegates all the team members in their various roles and manages the details of the day. The coordinator also ensures that the participating agencies are satisfied with the outcomes and deals with any arising issues immediately. One team coordinator works with the two children's teams and the adult team.

d) Community Preparation

Establishing an effective network of regional and community partners with a broad, integrated view is a priority. Communities are prepared to support and participate with the diagnostic teams and provide follow-up support. A diagnostic centre may not "parachute" as well into communities that are not prepared. A strong indicator of readiness would be that many community agencies are asking for FASD diagnostic service.

e) Client/Family Focus

A commitment to client-focused services ensures better services and more enthusiastic staff participation.

f) Cultural Connections

Good working relationships, based on cultural knowledge and respect are established with all communities. Aboriginal professionals are included as team members to advise and give the team clarification about cultural issues and to support the family when appropriate. Individuals from other cultures in our region are accessing services and every effort is made to find an appropriate liaison to the team.

g) Politically Active and Visible

Political visibility and partnerships with all levels of government is cultivated and is critical for funding and support. The Centre organizes fund raising activities, makes presentations at national and international conferences, liaises with federal, provincial and local governments and politicians, all in an effort to represent the needs of individuals with FASD.

Challenges

In addition to the ongoing difficulty in accessing stable funding, one of the major challenges in implementing this model has been the limited availability of rural professionals, both as primary team members and in filling back-up positions. Finding the right person can be challenging and having agency partners "send" someone has often proven difficult. The Centre provides team training sessions annually to train new members for their own teams as well as for communities who wish to train new teams. This training has proven to be critical to team functioning. In the beginning there were many challenges such as

explaining to people the benefits of diagnosis vs. the fear of labelling, and explaining the need for a diagnostic fee. Today, these are rarely raised as issues. The Centre is currently working with more complex families where parents have been prenatally affected as well as the children making it more difficult to collect good prenatal histories.

CONCLUSION

The service delivery model developed by the Centre has turned out to be appropriate and effective as well as innovative for the rural areas served in north eastern Alberta. It addresses the need for professional, timely assessment and diagnosis with an emphasis on client support and respect in a non-urban setting. As a result, the Centre is recognized as a best-practice model for FASD diagnosis. Centre staff and team members provide training sessions annually to other communities/organizations seeking to establish diagnostic services in community settings.

REFERENCES

1. Lemoine P. The history of alcoholic fetopathies. *J FAS Int* 2003;1:e2.
2. Jones KL, Smith DW. Recognition of the fetal alcohol syndrome in early infancy. *Lancet* 1973;2(7836):999-1001.
3. Stratton K, Howe C, Battaglia FC. Fetal alcohol syndrome: diagnosis, epidemiology, prevention, and treatment. Institute of Medicine and National Academy Press, Washington, D.C., 1996.
4. Astley SJ, Clarren SK. Diagnostic guide for fetal alcohol syndrome and related conditions: the 4-Digit Diagnostic Code. 3rd ed. University of Washington Publication Services, Seattle, WA, 2004.
5. Chudley AE, Conry J, Cook J, Loock C, Rosales T, LeBlanc N. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal (CMAJ)* 2005;172.
6. Astley SJ. Fetal Alcohol Syndrome Facial Photographic Analysis Software. FAS Diagnostic & Prevention Network, University of Washington, Seattle, WA, 2003.
7. McFarlane, H. Simon Says: A book about FAS for kids, parents and teachers. Lakeland Centre for FASD, Cold Lake, Alberta, 2003.
8. McFarlane, H. Polly Anna the Second: A book about FASD for teens. Lakeland Centre for FASD, Cold Lake, Alberta.