

# **Diagnostic Services Model Lakeland Centre for FASD Cold Lake, Alberta**

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## **1. Background and Context**

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 Alberta, a group of concerned agency representatives joined together in 1994 to plan the first FASD conference in this area hosted by the Bonnyville Canadian Native Friendship Centre in Bonnyville, AB. Following the conference, a core group of individuals 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. The committee heard Drs. Sterling Clarren and Anne Streissguth from the FASD diagnostic clinic at the University of Washington speak about the benefits of a multi-disciplinary team -based diagnosis, and felt this was a model that could be used effectively in the local rural region. The Committee began planning to provide providing diagnostic services.

In 2000 the Committee sent a team of local professionals recruited from committed agencies to Seattle to receive diagnostic training using Dr. 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 a provincial government health innovation grant. The model is outlined in Section 2.

The Centre provides services to and takes its name from the Lakeland region which is an area in north eastern Alberta that includes 1 small city, 25 small towns/villages, 7 First Nations communities, 4 Métis Settlements, and 1 military base, with a 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, AB but provides its services in the region's communities through mobile diagnostic teams and follow-up support personnel.

The Lakeland FASD Committee became the Lakeland FASD Society in 2003 and in addition to diagnostic services for children and adults, they 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 Ministry of Children Services as a demonstration project and the fundraising efforts of the Board of Directors. This model requires minimal sustainable funds for team coordination, infrastructure (office, etc), and clinic costs.

## 2. Diagnostic Service Delivery Model

The Diagnostic Services Delivery Model utilized by the Lakeland Centre is based upon the Seattle Diagnostic Clinic model. The focus of the service delivery model is the diagnostic team of area service providers who come together from throughout the region on pre-determined clinic days in a variety of communities.

### Diagnosis of Children

The Lakeland Centre currently has two children's diagnostic teams made up of the following professionals:

- Pediatrician:
- Neuro-psychologist:
- Speech language pathologist :
- Occupational therapist:
- Public health nurse:
- Aboriginal liaison:
- Mental health therapist:
- Social worker:
- Addictions counsellor
- Team coordinator

Depending on the situation, secondary team members may be added to the clinic to meet specific client needs. These secondary members may include, for example, an educator, a legal representative, or psychiatrist. For example if the teenager is in trouble for the law the probation officer or an RCMP officer may be brought in to assist the team. The teams diagnose four children per month in two clinic days. Each diagnosis takes 4 hours. Since November 2000, the teams have seen almost 180 children.

### Diagnosis of adults

The Committee always envisioned diagnostic services across the lifespan, so in 2002 an adult diagnostic team was launched. This team comprises a physician, psychologist, mental health therapist, career counsellor, addictions counsellor, Aboriginal liaison, disability services coordinator, and team coordinator. Recently funding was secured to add an FASD adult support advocate to this team. It had been found that the adults had a great deal of difficulty accessing the services recommended by the team. The adult team is also a mobile team seeing only one adult per month as the volume of information needed for adult clients is very extensive (book of health records can be accumulated by someone 40 years of age) and the testing is all done in one day.

### The Clinic Process

The clinic process consists of 6 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 for the children and has some slight variation for adults.

#### Phase 0 – Pre Clinic:

Referrals are received by the coordinator who completes the Initial Intake Form and determines eligibility (i.e. lives in service area and confirmation of mothers drinking during pregnancy). An advocate (community worker, public health nurse, women shelter, etc) is identified to assist the

family to complete the application package. Most referrals come from schools, parents, and social workers.

Upon receiving the application package the coordinator reviews all information and begins to collect the missing required documentation. Once this is completed the family and referring agency is contacted by the coordinator to set up a clinic day. The Aboriginal liaison may assist with this process if necessary. The coordinator also ensures that all team members have information about location, dates, times and a very brief overview of the case for each clinic day. The team moves around to different communities in the region so it is critical that everyone know the correct location.

### Phase 1: Clinic day

The team arrives before the family and the clinic begins with introductions of any guests or new team members. Documentation that has been gathered (including application package, testing results, social history, medical history, birth records, etc) is presented to the team by the coordinator, information gaps are identified, and possible questions for the family are formulated to gather information necessary to make a comprehensive diagnosis.

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

At the same time, the public health nurse takes the child for facial measurements, followed by any necessary testing (i.e. speech, occupational therapy, etc). Psychological testing is often completed prior to clinic by our team psychologist. Psychometric testing completed depends on what has been completed in the past and what might be current from other sources, such as the school. The physician leaves the interview with the family at the half way point for the neurological and physical medical examination of the child, and complete the facial measurements. Having both the physician and nurse take the measurements gives the team confidence about their accuracy. (The team uses the new computer program provided by University of Washington Diagnostic and Prevention Network 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 or who ever is currently not busy 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:

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 all areas (growth, face, brain & alcohol) 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). Then the team formulates the recommendations that will be given to the family that day.

When teenagers are being assessed in clinic, the family determines how the diagnostic information is delivered to them (participate in case conference, meet one on one with a team member, or have the family discuss the results with them). 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 in the case conference.

The physician takes the lead role during the case conference and begins by providing an overview of the diagnostic process. Each team member presents their testing results relevant to their area 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” or “Polly Anna” books developed by the Centre.

During the case conference, if the child is not participating, a team member stays with the child in another room.

### Phase 3:

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 supports if needed. With a teenager, the psychologist or addictions counsellor will meet with the teen and provide some debriefing about the day, determines their understanding and reviews what will happen now.

### Phase 4:

The team waits for the mental health therapist and completes the necessary paper work including the writing of the final report (completed by the physician, and team members who completed testing). The report is a template design that is completed on a lap top and printed on a portable printer. The only signature on the report is the physicians. Upon return of the therapist the team debriefs the case and emotionally debriefs among themselves.

### Phase 5: Post Clinic

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 short- term and it is therefore critical to assist the family in making local connections to access and implement suggested services.

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

## **3. Discussion**

### **1. 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 Centre’s 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. As a result, it became necessary for staff time to be donated on an in-kind basis from their member agencies. The physicians and psychologists on the team are on a fee for service basis.

**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 is a critical addition to the diagnostic team and the process.

**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 (for example, ensuring no family member to the client works at the mobile site), but the benefits of taking the service to the client have far outweighed the potential concerns.

**d. Client focus** - The Centre has a client-focused approach rather than a research focus like the Seattle clinic which is based at the University of Washington and its clients provide data for FASD research. A client centred approach means that the client/family needs come first before the needs of the team or the need for research. This commitment to client care and respect is likely the largest contributing factor to the overwhelmingly positive client feedback the Centre receives.

## **2. 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 and Staff Selection, Development and Management** - The conscious development of an effective team is critical. Team members apply to be part of the team and are chosen (or not) for specific reasons. 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 through team consensus. The work is serious but we have as much fun as appropriate. Passion for the cause is critical.

**b. 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 coordinates the 2 children's teams and the adult team. A team coordinator with a background in social work or addictions knows the community and community players, a strong communicator are critical skills in choosing a coordinator.

**c. 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.

**d. Client/Family Focus** - A commitment to client-focused services ensures better services and more enthusiastic staff participation. As defined above.

**e. 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. Many other cultural people in our region are accessing services and every effort is made to find a cultural liaison to the team.

**f. Politically Active and Visible** - Political visibility and partnerships with all levels of government is cultivated and is critical for funding and support. For example the Centre organizes fundraisers, is visible at conferences, liaises with Federal, Provincial and local representatives to put forth the needs of individuals with FASD.

### **3. Challenges**

One of the major challenges in implementing this model has been the availability of rural professionals, both as primary team members and in filling back-up positions. Finding the right person (i.e. someone with an interest and background in FASD, the ability to work effectively in a team and a good sense of humour) 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. labelling, and explaining the need for fees. Today, these are rarely raised as issues. The current issues seem to be around more complex families where parents may be affected by prenatal alcohol exposure as well as the children, and collecting good prenatal histories. We are also entering into more referrals for crystal methamphetamine using mothers; however, most of our women are poly drug users.

The longstanding issue of stable funding remains paramount.

### **Conclusion**

The service delivery model used by the Centre has turned out to be appropriate and effective as well as innovative for the rural areas services 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.