FASD SERVICE NETWORK PROGRAM EVALUATION
Expanded Portion

Lakeland Network
February 2012

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Introduction

In 2006 the FASD Cross-Ministry Committee (CMC) developed Alberta's 10 Year FASD Strategic Plan to provide a comprehensive and coordinated province-wide response to FASD that crosses the lifespan and is respectful of individual, family and community diversity. Twelve Networks have been funded across the province which were tasked with the improvement of supports and services that will address the impact of FASD at all levels. Services were to be provided in three main areas: targeted and indicated prevention (specifically the PCAP program), assessment and diagnostic services, and supports for diagnosed individuals and their caregivers.

The FASD CMC agreed on seven guiding principles for all Networks but has given each region the responsibility to choose their governance model, members, partnerships and patterns of communication, provided that they comply with program and accountability guidelines (FASD Network Program Guidelines, 2009).

In 2009, an FASD evaluation strategy was proposed which, over time, developed into a province-wide evaluation process facilitated by Sumera Management Consulting (herein after referred to as KPMG). In addition to this over-arching process, the South Alberta FASD Service Network and the Lakeland Network (operated by the Lakeland FASD Society through the Lakeland Centre for FASD) were tasked with the design and implementation of an expanded evaluation. These two networks were chosen because of their long history of FASD programming and partnering in their respective regions and because they operate at opposite ends of the FASD Network governance continuum represented throughout the province, which will be described in detail. In addition to governance differences, they both similarly access other sources of funding through federal, provincial and municipal grants, corporate support, income generating initiatives and private donations.

The expanded portion of the full evaluation was to focus on the governance models in both networks and how the chosen model may have impacted coordination, collaboration and outcomes overtime. To that end, the remaining document includes the following:

Section A - A network governance case study describing the historical development and current structure and it's attending issues and impacts. It will provide evidence that there is merit in giving regions the freedom to choose their own governance structure, while highlighting the competences and characteristics of a successful network.

Section B - A description and evaluation of services and programs which receive partial or no-funding from the CMC. By including other programs not funded by the FASD CMC, the expanded evaluation will present a more complete picture of regional services, the need to obtain funding for FASD beyond the CMC, and will identify key elements to ensuring broader program success.

In addition to this document, a separate document including a governance comparison of the South Alberta and Lakeland Networks has been prepared. The comparison is not intended to choose one model over another, but rather to highlight common elements that have made both Networks leaders

in Alberta as well as to point out unique strengths of each model that can be used by other Networks.

Methodology

The data for the expanded evaluation came from focus groups conducted by the evaluator with the following groups:

- the network manager and senior staff
- the current Board of the Lakeland FASD Society
- the first Lakeland FASD Committee members
- the Lakeland Centre for FASD staff including separate sessions with the Adult Coordinators and the Child and Family Coordinators
- Coordinator and clients of the Adult Employment group

Additionally, one-on-one interviews were conducted in person or over the phone with the following:

- the Youth Transition Coordinator
- two previous Summer Camp supervisors
- 15 regional partners

Historical and current documents were also reviewed to provide depth and context for the data.

The Expanded Evaluation Framework jointly designed by the two Networks took into account the different history and structure but attempted to design evaluation questions that would be applicable to both to ensure ease in program comparison. While the overall questions were the same, the specific sub-questions needed to answer the evaluation questions were designed specifically for each site.

A list of individuals interviewed and focus group participants are included as Appendix A. Unless otherwise referenced, all quotes within the document are taken from the transcripts of the interviews or focus group sessions.

Limitations

Acknowledging in advance that the task given to KPMG of designing common evaluation tools and processes across a broad range of self-governing networks was challenging, the unique service model used by the Lakeland Network put them far enough outside of the norm that the provincial tools, by and large, could not be meaningfully applied and therefore the resulting data did not paint a clear or accurate picture of the Lakeland Network. In an effort to provide the Lakeland Network and the FASD CMC with a document that would be more contextually relevant and therefore useful for accountability and future planning, the evaluator developed a parallel process and methodology. Even though the intent was to capture the essence of the CMC-SNP data, it is acknowledged, that the methodology was different enough that it severely limits the comparability of the data collected with other networks or the provincial data collectively.

Terminology

To provide clarity to this document the following definitions are provided:

Fetal Alcohol Spectrum Disorder (FASD) refers to the complete spectrum of alcohol related diagnoses used to describe the effects of pre-natal exposure to alcohol. Over the years a variety of terms have been used (i.e. FAS/FAE, ARBD, etc.). FASD is the latest term in use and will be used throughout this document in place of whatever terminology may have been used at the time being described.

Lakeland FAS Committee - original ad hoc structure in place during the formative years of service delivery. This committee was replaced by the Lakeland FASD Society and no longer exists.

Lakeland FASD Society - the legal entity that receives funds and provides overall direction to the Lakeland Centre for FASD.

Lakeland Centre for FASD - the operating organization that delivers services throughout the Lakeland region. It is the service delivery face for the Society.

Lakeland FASD Network - the term used by the CMC-SNP and by which the program reports. The term is not in general use throughout the region.

Lakeland Region - is a general term meaning the area of north eastern Alberta served by the Lakeland Centre for FASD. It has no reference to any other government regional boundaries.

Network Management - is generally meant to include the Executive Director and managers of the Lakeland Centre for FASD. It has no reference to the Leadership Team concept present in other SNP Networks.

FASD Coordinators - is the term used for the support-workers assigned to work with individuals and/or caregivers post-diagnosis.

Mothers-to-Be Mentorship - is the name given to the regional PCAP program.

Sumera/KPMG - Sumera Consulting Services was the contract evaluation company used to coordinate the provincial CMC-SNP evaluation. They were acquired mid-contract by KPMG. The name KPMG will be used throughout the document.

Section A - Governance Case Study

A. 1 History of Network Governance and Program Development

Rationale for Inclusion: The current governance model was chosen and developed over time. In order to examine the governance model in use today, it is important to describe how it came into being. This section will include the environment at the time, how the region and partnerships developed, how the governance model was selected and has changed over time. Finally a description of the programs provided within the structure will be defined.

Eighteen years ago, services for people with FASD did not exist in Alberta's north eastern communities. Within the human services prior to 1994 there were small bits of new information surfacing that began to describe the effects on developing fetuses of maternal alcohol consumption during pregnancy. Sporadic provincial initiatives were being piloted in the larger centers but in general terms the information was scarce and fragmented in rural north eastern Alberta. "The interest was bubbling up in many areas and a number of people were headed towards each other" with what they were hearing within their own systems. In response to this growing awareness of FASD and its impact on local residents and entire communities, a group of concerned agency representatives joined together to plan the first FASD conference in the area in November 1994. The conference was hosted by the Bonnyville Canadian Native Friendship Centre and featured a presentation by Diane Malbin who had written about the issue and developed strategies for working with individuals with FASD.

Following that first conference in 1994, a core group of local individuals from AADAC, Bonnyville Canadian Native Friendship Centre, Persons with Developmental Disabilities (PDD), and the local Health Unit began meeting regularly to develop prevention initiatives and in 1995 the Lakeland FAS Committee was formed. Though it was originally planned to include Cold Lake and Bonnyville, over the next five years, the Committee grew to over 60 members from the entire region covered by the Lakeland Regional Health Authority, which at that time included communities east of Fort Saskatchewan, north of the Yellowhead Highway (16) and as far as Lac La Biche on the north. The committee expanded by word of mouth or by invitation. "If they were willing to travel, they were welcome to come." The hope was that the more people that became involved, the more the message would spread to other organizations and communities.

Early meetings were about sharing new FASD information that members had found and/or ideas for a new awareness campaign. The committee was governed informally by a chair, or later, co-chairs with decisions being made by consensus of the group that was present. There were no terms of reference or bylaws. As the knowledge level of the group increased, some of the members began doing presentations to other professionals. A document review indicates that the early committee trained approximately 5000 people from 1994-1997. The main goal of the Lakeland FAS Committee was to raise awareness and they developed a variety of initiatives (see Appendix B for a full listing) as well as direct training by committee members to interested organizations.

By 1998 it became apparent that the committee had become too large to be effective in keeping the participants engaged. It was decided to split the committee into what had become apparent were the two main issues: prevention of future FASD births and the care and support of individuals already dealing with its impacts. These working groups met separately and reported back to the main committee monthly.

In 1998/99 a small amount of provincial funding was made available to help communities or health authorities develop FASD committees. The already existing Lakeland FAS Committee used the funding to hire an administrative assistant who was charged with finding program funding for diagnostic and support programs. The committee knew that prevention and awareness was having an impact, but that more needed to be done to support individuals and families dealing with FASD. In September 2000 a hand-selected team of local professionals, recruited from agencies willing to provide an in-kind staff contribution to diagnostic services, was sent to Seattle to receive diagnostic training using the University of Washington model developed by Drs. Sterling Clarren and Anne Streisguth. After adapting the model to meet local goals and realities, and developing a working terms of reference, processes, and forms, the team began providing diagnostic and assessment services for children in November 2000. At the time, the process was being managed by Children's Services and diagnoses were being provided for children in care only.

Alberta Health and Wellness, through its Health Innovation Fund, provided the first core funding in 2001 and the Lakeland Centre for FASD officially opened in May 2001 with a 3-year funding commitment. This funding made it possible to hire an executive director, administrative support, a follow-up support worker and an adult diagnostic coordinator. The federal government's Department of Justice Crime Prevention Strategy funding was also received in 2001 for the "First Steps" mentorship program (now called Mothers-to-Be). It was developed to serve women in the Cold Lake area who were pregnant and at the highest risk of using substances.

With the receipt of core funding it became apparent that the informal structure of the committee would need to change. The Dr. Margaret Savage Crisis Centre offered to provide the legal entity and banking services for the new program. An Executive Committee was elected to manage the services which would report back to the larger committee annually. It was at this point that the large, regional committee began to diminish as the awareness and community building functions that were previously completed by the committee members were now being handled by the hired staff.

The Centre was physically established in Cold Lake but provided services throughout the entire north east region until 2003 when the decision was made to limit services to the eastern portion of the then Aspen Health Region (the Cold Lake, Bonnyville, Lac La Biche, St. Paul areas).

In 2002, the original children's diagnostic team trained a group of professionals specifically chosen to diagnose adults with FASD. The adult diagnostic team was the first of its kind in North America and made it possible for an FASD diagnosis and support to be provided throughout the entire life span of an individual.

The Executive Committee, along with establishing the physical and service structure, developed the first vision and mission statement for the group which is essentially the same today. The Committee:

- envisioned a region with no new FASD births and where currently affected individuals are well supported; and that
- will ensure that accurate information about FASD is available and prevention, diagnostic and support services are accessible in the Lakeland area.

In May 2003 the committee became a not-for-profit society in Alberta and a registered charity in Canada. The name of the society became the Lakeland Fetal Alcohol Spectrum Disorder Society which operated the Lakeland Centre for Fetal Alcohol Spectrum Disorder. The Board of the Society currently oversees a wide variety of services provided through the Centre that have not changed significantly from the beginning. The priority was, and still remains, to educate people about FASD, to provide diagnostic services to children and adults, to support individuals and families post-diagnosis, and to mentor high risk women into a less harmful life style.

A. 1. 1 Regional Development

The goal of the original Committee was to spread the word about FASD, so expanding as far as the message could be carried by those willing to participate on the Committee was encouraged. It wasn't until the committee contemplated providing regional services was there a need to specifically define a service area. The need to bring services to clients throughout the region was the impetus for the design of a mobile diagnostic team that would hold a clinic in whichever community was closest to the client being diagnosed. This turned out to be one of the factors that most contributed to the success and acceptance of the services throughout the region. Living in a rural area already necessitated travelling to Edmonton for services. If a local service was being designed to mitigate the need to travel to Edmonton, there would have been little sense in simply locating it to a different place and making people travel there instead. The committee also had established the commitment to provide support following a diagnosis so engaging the clients with their own community support structures became the secondary reason for taking the diagnosis to their own communities.

As stated earlier the original region was defined as the borders of the Lakeland Regional Health Authority which went from Fort Saskatchewan to the Saskatchewan border, Highway 16 to Lac La Biche. Initially services were provided to this area but with the limited resources available at that time, it became impossible to provide quality support to such a large region. When the Lakeland RHA was absorbed into the larger Aspen Regional Health Authority the decision was made to redefine the service boundaries to the areas around the four main communities in the eastern portion of the region (St. Paul, Bonnyville, Cold Lake and Lac La Biche and the First Nations and Métis Settlements within that area).

A. 1.2 Partnership Development

The original desire to address FASD began with government and not-for-profit groups coming together to share what they knew about FASD and talk about how to prevent it. The committee quickly

expanded to involve any who expressed an interest and desire to participate. Early program minutes indicate that participants at one meeting were told to bring two new people to the next meeting. Early participants included not only agency staff but local residents, aboriginal community members, parents and business owners. The net was spread wide to go beyond a "government" program development model to developing the entire community's awareness of FASD.

Focus group participants did identify two critical service sectors that were a "tougher sell" in the beginning: school personnel and medical doctors. Both groups felt that FASD was not a significant enough problem to spend time on or that it was not an issue that affected their work directly. Having said that, even in the early days there emerged champions from both of these professions, but systemic change within both has been slow in coming and continues to be a work in progress.

The Lakeland Committee was doing its work over a number of years of turmoil in government service provision. During the years of government cutbacks, some agencies withdrew their support for their staff to be involved in anything but core service delivery, which did not include the type of community development committee work the FASD Committee was doing. An example of the commitment of the early committee members was when the staff working for a regional agency were told they could no longer participate due to the agency's new focus on core services only, they continued their involvement by taking personal time to attend the meetings and participate in clinics.

The early participants indicated in the focus group session that while the work of this original committee was supported by their managers, the extensive work that each was doing to promote awareness was outside of the mandate or permission of the organizations by which they were employed. While an interesting historical fact at this point, each felt that their commitment to this issue, which caused them to work quietly off their organizational grids and at some level of professional risk, was one of the factors that contributed to their ultimate success and as such will be described later in this document.

Once the committee added to its mandate the need for diagnosis and support, it became apparent that the need for formal partnerships was required. The Seattle diagnostic model included full time team members employed by the University of Washington. The ability to replicate that in rural Alberta was a non-starter for the Lakeland FAS Committee. They obtained local agency support to provide their staff member in-kind for one day per month to participate on the FASD diagnostic team. Generally speaking these agreements were and are still today informal, however in the current training provided to new diagnostic teams the Centre trainers strongly encourage that these agreements be made formally.

One focus group participant stated, "We have never lost an agency due to lack of interest or support." During times of government cutbacks certain departments had to pull back their involvement but this comes and goes with bureaucratic changes at higher levels. This in-kind structure is still the arrangement today, with the exception of the medical doctors and the neuropsychologists who receive payment/honoraria for their participation. Current partnerships for the diagnostic teams include: several branches of Alberta Health Services, Northern Lights School Division, Alberta Children and Youth Services, Alberta Employment and Immigration, Alberta Justice, and Persons with Developmental Disabilities. The Executive Director indicated that a conscious effort is made to build

and retain strong working relationships and when diagnostic team partnerships have shown signs of faltering due to shifting structural winds, targeted attention is given to strengthening these relationships.

At this point it is important to clarify the concept of partnerships in the Lakeland Network which is different than in other service networks. Partnerships are about working together to improve services for individuals with FASD. Whatever may be required for a client is sought out and worked out with the others who are involved in the client's life. To the Lakeland Centre for FASD a partnership is a working relationship formed to help a client or a community. Relationship building was established as a priority in the early days of the committee and has been at the foundation of the Centre's success. Some relationships have taken longer to form than others (i.e. some schools and doctors) but even in these instances, the picture is brighter than it was 18 years ago.

A. 1.3 Model Development

When asked why the original committee selected the direct service provision model of governance (as compared to the contracting approach utilized in other networks) the response was, "There was no one else in the area providing services to FASD clients to sign a contract with." While the knowledge about FASD was beginning to filter down through agency structures to front line staff, there were no other programs providing diagnostic or support services to people with FASD in the region. The closest diagnosis was provided in Edmonton at the Glenrose Hospital which made it virtually inaccessible for most and provided no post-diagnostic follow up support, which was deemed to be critical by the committee.

The diagnostic model which was developed was a version of the University of Washington's model adapted for use in a rural setting. How it was rolled out in a rural setting was based on committee member intuition and experience, local planning and decision making and not based on any known model of the day.

There were several private and not-for-profit organizations who came to the table in the early days when it became apparent that the FASD Committee was going to be accessing funding to provide services. The Committee did discuss the possibility of simply contracting the diagnostic and support services to one of the existing non-government agencies operating in the disabilities field but in the end decided that their vision would best be maintained by developing the services themselves. They had been working together for 9 years and didn't want to hand off what they had achieved to a contractor who had not been at the table and who didn't have their vision or passion for it. They knew the funding they were receiving needed to be managed more formally than what currently existed but they couldn't give it away to others.

Having said that, the original intent was not to develop a permanent organization. Once service delivery became the next step, the intent of the committee was that they would proceed to develop FASD services but the plan was to assist other agencies to develop their FASD service capacity and that the Centre would be able to pass off the service delivery to them and fade out of existence. This did not occur and over the years the Lakeland FASD Society board made the conscious choice to stop trying to disappear and to move forward with the commitment to develop and provide the needed

services for people with FASD.

The original Committee members participating in the focus group could recall no serious disagreement at the Committee level with the direct service model chosen. The passion for the cause had unified the vision of the primary participants .

First Nations communities who had been at the planning table over the years began to receive funding from the federal government during this time to provide on-reserve services for individuals with FASD. For the most part, they withdrew from the committee at that point and began developing their own programs. Over the years the Centre has partnered with them to provide services on First Nations reserves in the area and has helped them develop programs for their residents.

When asked if they would do it again the same way if given the chance, all responded that they felt they had made the right choice and would choose direct service delivery again. They are satisfied with the work that has been done and also continue to feel that it is the best way to provide services in a diverse rural geographical area.

A.1.4 Program Development

The original FASD Committee divided its efforts into two primary working groups that focused on Diagnosis and Support as well as Education and Awareness. The work of the current Lakeland Centre is still built around these two components. Below is an overview of the programs that developed and are currently provide.

Children's Diagnosis and Support

After team selection and training, the first FASD assessment and diagnosis was performed in November 2000 before there was funding, staff or a formally designed process in place. What they did have was energy, passion and determination to move forward.

The adapted model remains essentially the same today. In the early days, two children were seen on one clinic day per month. As back-up team members have been trained, it is now possible to hold two clinic days per month with the ability to diagnose 4 children. The teams are mobile with the clinic held in the client's community to make the day as easy as possible for them. Initially there was a charge to the referring agency for the cost of the diagnosis, but with the funding the Centre now receives it is possible to provide diagnosis at no cost to the client or referring agency.

While the diagnosis is important to establish a service foundation, it is the support the family receives afterward that makes the most difference for the family. There are currently three FASD Coordinators who travel the service area to help the diagnosed family connect to local services and find the support they need.

Adult Diagnosis and Support

While the Centre began its work with families of children with FASD, diagnosing and supporting adults with FASD was also part of the original plan. In 2001, a diagnostic support worker organized the team and the client for the clinic day and attempted to provide some level of long-distance support following the diagnosis. Clients were being diagnosed in locations all over the region, making any meaningful

follow-up support very difficult.

Today, in addition to the Diagnostic Services Manager, there are three FASD Coordinators who work specifically with adult clients post-diagnosis throughout the region. They are assigned cases in the way that best meets the needs of the client and in some cases begin working with the client prior to the clinic day so that the client feels supported throughout the entire process.

One of the goals for the near future is to recruit and train a second diagnostic team for adults so that they do not miss a usually small window of opportunity by not being available when the client is ready.

The Centre's adult support team also supports clients who have been diagnosed by other clinics and who have moved to the area. With the work being done by the Youth Transition Coordinator (see below), more youth diagnosed as children will also be receiving support from the adult FASD Coordinators.

To try to define the work that the Coordinators do with the clients is challenging and can best be summed up by saying "whatever needs to be done" to help the client connect (often reconnect) to other supporters in the community. It involves stabilizing ever-emerging crises and offering the clients unquestioned support.

Mothers-to-Be Mentorship Program (PCAP)

The brochure for the Mothers-to-be Mentorship program calls it a "free, non-judgmental support program for women who are pregnant or have recently given birth and who have concerns about their substance use." The goal of the program is to prevent FASD births among the communities' most vulnerable population and as such this program is both prevention and intervention.

The program began in 2001 in Cold Lake and there are now four Mothers-to-Be Mentors working in Cold Lake, Bonnyville, Lac La Biche and St. Paul. While there are mentorship programs for similar client groups across Canada, the Centre's program was the first to work in a non-urban setting.

Summer Camp

Children with an FASD diagnosis, ages 8-17 are able to participate in a one week overnight summer camp in the Cold Lake area. These camps are specifically designed and highly supervised to ensure children have a positive experience. Campers participate in a number of activities such as swimming, hiking, crafts, local field trips, horseback riding, geography, animal tracking, games, etc.

The camp has been operating every summer since 2006 and is funded by private donations and local fundraising as well as the STEP program which provides funding to employ university students as camp workers. The camp is held at a Girl Scout camp on Ethel Lake in the Cold Lake area. The Society Board has identified the need to have their own camp facilities as a programming priority. These camps are funded through community fund raising events and private donations.

The goal in developing the Summer Camp was twofold: to provide caregivers with a break from the difficult challenges of raising a child with FASD and to provide children with FASD the opportunity to have a positive camp experience without the fear of rejection. It is the long term goal that these

children will discover positive life experiences and develop social skills.

Project for Youth Transitioning to Adulthood

In 2009, the Centre was able to obtain funding from Alberta Employment and Immigration to design and implement a transitioning process to help youth with FASD to prepare to leave home and become adults. In May 2009, after researching and designing a model for service, one client was selected to pilot the transition process. Since that time the Transition Coordinator has further refined the model in working with 18 youth.

Adult Employment Program

The purpose of this program which began in 2009 is to help adults diagnosed with FASD to develop the skills necessary to better participate in competitive or non-competitive employment and/or volunteer opportunities, according to their abilities. The program also includes a major life skills component as most clients require significant assistance in managing the skills of daily life needed for employment. The format of the program is a weekly group session with activities and training. Additionally, the Coordinator works one on one with clients helping them to find suitable employment and then assisting employers to understand the clients strengths and challenges.

Second floor Women's Recovery Centre

The Lakeland FASD Society has received funding from the Safe Communities Initiative Fund to implement the 2nd Floor Women's Recovery Centre project to provide addiction treatment services to pregnant women who come to the Centre from both inside and outside the service area. This project is based on a harm reduction treatment approach in which pregnant women who are at risk of delivering FASD babies are housed during their pregnancy and provided with addiction treatment, on and off site health interventions and life skills training. The Recovery Centre will be open in the spring of 2012.

A.2 Structure, Relationships and Perceived Impact of Network Governance

Rationale for Inclusion: Having described the historical development of the current structure and programs, it is necessary to provide a thorough discussion of the current governance model and its impact on: service delivery in the region, community capacity, coordinated services and the ability to develop private partnerships.

The Lakeland FASD Society is the governing body that provides strategic direction as well as program and policy approval for the work done by the Lakeland Centre for FASD. The Society conducts annual strategic planning and has developed a program vision and direction for the Centre and its services for the next 10 years.

The Board's involvement with program development is as an approving body. They ask the questions (i.e. "Can we staff it? Can we afford it? Is it sustainable? Is it part of our vision and mission? Does it fit everywhere in the region or is it specific to a smaller area? Will it work in an Aboriginal community? Is there risk to the agency, staff or clients?"). Their role is to ensure that "all the thoughts have been thought" before proceeding with implementation.

The Board is made of up of community members, not agency representatives, which facilitates private and public sector fund development, the ability to lobby for changes and to represent the agency in their own communities.

The other issue worth noting at this point, and that will be discussed later in this document, is that the model is widely supported throughout the region by the other service providers. The result of one-on-one interviews with partnering agencies in each of the communities served by the Centre indicated that they are totally satisfied with the governing structure as it exists, are satisfied with the level of input they are able to provide the Centre both formally and informally and have no interest in taking on the services currently provided by the Centre.

The values of the organization around service delivery were instrumental in the choice of this model and their continued commitment to it. The ability to choose their own values and philosophy as compared to having them assigned from a more structured bureaucracy was what attracted the original committee members and encouraged them to design the services the way they did originally. The desire to be able to have those values inform their design rather than have to live with the practice model of the agencies they all came from contributed to their passion and commitment to the vision. The Board and staff felt that a client-centered approach was possible and a one-stop-shop is how it should work on the street. Coordinated services are a commitment not a goal. Programs are piloted and adapted to best fit the client's needs. Innovation is encouraged and "doing whatever it takes" isn't a career risk.

It should be noted that this way of working doesn't come without risk, and steps have been taken at both Board and management level to ensure program, staff and client safety, but all interviewed felt that the risk was worth both the potential positive impact for the client and the job satisfaction that comes from working outside of the standard bureaucratic box.

A.2.1 Service Delivery

As previously noted, the geographical area covered by the Lakeland Centre is large and diverse by any standard. The area covers one small city, three larger towns, seven First Nations reserves, four land based Métis settlements, one military base and many small villages and hamlets for a combined population of just under 100,000 people.

To address the distances to services early on, the committee decided that diagnostic services would be provided in the clients home (or chosen) community and clients would be referred to agencies within reach for them. In recent years the Centre has set up satellite offices in each of the other three main communities in an effort to raise their visibility in local communities, to help enhance local efforts to support clients with FASD and to be able to provide better services on the ground with fewer resources required for time and travel.

Due to the transient nature of clients with FASD, parsing up the service area and assigning workers doesn't always work because as clients move the worker stays with them no matter where they go within the region. This is again evidence of a client-based service that is able to establish its own "rules." Travel is considered the cost of doing business in the way they want to do it.

The cultural diversity of this area, as described previously, is broad. In addition to the Aboriginal communities listed, large groups of White Russian and Lebanese residents as well as newer groups of immigrants from the Philippines and Mexico are also represented in the area. Aboriginal representation on the original committee and on the Society board has always been a priority.

Aboriginal community partners interviewed for this evaluation indicated that the staff at the Centre are, by and large, culturally appropriate. They know how to operate within Aboriginal community structures and family systems. "They try to hire Aboriginal staff which means a lot in all the communities. They have built credibility with Métis organizations by hiring Métis staff. They seem to understand the importance of that. They have no hesitancy in taking services right out to the community. They get there, find out who to talk to and aren't afraid to go and collaborate with on-site agencies or even Council on behalf of clients. I hope they continue to do that. They demonstrate cultural expertise in the work they are doing, not just giving lip service to it."

One agency whose clientele is largely Aboriginal, when asked if the Centre staff are culturally effective when working with their clients said, "Yes, more than any other agency we work with." Another worker from an Aboriginal community said that the Centre staff are accepted in their community, which doesn't always happen when outside agencies come to deliver service.

The question remains, is this cultural effectiveness a factor of the service delivery model employed by the Centre? It is a factor of the foundational commitment to client services, whatever that requires. It is supported by a centralized management system that ensures thorough training and manages staff consistently throughout the region requiring a consistent message, approach and style from all staff.

Work in Aboriginal communities and organizations within the region has waxed and waned since the early days, often based on the communities' readiness, ability to provide its own services, politics and

presence of FASD champions at their own governing and planning tables. The Centre has a current CMC-SNP contract to provide diagnostic services to the eastern Métis Settlements. They have also in the past had contracts with the Tribal Chiefs Health Services to manage their FASD dollars.

The model was originally designed to cover a large geographic area of diverse people. Any adaptations that have been made since its original design have been made to make that coverage more effective for them and the clients.

It was felt by focus group participants that the design of new services is facilitated by this model. Since they have the responsibility for the whole pie and not just a piece of it, they know where the gaps are for clients and are able to plan strategically how to address them. The latest strategic planning session (September 2011) includes a list of services to be achieved in 5 year increments up to 2031.

A.2.2 Community Capacity

Building an agency's and a community's capacity to support its own clients/residents was identified early as the reason for the awareness raising/training they had so heavily invested their time in during the formative years of the committee and Centre. As stated earlier, the original hope was that agencies would take this practice knowledge and apply it to their clients and the Centre's job would have been done. The five year target for this transition came and went without much progress and by the 10 year anniversary it had long since been put to rest.

Interviews conducted with community partners throughout the region indicated that the Centre had assisted them in learning more about FASD and learning how to more effectively work with their FASD clients. They indicated that the Centre staff were always available to support shared clients and the comment that their input and work with these clients "makes my job way easier!" was common.

The Centre and the original committee was focused on a community's readiness and capacity to deal with FASD. As indicated in the original evaluation of the Centre (2003) one of the factors indicated as contributing to the effectiveness of their service delivery model was that communities were prepared to support and participate in delivering services to their residents with FASD. It takes more than a good diagnostic process to make this model work - a community has to be able to take ownership for the issue.

The overall question asked by the evaluator was, does the Centre's direct service delivery model build or inhibit a community's capacity to manage FASD for its residents? It was generally felt that without someone on site to deliver core services to people with FASD, the community would not be able, with its existing services and structures, to provide the support needed by individuals with FASD. Existing agencies that provide services for individuals with all types of disabilities do not have the resources necessary to support and coordinate services for people with just one disability (FASD).

This is one of the many realities of rural vs. urban service delivery (i.e. lack of ability to recruit certain service providers to work in rural settings with the resulting increased case loads for those that are on site; limited resources requiring a concentration on core services only; only the core agencies are present in rural communities and not the network of private/not-for-profit organizations that often

exist in urban centers that add needed support on the ground; people living in diverse geographical areas unable to access centralized services or too remote for service providers to go to them in any meaningful or responsive way). While the Centre has increased each one's practice knowledge regarding FASD and is available to assist when needed, they have to work within the system as it exists in the rural area they serve.

Having consciously moved away from their goal of planned obsolescence to building a network of services for individuals with FASD throughout the region does not mean that they are not still trying to increase service effectiveness on the ground. Their main goal in follow-up work with clients is to connect (reconnect) them to other services in their own community so that they can access the expertise and benefits offered by these agencies and so that the entire "load" is shared between all that have stewardship for these individuals.

A.2.3 Coordinated Services

The Lakeland Centre for FASD's service model includes direct provision of the core services identified in the CMC's 10 year strategic plan. Coordination of these core services for clients is an in-house matter and handled routinely. This also includes programs that fall under the Centre's umbrella that are not funded by the CMC (i.e. Adult employment program, Transition program, Adult support services, etc.). There are no other FASD-specific funded initiatives in the region other than the Métis or First Nations programs already noted.

When asked if they would "make room for" other organizations who may like to develop services for FASD clients, they said "absolutely" and would happily pass off some of what they believe will become their work in the future if no one else takes it on.

A.2.4 Private Partnerships

In the beginning days of the FASD Committee, members were primarily employees of government or not-for-profit organizations. One of the downsides of adopting a society model was that they would lose the government voice which had been needed in the beginning to provide legitimacy and to form partnerships. Once the Society was formed, the new Board helped them to grow in different ways and to adopt a business model as compared to having a total reliance on government funding. This, coupled with the Board's commitment to innovation and the need to provide services in as many different ways as is possible, has caused them to look outside of traditional agency funding models for the resources they need. Corporate donations for infrastructure, fundraising galas for the Summer Camp and 2nd Floor Recovery Centre, to name only a few, have contributed greatly to the services they are able to provide.

A.3 Competencies and Characteristics Needed to Support the Governance Model

Rationale for Inclusion: Governance models depend on individuals, organizations and communities to succeed. This section describes what is necessary at each level to make this model successful.

A.3.1 Personal Competencies

Personal competencies for this governance model would, on the surface, be about what a manager would need to bring to the table. These same personal competencies would also be required of Board members and to some degree the leadership of partnering agencies in order to work together in optimally successful collaborations. When asked what these competencies should be, focus group participants suggested the following:

Vision and Leadership

Vision, passion and belief that the organization is doing the right thing in the right way and then being able to instill that throughout the organization. A strong leader of strong staff. One interviewee described it as "an effective herder of chickens." The ability to train and then trust staff to get the job done and to harness their passion and use it to make the needed difference. Large, long standing organizations focused on one issue can become insular and resistant to community feedback so the ability to keep the organization nimble to ensure its relevance to regional need was seen as critical.

Connected

The ability to connect with and understand community members in a large geographic and culturally diverse region. Someone who is well connected in an effective way to public and private partners and politicians. Since the Society is the program developer for the Centre, which is the provider of FASD services for the region, the need to ensure that they listen extremely well to other agencies serving FASD clients is critical.

Business Minded

The ability to manage the organization as a business, financially and structurally rather than a government agency would increase its likelihood of stability and survival in times of political uncertainty.

A.3.2 Organizational Competencies

When asked what organizational competencies are needed to make this particular model successful, the focus group participants stated the following:

Communication

Communication is critical. The organizational chart (Appendix C) has boxes that are program specific but the lines of communication on behalf of clients are totally open as one client may be involved in several different components of the program. If one FASD Coordinator is unavailable, another can fill the immediate need. So much of what they do is based on being responsive to client needs so the need to fill in for each other is evident. Additionally, venting of frustration is allowed and encouraged, but in

order to ensure program integrity and client respect, it is done in-house before going out into the community.

Equality
The Centre's programs are funded by a tapestry of government departments as well as private and corporate funders and donations. The organization does not segregate clients or staff by program funder. All are equally served or managed including the staff who are contracted to work on the Métis Settlements (for the Centre's contract to provide services there) who are included in the Centre's staff training and support mechanisms.

Congruent Message
The organizational message is the same in Cold Lake as it is in Kikino. A strong identification with the organization and a feeling of individual responsibility for its work and value in each community was seen as important.

Firm Foundation
In addition to have strong leadership, the organization has to be built on a solid foundation which develops most effectively over time. For the Lakeland Centre, the foundation is in place, policy and procedure are operational, leadership/mentorship is in place at all levels, all in an effort to ensure good development and succession over time.

A.3.3 Regional Competencies

Rural vs. Urban
The focus group participants were asked, "Would this model work in a different region?" It was felt that it would work well in other rural regions but would be a harder fit in a city where there are well established service providers.

Community Readiness
The people at both ground level and at the leadership level of a community have to be ready (i.e. have to be aware that there is a need for FASD services in their community and to then ask for and be ready to participate in service development and delivery on behalf of their residents). Understanding well the importance of community readiness, "we go where we are invited and try not to push where we're not." They do not push communities but do try to advocate for individuals within those communities. Community partnerships ebb and flow and can be affected by changes in leadership. "In some cases we have had to rebuild the same road a few times and will try to be responsive when they call." They felt that the possible upside of the model is that when a community is ready, community leaders know who to call.

Strong Partnerships
The Lakeland region has strong partnerships in parts of the region and developing partnerships in others. The Centre was initially asked to come and make presentations in communities all across the region and now communities have a greater capacity to train each other about FASD issues. One

mother indicated that since her foster child with FASD has left home she finds herself being asked for advice from other caregivers of children with FASD. As this strength grows at all levels in a community it becomes more able to support its children and adults with FASD, one of the main goals of the Lakeland Centre.

A.4 Assets and Limitations

Rationale: The gap between effectiveness and perfection exists in all organizations. This section will define some of the inherent realities that both support and challenge this model.

A.4.1 Assets

The participants in focus groups and in one-on-one interviews were able to identify the following assets of this model:

Consistent Approach to client services

People in the Lakeland region know that if you need access to anything about FASD you call the Lakeland Centre for FASD (using their toll free number if you live outside of Cold Lake). Community partners don't need to send their clients with FASD to different agencies to get different help which is less confusing for everyone. A client is less likely to fall through service cracks when there is one agency helping them to coordinate all of their services. There is consistent service delivery and standard of service throughout the region with the same policies and structures. A client knows that "someone has their back" when they are trying to maneuver their way through the complex support system that exist for them.

Consistent Administrative Approach

Having one core, stable organization was seen as an advantage over having a collection of agencies with different structures and abilities. There is the ability to train all of the staff consistently to the same level. With the centralization of knowledge and expertise, it was felt that best practice may be more likely overall. It is seemingly more efficient with less potential duplication of services and administration.

Consistent Geographic Coverage

There is the ability to cover a large rural area with this model due to the greater likelihood of recruiting staff to one larger agency than trying to fill contracted positions throughout smaller communities. The difficulty of recruiting staff to work in smaller communities is a rural reality that can lead to communities without services or to agencies "robbing staff" from one part of the region to work in another.

Consistent Regional Voice

There are no competing FASD programs in the region seeking a voice for FASD clients and services. Having one regional voice with one consistent message about FASD also provides legitimacy to a rural region which otherwise may be expected to have nothing new to contribute. One voice, with a catchment area large enough to matter and enough service experience to be helpful to others, has given Lakeland a place at the table with larger urban-based Networks.

Consistent Vision Forward

Taking direction from feedback given by agencies and clients throughout the region, service gaps can become crystal clear over time, and this can facilitate the formulation of a consistent future vision. The ability to be nimble and responsive and move forward with new initiatives is an asset of this model.

A.4.2 Limitations

Individuals identified "theoretical" limitations of a one-agency model. However they clearly said that these problems have not existed, nor do they currently exist in Lakeland, but potentially could:

Eggs in One Basket

"All of your eggs in one basket is only a good idea if the basket is good." There is potential risk of poor service delivery if the organization providing it isn't rising to the challenge. If it becomes complacent or unwieldy and fails," it would go down big" and rebuilding would take a long time.

Client Fit

If the organization doesn't fit for a client, the client would have nowhere else to go.

Single Vision

By having only one agency providing services, it could be possible to miss out on expertise or differing points of view that could be in other agencies. This could "limit the vision if you only talk to yourselves."

Community Input

There would be a lack of community input into program development if the organization did not actively seek it.

A.5 External Factors Impacting Governance Model

Rationale for Inclusion: Very good models exist in very complex environments which make them more or less able to manage effectively. This section will discuss how the environment both supports and challenges the governing of this network.

A.5.1 Environmental Challenges

Focus group participants felt that, even with the acknowledgment that they are funded by several departments of government, the primary external challenges that they face are related to the complexity of that government support, both contractual and informal. The responses were categorized and listed below:

Funding

Government decisions around funding are erratic and unpredictable and often difficult to manage on the ground. This puts tremendous stress on program and staff stability. A further complication exists when each funding department requires client reporting on their portion of a program that is funded by several departments ("reporting in silos").

Champions

FASD champions at the highest levels of government, where funding decisions are made, have come and gone over the years. The constant need to justify the importance of this work, while part of the disability's "growing up" process, keeps programs that are dependent on government funding uncertain of the future.

Rural Service Delivery

Funders do not generally understand the cost of delivering service to clients with FASD (i.e. the commitment is long term) in a large geographical area where travel costs are high. Urban understanding of rural service delivery realities is often incomplete. The expectation that the same factors exist in rural as in urban communities causes difficulty in program implementation and justification.

FASD Practice

FASD practice is still affected by ineffective human service system policy. While this is not a factor affecting the governance of the Lakeland Centre, it certainly impacts their ability to support clients with FASD in an effective manner.

A.5.2 Environmental Supports

Champions

Notwithstanding the previous statement regarding lack of champions at the highest levels, there are mid-level departmental decision-makers who came up through their career ranks in rural north eastern Alberta and have a good understanding of the development of services for clients with FASD. These individuals have proven valuable to the Lakeland Centre and to FASD in general in supporting planned

program development at higher levels.

Community Support
Because the Centre emerged from each of the communities in the area over the years, there is a support for them at the community level. While they consciously commit to maintaining relationships on a continuous basis, they do not have to spend time carving out a place for themselves at community or government tables. That work is done and allows them to focus their energy on supporting clients.

Political Support
The Centre has good support from, and working relationships with, the local, provincial and federal politicians representing the region. This support has proven critical at different times in the past and fostering it continues to be a priority.

FASD Visibility
Because of their visibility and early decision to seek private funding, the Centre has built strong relationships with the business community. The Executive Director reported her recent attendance at a regional "Oilmen's" meeting which included approximately 70 men who are managers/owners of local oil companies. 80% reported knowing about FASD through their attendance at the Centre's annual comedy-gala fundraisers. Taking FASD out of the shadows through such initiatives as public gala events and having a main street office with a large sign on the front are part of a conscious strategy to remove the societal stigma around FASD.

A.6 Impact of the FASD Service Network Program

Rationale for Inclusion: The Lakeland Centre for FASD and its services existed prior to the Cross Ministry Committee's development of the Service Network Program and the subsequent provision of network funding. This section describes the impact of the CMC program and funding on the Lakeland Centre's existing services.

When asked about the impact of CMC Service Network Program funding on the governance or services provided by the Lakeland Centre for FASD, both the Board and staff reported that the CMC funding is just one of several streams of funding that they receive. Neither the Board nor staff were particularly aware of, or impacted by, its presence separate from the other funding streams that jointly make their work possible.

When community partners were asked about the impact of the CMC funding on the Centre's work and therefore their work with the Centre, none could state with any certainty that they were aware of any impact beyond enhanced services. The Centre did not change its name or identity (i.e. to Lakeland FASD Network) or way of governing or developing services as a result of the funding.

The CMC funding is used for specific programs offered by the Centre but does not cover the entire cost or all of the FTE's of that program. Additionally, funding has been sought beyond the CMC for specific projects that the CMC has no involvement with (see Appendix D).

The Centre's program aligns with the 10 year strategic plan developed by the CMC and no adjustments were required with the receipt of the CMC funds. Each of the Centre's existing and/or new programs under development (funded outside of the CMC funding) are also in line with the CMC's strategic priority programs (i.e. assessment and diagnostic services, family support, targeted and indicated prevention).

The governance and management structure of the non-CMC funded programs and services did not change with the receipt of CMC funds. The supervision structure needed to manage the new staff that were acquired changed in certain instances, but the governance structure itself remained the same. Service enhancements have made it possible to provide existing services to more communities in the region (i.e. more PCAP sites). It has also made it possible to accept clients for support services who have moved to the region and been diagnosed elsewhere.

The Centre has not adopted the CMC supported/designed tools. The required business planning process has been implemented and provides a different structure to work through the big picture.

With that as background, the Centre management was able to identify specific benefits that have been received as a result of the CMC-SNP funding.

A.6.1 Program Enhancement

The funding made it possible to put more "boots on the ground" in some of the regional communities. There are more PCAP workers and FASD Coordinators in some of the communities. Additionally, because of the CMC funding accessed by the Métis General Council, with whom Lakeland has a

contract to provide diagnosis on the Métis Settlements, more diagnostic services are being provided to regional residents. With more staff available, there are more opportunities to do work with other communities initiatives outside of the four main centers (i.e. participation in Interagency meetings, community initiatives that will help clients and increase awareness of FASD.)

Existing Program Fidelity

Prior to the CMC program, the Mothers-to-Be Mentorship program was operating based on a locally adapted model of the PCAP program. As a result of this funding, the local program has aligned itself with the PCAP model and has benefited from that realignment both locally and provincially.

Funding and Administrative Stability

The CMC funding has provided some of the needed financial stability making it possible to focus less on fundraising and more on other priorities and to leverage that stability to receive other support.

Network Councils

Greater connection to other provincial FASD programs through provincial councils has made it possible to expand the provincial visibility of FASD and to standardize excellence throughout the province.

Equipment

The acquisition of audio/visual networking equipment has been useful to the Centre overall and would not have been available without CMC funding.

Web Training

The staff identified the usefulness of the FASD Learning Series sponsored by the CMC and facilitated through the Alberta Centre for Child, Family and Community Research. They have both learned from and contributed to these webinars.

Section B - CMC Funded and Non-CMC Funded Programs and Services

Rationale for Inclusion: The FASD CMC-SNP provincial evaluation focused on the CMC-funded programs and services only. In order to present a complete picture of the services available in the Lakeland region, a more complete evaluation of FASD programs and services offered through the Lakeland Centre for FASD is provided.

B.1 Formative Evaluation

The FASD CMC-SNP formative evaluation conducted by KPMG provided feedback on how network Leadership Teams and funded service providers developed and implemented the SNP in the region. As the Lakeland model did not fit the evaluation framework or questions developed by KPMG, little useful information was produced representing how the Lakeland region works in implementing its model with community partnerships, which is one of the key guiding principles of the SNP model. The following information is provided to describe how coordination and collaboration work in the Lakeland Network and presents findings from the interviews conducted by the evaluator.

B.1.1 Agency Partnerships

While one of the core strategies of the CMC-SNP is the formation of service partnerships for the provision of services to individuals with FASD, it is fully recognized that a single agency cannot do this work alone and the desire to ensure that others doing the work are working together on behalf of a client is at the heart of the desire to work collaboratively.

Collaborative (if not funded) partnerships are at the core of the work done by the Lakeland Centre. All of the Centre's diagnostic teams are made up of individuals from regional agencies. Service recommendations made by the diagnostic teams for service follow-up are intended to connect the clients to the resources provided by other agencies in their own communities. The FASD Coordinators' main goal is to connect their clients to other organizations and individuals who can establish a wrap-around network of support for each client. Funding to enhance programming is regularly sought from local and provincial agencies who can assist in filling the gaps in the current service network. How well this does or doesn't work on the ground is the purpose of evaluation and the cause of intense frustration for the staff, but the model as it exists is built on the need to work together.

The difference in the work needed to maintain these networks is perhaps subtly different than the typical SNP network. Indeed, one of the main responsibilities of the Executive Director is the establishment and maintenance of these collaborative partnerships throughout the region and it is done by herself and by every member of the staff who work in each of the communities by participating at planning tables or with individual clients. It has to do with establishing good will, credibility, communication and transparent vision, professionalism, a consistent message and providing good

service.

In an effort to gauge partner satisfaction with the current structure and services provided by the Lakeland Centre, the evaluator conducted one-on-one interviews with 15 regional partners representing both government and non-profit organizations who regularly work collaboratively with the Lakeland Centre. The preamble to the interview included a description of the CMC-SNP funding model, how it is provided throughout the province and in the Lakeland area. Each was then asked for their assessment of the effectiveness of the model in the Lakeland area and what recommendations they would make to the Centre regarding either the model or specific service provision. Their comments are summarized in the Assets and Limitations section of this document (page 16-17).

One of the comments was echoed by many, "The service we need is there and it's good. How it's governed doesn't matter." When asked specifically if they would want more input in how services for individuals with FASD are designed for the region, most indicated that the Centre regularly seeks input and responds to concerns and suggestions when they are made. When asked if they would prefer a more direct role (as with the other network leadership teams), one reply was typical of most, " If it isn't broken, why would I want to mess with it? It's fine as it is."

As far as collaboration, they indicated that someone from Lakeland is always at "the table" when interagency or specific-issue discussions occur at a community or regional level and they always participate consistently. One specific comment was, "I like it that when someone from the Lakeland Centre is at the table. It's the same person each time and they can make decisions and provide input, they're not just a body filling a spot who has to take everything back before making any moves."

General evaluative comments included overall satisfaction with the responsiveness of the services provided, the knowledge and professionalism of the staff, the amount of communication from the Centre, the cultural ease of the staff when working in Aboriginal communities or with Aboriginal families, the excellence of training provided by the staff, visibility and transparency, the passion and commitment of the staff and organization overall.

Additionally, agency partners indicated that the outcomes for their clients with FASD are improved as a result of their collaborative work with the Centre because they themselves are provided with better strategies in working with their clients and the clients are better able to access and maintain their services with the Centre's support.

These collaborative partnerships take time to build and have improved in the years that the Centre has been providing services. An FASD Coordinator gave an example of how the collaborative working relationships have changed over time. An FASD client told her AISH worker in anger to cancel her AISH. In the past the worker would have done as the client told her to but instead this time she called the FASD Coordinator who worked through the problem with the client and resolved the issue, thus saving the client grief from a bad decision, the AISH worker time and the Department money.

B.2 Summative Evaluation

The summative portion of the CMC-SNP evaluation conducted by KPMG was focused on the network's achievement of client specific short-term outcomes. The provincial summative data collection tools were deployed with Lakeland clients from the portions of their programs funded by the CMC. The KPMG data processes were designed for the more typical network structures and were difficult to administer in the Lakeland's direct service structure. Difficulty in separating client data by funders coupled with the larger volume of clients served directly by the Lakeland Centre made the surveys impossible to administer in a way that provided any meaningful amount of data. This was the case particularly with the assessment and diagnosis surveys as well as the support surveys portion of their protocol.

In an effort to provide a more complete picture of the Lakeland Centre's outcomes, the evaluator implemented a series of qualitative methodologies to enhance the information garnered through the provincial process. The findings for each of the funded and non-CMC funded programs offered by the Centre is provided below:

B.2.1 PCAP

The KPMG survey was administered to the CMC-funded portion of the PCAP program by the PCAP supervisor during in-person interviews. The CMC-SNP funds a portion of the PCAP program provided in two of the four communities and that portion of the clients were interviewed. The results are below:

PCAP Client Survey Results						
Q#	Questions	Total Number of Survey Responses	Response Levels			
			Poor	Fair	Good	Excellent
1	How would you rate the quality of the services you received through PCAP?	14	0	0	4	10
2	Did you get the kind of service that you wanted?	14	0	0	2	12
3	To what extent has the PCAP mentor met your needs?	14	0	0	6	8
4	If a friend were in need of similar help, would you recommend the PCAP program to her?	14	0	0	1	13
5	How satisfied are you with the amount of help you received?	14	0	0	3	11
6	Have the services you received help you to deal more effectively with your problems?	14	0	0	3	11

7	In an overall, general sense, how satisfied are you with the service you received?	14	0	0	5	9
8	If you were to seek help again, would come back here?	14	0	0	1	13

The PCAP Supervisor was also asked to include any comments that the clients made during the interviews that would help to provide evidence of impact.

- "Candice has always been there through my troubles."
- "I would come back here for help because you always do everything in your power to help me."
- When asked if the client had received the kind of service that was wanted, she replied: "Gotten better than I thought it would be."
- "Pretty much helped me change my attitude and perspective on a lot of things."
- "Even when I'm upset and angry, I have someone to talk to who is neutral and will offer suggestions."
- "Even if I fall I know I'm still welcome here. When I know I'm going to fall I just talk through it."
- "They've totally turned my life around. I don't think I'd have my kid without them."
- "The service is absolutely amazing. They totally change lives."

For specific PCAP case examples, please see appendix E.

B.2.2 Assessment and Diagnosis

As described earlier, the assessment and diagnosis portion of the provincial network evaluation did not generate enough data to provide any meaningful conclusions. Previous evaluations of the Lakeland Centre's diagnostic process indicated that the process is completed respectfully and effectively, and that as a result of the diagnosis, caregivers:

- experienced an increased knowledge of FASD (58%)
- experienced an increased understanding of their child's behaviour (64%)
- are doing things differently for the children (60%), for themselves (27%) and for the community (31%).
- 82% of caregivers received what they were hoping for when they sought a diagnosis and 93% would recommend that others go for a diagnosis if FASD is suspected.
- 67% of the parents felt that the diagnosed child's behaviour at school had improved after the diagnosis and 38% felt that the child's behaviour at home had improved.

Though not within the structure of this evaluation, but of potential interest is the review currently in progress of caregivers being interviewed 7-10 years following their child's diagnosis by the Centre's diagnostic teams. Each was asked in a telephone interview whether the diagnosis they had received for their child had proven to be useful in raising that child and in what ways:

- 23/24 parents interviewed felt that the diagnosis had been helpful or very helpful in raising their child.
- The top three reasons given were: helped them understand the child's abilities and behaviour, helped them to better manage the child's behaviour, and helped them to access other services for the child (primarily school based support and funding). Also mentioned were the reduction in parental stress and the calming of the home atmosphere with better management techniques being used.

As the diagnostic process has not changed significantly in the past 11 years and occasional post-diagnostic surveys indicate continued client satisfaction with the process, we are confident that these findings are generalize-able for the purposes of this evaluation.

B.2.3 Follow-up Support - Children and Adult

In order to assess the quality and issues that exist in providing follow-up support for adults and children post-diagnosis, focus group sessions were conducted with each of the Centre's adult and children's support teams. Resulting analysis showed that while they deal with different clients, the issues impacting their ability to provide the best support possible are the same, so will be reported together. It should be noted that the Children's FASD Coordinators work with caregivers and children while the Adult FASD Coordinators work with adults who are diagnosed as adults or occasionally work with children who have become adults and been transitioned into adult services.

Both focus groups began with the preamble explaining their role in the session which was to assess the quality of service that they provide their clients and discuss the issues that impact their ability to provide the best services possible. Acknowledging the inherent evaluative oddity in asking the workers to rate their own service provision, it became clear that they fully understood the challenges of trying to gain that information directly from their clients and entered into the spirit of the exercise with openness and the desire to provide useful information.

When asked if they were **satisfied with the quality of the service** they are able to provide for their clients, they all acknowledged that they try their best to help the client with what they need at that moment. If you were to ask the client on any given day if they are satisfied with the support they are receiving, it would depend on whether the worker had been successful on that day in getting them what they wanted/needed. The Coordinators are used to being "loved one day and hated the next" and are satisfied that on the days that they are yelled at by the client that it is better that the client is yelling at them in their office than in some other agency where they would be removed and cut off from

services.

The Coordinators felt strongly that they sometimes care too much and try too hard and the most difficult part is that in spite of their best efforts, sometimes the system doesn't come through for the client and not much progress is made. In their role as advocates and "arrangers" they have become adept at knowing when to push and when to back off, where to go to get what they need for a client and how to cushion the fall for a client when things just don't work out or absorb the yelling or "being fired" when a client gets angry, which apparently is a fairly regular occurrence.

When asked if they were **satisfied with the amount of service** that they are able to provide, the response was a unanimous "no." It was suggested that it will never be enough for some of the clients, particularly the adults, who require 24/7 care and a solid team to ensure that they are surrounded with support. Both groups stated that each client's need is different and they can't do everything that would benefit that client but that whatever they can provide is better than the client would be receiving without them. One Coordinator indicated that the work they do keeps many of the clients out of costly social systems and that, "They can pay us to care for them or they can pay for their incarceration or their addiction."

When asked if they are confident that what they are doing is **helping their clients move forward** in their lives they said for the most part, yes. For every FASD client, progress is primarily one step forwards and two steps back and progress can be made for several months and then the client makes one bad decision that takes them back to square one. They feel they are making progress when the client is only in crisis mode instead of "apocalyptic mode" which is where they normally would have been. They try to get the clients supported and connected so that they need the Coordinator less, but they never totally go away and their file is never closed. The Coordinators also indicated that in the experience gained in their years of working with clients with FASD, their ability to help the client manage his/her crises has increased.

When asked what they would **change about the program** over all, they wished for more money to be able to put more people on the ground throughout the region so they could be more responsive to client needs and be more able to work at community planning tables.

When asked about **work with community partners** in providing services to their clients, all acknowledged that it is better than it used to be but that there are still gaps in both knowledge, system wide policy, and individual staff willingness to "step up to the plate." They felt it was a work in progress and indeed progress had been made. However, most of the client failures that were discussed had to do with the larger system failing the client.

The groups were asked to provide an example of both a case that had worked out well and one that was a "failure." They suggested that all clients are successful or failures for a time, but were able to come up with two representative cases.

"L" and her spouse of 20 years are both alcohol affected (one diagnosed, the other not). She has an IQ of 60 and struggled for many years to parent. Their six children have been apprehended five times by Children's Services. All six children have been diagnosed with FASD. The Coordinators have been

working with her for many years and she has made significant progress. The last time the children were apprehended was two years ago and they have had their children back for a year. She and her spouse completed addictions treatment and have had one relapse in 2 years. She has become actively involved with the children's schooling and attends IPP meetings and openly advocates for herself and her children which she would not have done before. The school counsellor reported to the Coordinator that "L" has "grown leaps and bounds" with the Centre's involvement. "L" keeps a book in which she writes down everything so she can remember (appointments, conversations, visits, what she does with her children, etc.). She writes her children stories and poems because she can't communicate very well. She has received two of the Centre's Shining Star Awards (given to recognize success). She still has to call for advice on what to do in situations and sometimes she still gets it wrong and needs help thinking through solutions. The staff consider "L" a "huge success" even though she still needs their help and support and they will be working with her and her diagnosed children for years to come.

The "failure" case is about a young man ("T") that the Coordinator began working with at least five years ago who was considered very low functioning and eligible for both AISH and PDD though he was never able to connect with PDD services. He had complex needs caused by mental health issues, addictions, diabetes and an unhealthy home environment and no family support. He lived in a community where no supports were available locally and travel to access them was nearly impossible. Failures all along the system were described and led to the young man's ultimate death in a snow bank.

When asked to define the factors that made the difference in these two cases, the Coordinators identified the following:

- The clients' abilities and how they feel about themselves and their lives. "L" felt more positive more often (not always, but more often) and was able to develop the strength to advocate for herself or has learned who to call when she needs help and will do so. "T" was functioning at a lower level and had no positive context or experiences in his life.
- Family support - "T" had no family support or assistance in dealing with his life. His father would take the phone when he left the house making it impossible to reach or support "T." "L" had long term support from her spouse.
- The client's physical environment can sabotage the best efforts of the client and those who work with them. After many years of not controlling their environment, "L" and her spouse made rules about who could enter their home. "T's" home environment included drug trafficking by others who lived there making it impossible for him to deal with his own issues.
- "L" did not progress until she learned to trust the staff from the different agencies who came to her home to help.
- An agency's ability and inclination to provide assistance. Stringent departmental policies and staff unwillingness to be client focused in their practice caused "T" to remain largely unsupported which eventually led to his death.

The staff reported that "T" represents the worst case success scenario and "L" the best. The rest of their clients fall between them, but most closer to "L's" end of the continuum as the clients at "T's" end most

often disconnect from service.

B.2.4 Youth Transition

The evaluator did not have contact with the client's of this project, but did spend time researching the program and its background to review its place in the Centre's offerings.

Since beginning to provide services in 2009, 18 youth have participated with the Coordinator and 7 have completed the process and have moved into adulthood with the goals and supports identified and in place. The Coordinator is working with 5 currently and 6 did not complete the planning process for various reasons including moving out of the area, the client didn't feel the need for a written plan, or finding employment.

Not all FASD youth will be able to complete the transition planning process. Currently the Children's Coordinators recommend youth to the program based on what has been found to be the two most important program criteria: the youth's life must be stable and they must have a supportive family system. This means that the youth being transitioned exist in the middle of the client spectrum. At either end are the youth who are so stable they don't need assistance and youth who are so unstable the program wouldn't be effective. There are approximately 97 children who are potential candidates for transition planning. Not all will be suitable or in need of support. In any case, it is more than is currently possible to serve. Plans for increasing capacity were not discussed with the evaluator.

B.2.5 Adult Employment

The evaluator met with 2 workers and 4 clients of the Adult Employment program which is funded by Alberta Employment and Immigration. It also received one year of funding from the ACE Program (through Alberta Recreation and Parks Association) which allowed it to add participants and increase program activities. The program meets weekly as a group with usually 8-10 clients. Appendix F includes written statements from participants in the employment program regarding their feelings about program benefits.

The Coordinator did indicate that employment is still illusive for this group, that they tend to come and go from jobs. Her role (with the client's permission) is to help the employer understand the client's FASD abilities and FASD in general, what to expect and what doesn't work well. She usually checks in on the job weekly and is available to step in to solve issues at any time when needed.

The Coordinator was asked whether the clients were able to separate out the benefit gained from attending the employment group from the benefit they gain from the other services they are also accessing from the Centre. She said that they enjoy attending group and expressed that clearly to the evaluator but likely were not able to separate out the impact of the group from the support that they receive from other Centre programs.

B.2.6 Summer Camp

The KPMG Support Services/Parent Caregiver Survey was adapted and administered to families who had sent a child to the summer camp. Interviews were completed for 8 participants. The results are as

follows:

1. How would you rate the quality of the Camp your child/dependent attended?

   8/8 - Excellent

2. Did your child/dependent have the kind of experience that he/she wanted?

   8/8 - Yes, definitely

3. To what extent did the Camp meet your child/dependant's needs?

   6/8 - Almost all of my needs were met.
   2/8 - Most of my needs were met.

4. If a friend were in need of similar help, would you recommend this Camp to him/her?
   6/8 - Yes, definitely.
   2/8 - Yes, probably.

5. How satisfied are you with the amount of help your child/dependent received at Camp?
   8/8 - Very satisfied.

6. If you were looking for a Summer Camp again, would you come back here?

   6/8 - Definitely.
   2/8 - Yes, probably.

7. My child/dependent learned new skills from attending Camp?
   5/8 - Completely agree.
   3/8 - Somewhat agree.

In addition to the survey the evaluator interviewed two previous Summer Camp Coordinators who will not be returning to work in the camp as they no longer qualify for STEP funded positions.

In both cases, the Coordinators' only concern was they felt that the camp would benefit from a larger and better equipped facility and a camp cook if funds would allow. Other than that their support and praise for the camp were unqualified.

They felt that the greatest factor in ensuring a successful camp is the quality and training of the staff who work there. It was identified as an exhausting job as the 4 staff provide full time "care and feeding" as well as plan and implement all camp activities for the full 7 weeks. Having a variety of activities geared to the needs of children with FASD and a solid structure were also identified as critical elements.

Though the evaluator did not review participant information, the staff indicated that a large portion of the children who come to Summer Camp are from foster or group homes. They felt that the

registration process and cost structure may be the factors limiting the participation from birth parent homes. Most of the Coordinator's interaction with the caregiver/social worker are during the registration process so they do not receive regular or structured feedback from them regarding the child's enjoyment or impact of the Camp. One mother (in a grocery store sometime later) did indicate that her child had previously been very quiet and non-verbal but came home from Camp recounting his experiences in great detail which was very satisfying to the parent. The child attended Camp every year after that. Both individuals interviewed independently stated that this Camp is the only positive experience that some of these children will have all year as they struggle in school and at home.

When asked, both former staff members indicated that they had no concerns about the value of the Camp or its program design and they hope it continues. They also indicated that the value of working at the Camp for them was both financial and experiential. They are currently school teachers and the things they learned about FASD and how to deal with children with FASD (or any disability with similar behavioural manifestations) have provided insight and strategies that have helped in their classrooms.

As a result of these discussions it is felt that a better system of tracking camp participants year to year as well as a more structured system of caregiver feedback would provide better information for evaluation and accountability purposes and are therefore recommended for future consideration.

B.3 Factors that Contribute to Success

The Lakeland Centre for FASD has been formally providing services to the Lakeland region for 11 years. During that period of time they have established a strong foundation of excellent services that are well utilized, supported and even lauded by their peers throughout the region. The model that has worked so well here is dependent on specific factors which have led to its success. These have been discussed previously in this document but are repeated here for emphasis.

B.3.1 People

There is no question that the success of the Lakeland Centre lies largely at the door of the people who have participated in making it work. During the focus group with the original committee members, they were asked to define what made this initiative successful when many funded programs have come and gone over the years. Among other things, they identified the willingness of the people involved right from the beginning to do whatever was needed to make it successful. This determination was, and is still, evident at many levels and would be required to replicate this model. Specifically needed would be:

- A group of people who see the need and are willing to do the work over the long-term - The original Lakeland FASD Committee came from other departments and extended themselves beyond their own organizational policies and worked without a net to see that something came together for people with FASD.
- An organizational leader who can also manage - The right combination of business savvy, vision, passion, determination, and compassion are needed to grow an organization in the FASD field which is largely under-funded, under-supported, and misunderstood.
- The right staff and diagnostic team members who are passionate and compassionate, and willing to bring their best game to work outside the box.
- Society Board members who are willing to provide steady support and vision.
- Families are perhaps the most important people involved in this model and they are not seen as just clients but partners as well. They are courageous and have been willing to lead and to teach about the services they need.

B.3.2 Community

FASD can be a difficult issue for a community to come to terms with. Ensuring that a community contemplating FASD services is prepared, at all levels, to participate and take ownership takes time and patience. Trying to provide services without this ground-level preparation will most likely lead to failure.

B.3.3 Client Focus

One of the leading contributory factors to staff job satisfaction for the Centre staff is that in this job,

unlike others they may have had elsewhere in the human services, they are able to do whatever it takes to help a client. This commitment to client support is at the philosophical foundation of the work they do and has been from the beginning committee days. As the organization has grown, policies and procedures have been implemented to ensure accountability and safety, but the core concept is still to creatively bring about whatever the client needs to succeed. It was this commitment that led to:

- the original decision to join diagnosis and follow-up support as one service;
- the decision to never close a client file - the door is always open;
- not assigning clients to support workers by geographical location but by an assessment of best worker-fit with that client;
- a mobile diagnostic clinic model which takes the diagnostic teams to the client's community instead of making the client travel to a central clinic.

A client-centered service delivery model is not always the most economical, which is why it doesn't often exist, but it is the most effective which is why it still is at the heart of all service decisions.

B.3.4 Partnerships

Discussed previously in this document, building and maintaining effective partnerships with other client serving agencies and individuals is critical to effectiveness. The programs of the Lakeland Centre would not exist without the active participation of other service providers in the area.

B.3.5 Funding Outside the box

Relying on government funding to carry the burden is not a good long term strategy. While still necessary for core services, finding other sources of funding to assist not only contributes to community ownership but provides a stability that would not otherwise be possible.

B.3.6 Politics

The Centre would have failed at several critical points in its history if it had not been for the intervention of politicians who spoke on their behalf. Cultivating the support of local politicians is prudent and lends legitimacy to both the work of the organization and the issue of FASD itself.

B.3.7 Long Term Planning and Vision…

…And patience. FASD was not on the radar in north eastern Alberta when planning began and slowly over time, the need and the practice have taken shape and continue to expand along with peoples' vision of what is possible. There are still significant service gaps for people with FASD, but much has been accomplished in 18 years in the Lakeland region. The rest will be accomplished with patience and persistence.

B.4 Threats

In spite of a perceived positive trajectory for the continued growth of the Lakeland Centre for FASD, several issues of concern should be taken into consideration:

B.4.1 Growth

The one-agency model coupled with a desire to continue to fill the gaps for clients with FASD has turned the Centre from a 3 person office in 2001 to and organization of 19 today. With the staffing of the 2nd Floor Women's Recovery Centre, that number will increase substantially.

Clients diagnosed with FASD will require lifelong supports and while the plan is to build support networks for each client, the reality is that with the commitment to never close a client file along with the continuation of new client diagnosis, the system could be overwhelmed. None of the staff in a variety of focus group sessions, when asked, were able to identify what or if there is a plan for the future on how to manage the potential growth.

B.4.2 Difficulty in Defining Success

The FASD field, at both the academic and practitioner level, have had a difficult time coming to terms with how to account for success with a client group whose life trajectory is not linear and will always need support. While we can leave it to the academic community to eventually figure out how to do that most effectively for the field overall, the staff at the Lakeland Centre are left to define it for themselves and they currently base it on anecdotal evidence of impact, for that day at least. While this has been enough to keep them moving and passionate about their work, it is an important issue to come to terms with. The staff with their years of work are experiencing success everyday and with some guided effort could ferret it out and structure it in a way that is meaningful if, for no one else, for themselves, but trust that it will be useful in a broader context.

B.4.3 Funding

No discussion of FASD threats would be complete without a section on the absolute need for a continuation and increase in core funding. While the Centre would not cease to exist without the CMC-SNP funding, it would have to scale back its current reach and undo some of the significant work it has been able to do in the broader region.

B.4.4 Client Record Management

When one agency provides a variety of services funded by a variety of funders to a large group of clients from all over a region and then has to account for client participation and impact on certain portions of the program only, problems can occur. This problem became most apparent in the current CMC-SNP provincial evaluation process when staff were tasked with identifying and contacting clients for surveys in a timeline that was better designed for small agencies with fewer clients in a single program than Lakeland with several hundred clients going in and out of all of the evaluated services. The program philosophy is that clients receive seamless services but they're expected to keep them separated statistically. Were resources available, the Centre would benefit from an electronic case management system.

Appendix A - Focus Group Participants

Lakeland Centre for FASD Management Staff - April 18, 2011

Audrey McFarlane
Joanne Ring
Tracey Knowlton
Donna Fries
Kim Kachmarsky

Lakeland FASD Society Board - June 1, 2011

Coleen Manary
Lorraine Deschambeau
Ann Tucker
Bridgette Noel
Paulette Dahlseide

Original Lakeland FASD Committee - September 23, 2011

Audrey McFarlane
Sue Lysachok
Joan Panteluk
Levina Ewasiuk

Adult Employment Program - November 3, 2011

Ingrid Harvie
Candice Sutterfield
4 clients

Children's FASD Coordinators - January 16, 2012

Brenda Feeland
Lisa Murphy

Adult FASD Coordinators - January 16, 2012

Heather Zink
Ingrid Harvie
Alania Sanregret
Mark St. Germaine

Staff Interview Participants

Megan Tucker, Transition Coordinator - January 19, 2012
Melodie Cochrane, previous Camp Supervisor - January 17, 2012
Diana Douglas, previous Camp Supervisor - January 10, 2012

Partner Interview Participants

Interviews conducted January 4-13, 2012
Janice Fulawka, Northern Lights School Division
Patricia Gervais, St. Paul School Division
Randy Basom, Alberta Employment and Immigration
Tamara Urlacher, AISH Generalist
Linda Boone, FCSS, St. Paul
Anita Polturak, FCSS, Lac La Biche
Sharon Winik, Alberta Health Services
Bonda Thompson, Alberta Children and Youth Services
Shannon Ballas, CFSA - Métis Settlements
Dale Drummond - PDD
Florence Large - Saddle Lake Wellness Centre
Pauline Thompson - Kikino Métis Settlement
Yvette Houle - Dr. Margaret Savage Crisis Centre
Yvonne Szydlik - PDD
Christine McWillis - FCSS, Cold Lake

Appendix B - Lakeland FAS Committee Awareness Campaigns

1994-2001

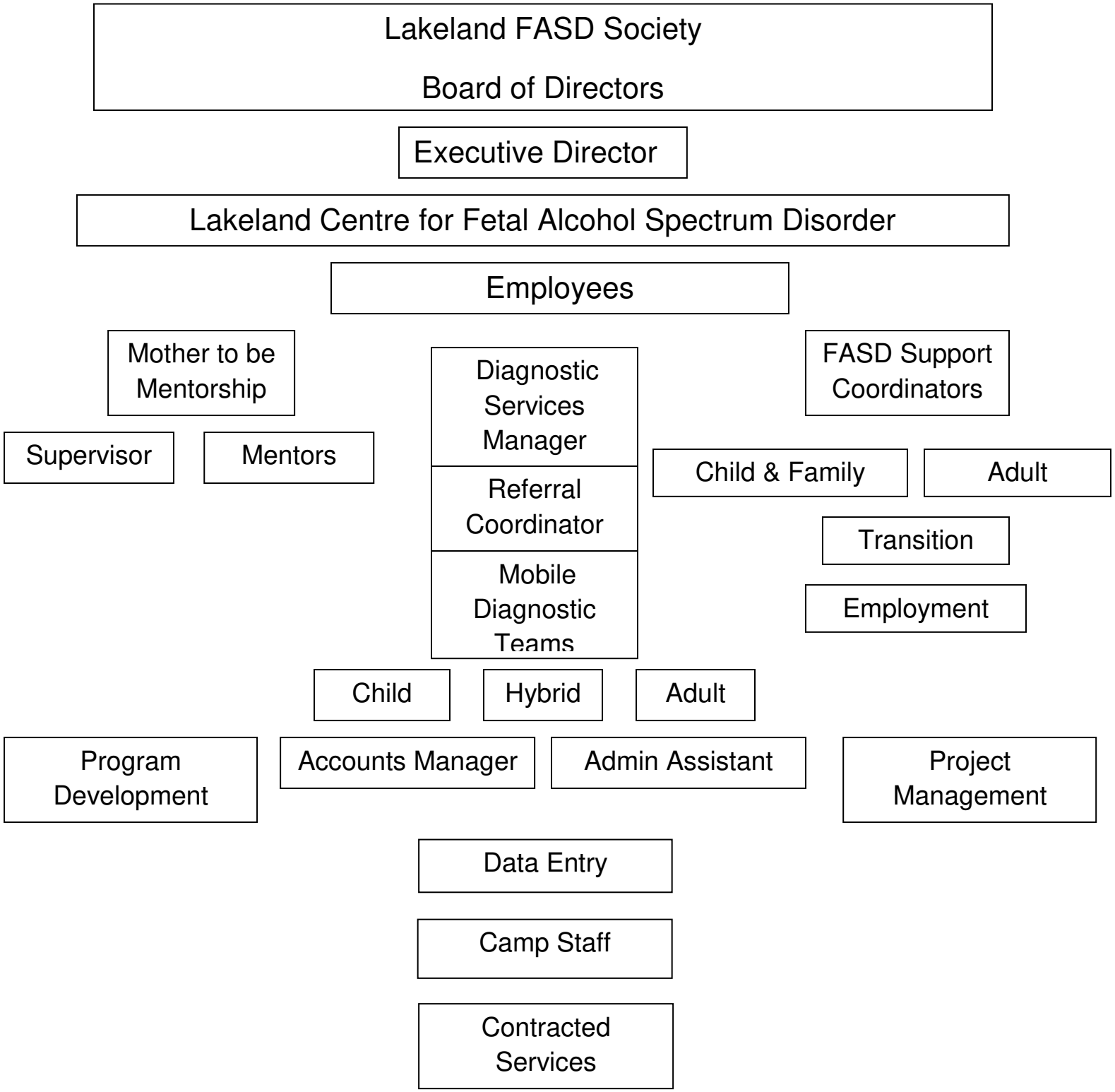
- Book markers that were placed at the public and school libraries.
- Snickers bars (small) were presented to high school students after a brief presentation with a tag that read: "You can snicker at drinking during pregnancy but FAS lasts a lifetime"
- Trail rides were organized with information bags given to all participants and horse trailer bumper stickers.
- Horse trailer bumper stickers were given out at rodeos and other horse/riding events.
- Small "Think of me" posters with a baby holding this sign and a caption that read "No alcohol during pregnancy, please." These were carried by all committee members and placed in public washrooms wherever they went. Hundreds of these posters were placed on the backs of washroom stalls.
- Larger posters were developed and delivered to bars and restaurants to be placed on the mirrors in men's and women's washrooms.
- The committee worked with hairdressers in the community to have the small "Think of me poster" placed in the bottom corner of their mirrors and provided some information if anyone asked about the poster.
- Liquor stores were provided posters regularly.
- Brief presentations with Kindergarten and Grade One children who then drew the message learned on liquor bags. The bags were then taken back to the liquor store to be used.
- Half page flyers were placed in grocery bags at the local grocery stores.
- A "Mocktail" (non alcohol beverage) cookbook was developed and given away at functions and just prior to Christmas through the grocery stores.
- Posters were put up in doctors' offices, human service offices and hospitals.
- Coasters were developed and given to be used at bars.
- Father's Day declaration forms were available in human service government offices for expectant fathers to sign to be abstinent from alcohol in support of their partners.
- Placemats were developed and thousands given to various restaurants over the years.
- Displays were developed: "Protect your brain" displaying a picture of a snowmobiler with a helmet, a cyclist with a helmet, a quad rider with a helmet and a baby in the womb with a helmet. "No alcohol is best during pregnancy." This display was set up at various public venues, conferences, gatherings and events.
- On September 9, 1999, International FAS Awareness Day was announced in Toronto by a Canadian group, signifying the importance of 9 months of pregnancy (Buxton, Philcox and Kellerman, 2008). The Lakeland FAS Committee launched into action around this time and many of the above activities happened on or around that day.
- Many events were written about in the local newspapers.
- A local businessman invited the group to use the question/buzzer system on the outside of his building to place questions about FAS
- Developed a brochure with information about FAS.

- Developed a flip chart resource for professionals and support workers to use with pregnant women.

2001-2009

- Provided canvas bags or purses with a discrete FASD prevention message to women's conferences around the region as well as youth conferences.
- Provided pens with prevention message to women's golf tournaments.
- Developed a "Mocktail Challenge" that is annually delivered in the high schools with teams of students and invited teams such as media, teachers, health unit, etc who develop a mocktail in a few minutes from a secret ingredient list provided by the LCFASD. Winners had bragging rights with the winning drink featured in the local newspaper and in 2009 the LCFASD had enough winners to make a calendar.
- Linking with the local PARTY program to deliver FASD information to grade 9 students.
- Teaching the grade 10 CALM classes in the region about alcohol and pregnancy.
- Providing resource material to libraries in schools and community.
- Helping the First Nation communities in the region to develop BreakFASD for International FASD Awareness Day.
- Summer lake swim across Cold Lake – swim for prevention of FASD!
- Open houses with free hot dogs over the lunch hour.

Appendix C - Organizational Chart



Appendix D - Program Listing and Funder

	Name	Current Funder	Year first funded	Program Focus	Clients	FTE's	Purpose
Receives no CMC funding	**Youth Transition Planning**	Alberta Employment and Immigration	2009	Support Services	Children and Youth 7-18	1	Assist youth with an FASD diagnosis to transition to adulthood.
	Adult Employment Program	Alberta Employment and Immigration	2009	Support Services	Adults	1	Assist adults with an FASD diagnosis to enhance their life and job readiness skills
	FASD Summer Camp	Private Donations (90%) Government STEP (10%)	2006	Support Services	Children and youth	4 (seasonal)	Provide a fun experience for children diagnosed with FASD in a natural setting. Providing caregivers a week of respite.
	Adult Support Services	Alberta Seniors and Community Supports	2005	Support Services	Adult	2	Provide post-diagnostic follow up support services for individuals diagnosed with FASD as an adult.
Receives partial CMC funding	**Diagnosis and Assessment**	CFSA (15%) CMC (75%) Métis Network (5%)	2000	Assessment and Diagnosis	Children, Youth, Adults	1 ?	To provide assessment and diagnosis services for clients with FASD.
	Children's Support Services	CFSA (100%)	2003	Support Services	Children and Youth	1	Provide post-diagnostic follow up support services for children diagnosed with FASD.
	PCAP	CFSA (5%) CMC (80%) Métis Network (15%)	2003	PCAP	Youth and Adults	1	Provide targeted prevention support services for women at risk of having FASD children.

Appendix E - Client Stories and Program Highlights

All of the following client stories have been included in this document with the client's permission. They were written by the clients and have not been edited for spelling, grammar or content. Punctuation has been edited for ease in reading.

Kagney

Honestly, I was lost before I was in the Mothers' mentor program. I had quit drugs and drinking when I found out I was pregnant and shut myself out of everything until Candice told me about the program. I came a long way and not scared to admit my past and what problems I was in and I know I can speak out and get help if I were to fall again or even a confidence boost if needed. I learned how to handle my problems in a better way and got out of my shell that I was building to block the problems and stay cooped and stranded. I have hope, love and get along with my parents and sisters now. I am taking the roll of being a mother and loving every moment of it. I can say I am a beautiful single mother who is doing well and accomplishing a lot in the past couple years I have been with this program. I know I have a great support system with this program and I consider Candice as my journal/diary, is how I would put it; to telll or say anything to, from my old habits to my new beginnings and my goals I am constantly working on. I will succeed and hope I won't fall again, but it's a battle everyday wanting and thinking, what if I do a line, it shouldn't be a problem but I look at myself as in those teen commercials when they look in the future but I look in my past and what could have been if I didn't join this program. Would I even be alive? My immune system was slowly shutting down and in and out of the hospital with kidney problems and becoming too sick to handle work. So this program is great and I thank this program for who I am and becoming.

PCAP Mentor's comments regarding Kagney:

When Kagney first came into the Mothers-to-Be program (PCAP) I was still working with the Healthy Babies program (Canada Prenatal Nutrition Program) and thought it was a good idea to refer her to this program. She seemed very depressed and anxious. She really did not expect this pregnancy and was using drugs and alcohol but was trying to quit. She was a little unsure if she wanted to join Mothers-to-Be but did because she wanted her child to be healthy. When I came to work for Mothers-to-Be, Kagney was still expecting and was still very, very down on herself. She didn't go out much and didn't want to be around friends or family. I thought that she needed some one-on-one so would go to her place to keep her company and just talk. After she was on maternity leave, the Lakeland Center had the ACE program going on and she came to every session. In the beginning she thought she didn't need the extra support. She was living in a rundown place and wanted to get out. We worked hard to move her to Lakeland Lodge and Housing (subsidized housing) so she had one worry off her shoulders - the rent payment. She was still feeling very down so we worked on her self-worth with programming and different workshops. I could see her coming out of her shell each week. After her baby was about 10 months old, she had an opportunity to go to work but was scared that the money she was going to

make was not going to be enough to support her and her daughter but the hours were perfect. Before Kagney got pregnant she was working in the oil field and was making good money so she was not used to making less but as I see Kagney working again and being a single mother and doing a great job you can see what the Mothers-to-Be mentor program did for her. It gave her: 1. confidence, 2. self-worth, and 3. being able to look back and see where she was and where she is now.

Courtney

The FASD clinic has helped me grow stronger in several ways a few of which improvement on attitude, outlook on life, and a healthier lifestyle.

I have been given an incredible opportunity by being able to work from home making my handmade/custom cards. Most people have their hobbies as which my job was one of mine till it began to grow strongly into a passion of mine. I've grown to know so many new ideas and strength that I did not know I had. My work from home is very comforting for me, anytime I feel overwhelmed with daily life I go work on my cards, or if something is upsetting me, or even an instant idea its right there and easy access for me to get to which is very convenient for me since I do not drive. Sometimes the cost on my own is kind of an annoyance & stressful but that's what happens when you first start out on something new.

Since I have issues with anxiety, BPD, PTSD, & some FASD traits, for me to work a normal 8-4 job has never been a strong point of mine. I struggled with feeling so abnormal for awhile wondering why this was the way it was, and why things that seemed so easy to others was not hard but very challenging for me but after attending meetings with workers from the clinic, as well as regular sessions with a counsellor I began to see and realize that these issues do not define who I am, but that they only made me more unique.

I was not at a high point in my life before I had this opportunity I was constantly searching for a purpose and the more things didn't work out the harder it became for me to keep pushing forward. Then working from home became an option for me. An option I am truly grateful for. It's taught me that there are things I am good at that will help me succeed in the future, & I am always learning new things with it as well. My anxiety is not as high as it used to be with always being worried about finding a job, wondering how quick I would fail at, where would I go from there. I'm not so stuck on the "what if's" that much anymore since this opportunity has been given to me.

I was not able to do this on my own I have amazing support systems from family-to health workers, without these supports I would not be where I am today. My grandma who is present today has been one of these incredible support systems. As she attends many of the fasd functions, meetings, and group days. Many of my support systems are very important to me because as I said I would not be where I am, or grown to have been the strong person I am today without them.

I would like Ingrid, Alania, & my grandma Birdie to know how truly thankful I am for all their support over the months/years they have been helping me grow.

All the support I have had Not even just for helping and supporting me with this amazing opportunity but for being my supports in other aspects of my life as well, for it not have been for some of the incredible supports I have had I may not be here today so thank you!! As well as for all the rest of the supports I have had thank you!

Becky

What the ACE Program did for me…

Hello, everyone here should know who I am by now. I have been a client at the L.C.F.A.S.D. for the past 10 years. I have seen a lot of changes that the center has been through… including moving a few times.

I was drinking every day, doing drugs, getting into fights with anyone and everyone. I was hanging out with people who was harmful for my well being; and hurting those who cared about me. I was always black and blue from fighting, or I had broken bones. I had people take advantage of me all the time.

Then my worker, Ingrid, started the A.C.E. program. I liked it right off the hop. But I was coming in hungover. We have rules there, and i was breaking them. Now I don't. I can't learn anything useful when i am not at my best.

With the ACE program Ingrid and a couple of other workers planned out different activities for all of us to do. Like canoeing, line dancing, gardening, cooking and they would have speakers come in to teach us stuff. I enjoyed everything. Without realizing it I stoped getting drunk as often. As we did more things together the less I felt like I needed to drink. I met people who are like me. I was given the best support than i have ever had before. I didn't have anyone telling me i had to quit drinking, but now I don't.

Then ACE group helped me gain employment. So now I am Sobor everyday, thats so i don't mess up at work bad. I really enjoy my job. It gives me a sence of accomplishment, independence and responsiblity. I live in a beautiful 3 bedroom apartment with a roommate. Going to this ACE program has helped me out so much that I wish the center could afford to keep it running. Going to group has given me:

- support
- new friends with common Goals
- motivation
- values
- courage to try new things
- the ability to get mad without it ending up in violence
- gain new experiences

Christieann

I got to do something fun that I would not have gotten a chance to do.

Took my babies to daycare and didn’t have to worry about them and didn’t have to pay.

I live on the Reserve, right by the lake and don't have access to a canoe, so the day trip canoeing was a lot of fun. I learned how to canoe and like it. I learned how to cook some really good meals and was given the recipes to take home so I can practice at home and cook some good meals for my family. I also did some baking and fun crafts for Christmas. I made a Christmas gift for my baby Gabriel.

It was cool to paint, make different colors and learn how to make pretty pictures by tracing. The leaves were interesting to me. We had to paint them and learned how to blend in the colors with salt.

Had lots of fun shopping and picking out an outfit that was really nice clothing, something I couldn't afford to buy for myself.

Had lots of fun with the trips to OT's.

Robbie (dictated to Coordinator)

- Got me out of the house.
- Increased my self esteem by getting involved in the activities.
- Enjoyed making the wreaths and the stress balls.
- Something to do and get my mind off negative things, and I still use the stress ball to help me.
- The shopping trip at the end was a very nice surprise. I got some new clothes for Christmas and to go to my family Christmas dinner.
- I really liked the new clothes from Orbiting Trends. I wouldn't have them if I didn't go with the Group on those fun trips.
- Getting new clothes from Orbiting Trends was very exciting because I don't have a washer and dryer and I don't always have money for laundry, so I had clean clothes to wear in the meantime.
- I got a chance to meet new people, so now when I walk down the street I know some people.
- The people I met at Group are people I would not have met just by walking down the street. I like the people at Group.

Greg

I was employed for most of group last year, building the FASD bldg, supervising snow shovelers and doing group ethics.

Joining group meant I didn't have to watch tv all day and I wasn't on the street looking for drugs and alcohol.

Working meant I was able to afford to buy myself some new toys to keep busy doing positive things. I was able to feed a few homeless people on the side and I supported two cats.

My Boss gave me time off and I went canoeing with the group which was a lot of fun. I helped teach

people how to canoe, like my worker Ingrid.

I liked going to the beach which was relaxing and adventurous.

I don't have money to go out and eat, so Group provides me with a healthy breakfast and lunch once a week and I count on that.

The Ace funding helped me to start my cook-book project. I like to cook and make up recipes and people tell me they like my cooking, so I am going to be selling my cookbook.

Jannick

The mentorship program with Candice has made a very big difference in my life. If I ever need someone to talk to all I ever have to do is text her. She is always there for me giving me advice to help. She takes me to my appointments. Candice took me to Edmonton for my eeg. I was very nervous but she helped me calm down and came in with me. We always laugh together. She always makes things fun no matter what kind of foul mood I am she always makes me smile and feel better. She helps me when I'm stressed out she gives me advice on how to lower my stress levels. We always have fun. When I had my son and was living with a person that I did not get along with I was scared to leave for she threatened to take my child away. I went to her for help and she helped me. Candice has made a difference in my life and I love her for that. I hope that she will stay my mentor because I trust her and I do not trust many people with the small print in my life.

Birdie

Insights from a Grandparent.
How does Fetal Alcohol affect us? I never gave any thought to this until we moved to Cold Lake in 1999. My husband had just retired from the Comox air base and we wanted to live closer to our grandchildren. Our daughter, a single parent was working full time, and raising two children 10 and 12. Why not move in? I can cook, clean and keep house and my husband can do any repairs around the house. Sounds wonderful!

Visiting was great but now we are down to the real deal. Kids are in school, daughter is working. House is clean everything is wonderful.

Did not take long to see we had issues. Could not get our granddaughter up for school. She was always sick with some ailment. I soon got to know her Doctors and every one in emergency soon got to know us. The school teachers and councilors were calling. When she attended school she was disrupting classes, walking out of classes, skipping school, they even suspected that she was using drugs. It was

frustrating that she couldn't hold down a job, employment ranged from 1/2 a day to about 6 months. But the 6 month job was only a onetime thing. Most jobs were short lived.

Now on the home front it was getting worse. She had a nice room downstairs she liked. I thought maybe if she was upstairs where there was more light she would be happier and in a better frame of mind. No she was staying where she was. Okay her brother liked being downstairs and it had all been comfortably renovated so all is well. Everyone has their way, so we thought.

Now there was still outbursts of disruption, yelling, screaming, stomping, she didn't want to join in with the family, including eating downstairs and not with us.

She was nearly always late when given a time to be home, but she could tell the best stories as to why she was late. Oh, can they tell stories. My friend was having a miscarriage. I had to help her. My girlfriend was rushed to the hospital having an appendix attack. She needed me. The stories may not even have been her own but the story she once heard has now become hers. With a few embellishments of course.

It got to the point where friends and family members were accusing my daughter of not parenting properly. Everyone thought they had the answers. You are not strict enough with her, you let her get away with everything. She is spoiled, I would not let her get away with that. You need to ground her. Maybe she needs a good smack. She is so lazy, what a manipulator. Then someone else would say, "Oh she is just fine. She is acting out just like I did. It's just a faze. She will grow out of it."

At the time I did not realize that my daughter had already been in and out of counseling since my granddaughter was in grade 2. They knew something was wrong, but what, ADD? Hyperactive?

My husband and I moved to our own place the following spring. Not much changed at the house. Needless to say there were times when the RCMP were brought in. It could be for behaviour issues, stealing, fights, wild stories, even they did not know who to believe. Doctors said she will grow out of this, wait til she is 21. Some new hormones will develop then and the brain changes at that stage in life.

Oh yes, here is more testing by psychiatrists, psychologists, medication, living in Casa House for a year and then home on the weekends. Travelling to Edmonton 3 times a week, rain or snow, don't miss the meetings or they cannot keep her in the program for children with behavioural issues. Our daughter was able to keep working and had a wealth of awesome, supportive friends to talk with.

Our granddaughter was not always in trouble, she was loving, caring, cared about her appearance, had a million friends so it seemed. She is very beautiful to look at and normal in appearance, she could articulate quite well, but didn't really know what she was talking about sometimes. Tells a great story. She is not in a wheel chair. If she was people would consider her disability. But she is not. She is just like thousands of others - she is normal.

In 2005 pieces of the puzzle gradually started to fall together. Finally some serious testing. We used the resources of the local employment agency who agreed to do some mental health testing in Edmonton. So we knew at that time there were some issues. Finally about 3 years ago, a long time family friend suggested that maybe she should be tested for FASD. And we now know our granddaughter has FASD.

It takes tremendous amounts of courage for a mother to come forward and admit that they drank during pregnancy. My daughter was unaware of her pregnancy in the beginning but it was too late.

Now we have a diagnosis and medication to help normalize the brain functions. It is a miracle. FASD is not curable. It is serious and has lifelong effects. With medication, counselling they can lead normal lives.

I am learning this through the numerous workshops I have attended here at the FASD Centre trying to find out what you don't know. It is not easy finding the help you need when you're passed off as having a spoiled obnoxious child. We need more skilled workers in the schools and in employment sectors to recognize and be prepared for early diagnosis to help children and students to be successful and be a force to be recognized. FASD will not go away and it is not only one culture over another that suffers. It is something anyone could have, doesn't matter the race. In summing up, I am thankful for my granddaughter's resourcefulness, her gentleness, her beautiful smile, her laugh and she is so creative in art, music and poetry just like so many others. We just have to learn and give them a chance to be the beautiful people they are and take the time to understand FASD and what it does to people and know that not every person has the same signs. Patience is by far the best trait you can have when being with a person who is FASD.

Once we were connected with the LCFASD, and I started to want to know more of how to help my granddaughter, I was invited to come to the weekly Employment Group program as a support to my granddaughter who did not want to attend because of her anxiety amongst people. I attended when I could and learned a lot from interacting with the folk who attended. I started to see patterns that I had become familiar with and really enjoyed being with the Group. I really learned a lot of different things not only from the workshops but from the clients as well. I learned really to understand that what we were going through was real because as I listened and interacted with the clients I started to understand more.

I recently attended a workshop at the Centre called Understanding FASD and was very enlightened from that.

I hope to continue to attend the weekly Group program and continue learning more about FASD so that I can understand, help my granddaughter and educate other family members who don't yet quite understand.

Appendix F - References

All information included in this document comes from the following sources:

Focus Group sessions and interviews as listed in Appendix 1

McFarlane, Audrey A. (2009) Fetal Alcohol Spectrum Disorder: Is there a Community Economic Development Solution?

Stonehocker, Diane (2003) Final Evaluation Report: Lakeland Centre for Fetal Alcohol Spectrum Disorder

Lakeland FASD Society (2010) 10 Years of Service: LCFASD Anniversary