

***Final Evaluation Report
Lakeland Centre for Fetal Alcohol Spectrum Disorder
Cold Lake, Alberta***

Project #242

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July 15, 2004***

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Lakeland Centre for FASD
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Report Highlights

This report is a summary of the 3 year pilot of the Lakeland Centre for Fetal Alcohol Spectrum Disorder in Cold Lake Alberta. The Centre was established to provide FASD diagnostic and follow-up support services to clients living in the eastern portion of the Aspen Regional Health Authority, addressing the concerns of regional service providers about the high incidence and high cost of preventable brain damage in children and adults.

Adapting the diagnostic model used by the University of Washington for rural use the Centre developed a multi-disciplinary team to conduct assessments and provide diagnosis for children and adults referred to and qualifying for this service. Model adaptations include: in-kind professional participation on the team, mobile services provided in the client's home community, and follow-up client recommendations and support. The Centre's diagnostic model is recognized by the Alberta Medical Association and Health Canada as a best practice model. Annual diagnostic training is provided to participants from across Canada. The Adult Diagnostic Team is the only one of its kind in North America.

Centre clients report satisfaction with the ease of accessing the services, an improvement in their health status as measured by an increase in knowledge and understanding, improved behaviour of and behaviour towards their FASD child, and satisfaction with the outcome of the diagnosis and support received. Additionally, community organizations (in all communities served by the Centre) report an increase in their understanding of FASD and a positive impact of that increase in their work with FASD clients and on the community as a whole. 2250 participants in 75 sessions received training from Centre staff between 2002 and 2004. Team members and staff have presented at provincial and national conferences and been asked to consult to a wide range of organizations from Alaska to New Brunswick.

The report further provides a discussion of the factors that contribute to effective integrated service delivery, incentives for working collaboratively and benefits to the client based on the experiences of the Centre during the last three years. In spite of the effective diagnostic work done by the Centre, significant gaps still exist for FASD clients including respite care, long-term case management for adults, better support to birth mothers, transition planning for young adults, and life skills and parenting training for adults.

The following lessons emerged from three years of service delivery to FASD clients and have application for policy and decision makers in all human service fields and levels of government:

1. FASD diagnosis is important and should not be avoided due to the fear of labelling.
2. Diagnosis is not a cure for the brain damage caused by prenatal alcohol consumption.
3. FASD is not an "Aboriginal problem" but affects all cultural and socio-economic groups.
4. Multi-disciplinary work can address the lack of services to rural areas.
5. Medical professionals are important community partners and should be encouraged to participate collaboratively.
6. Community based solutions take time.
7. Effective, innovative models should be supported and not left to fundraising for core services.
8. Effective service delivery for FASD clients will require changes to departmental practice in all disciplines.

Executive Summary

Following 7 years of regional committee work around awareness and prevention of Fetal Alcohol Spectrum Disorder, the Lakeland FASD Committee received funding from Alberta Health and Wellness (Health Innovation Fund) in 2001. The three year funding was to pilot diagnostic services for children and adults with FASD in north eastern Alberta. The Lakeland Centre for FASD has been operating since that time, and using a multi-disciplinary team diagnostic model, has seen 128 children and 22 adults. It continues to be the only such centre in Canada and has set the standard for other rural communities to follow.

The Centre provides a wide range of services for individuals, families and professionals dealing with FASD and receives funding from a variety of government and community sources. The Health Innovation Fund contributed \$630,000.00 over three years to provide the diagnostic portion of the Centre's services.

Service Delivery Model

The diagnostic and follow-up services provided by the Centre are based on the model developed by the University of Washington FASD Diagnostic and Prevention Network. Adaptations included team member's in-kind participation, bringing the clinic to the client's own community, providing practice recommendations based on the completed assessments and service availability, a client vs. a research agenda, and providing follow-up support post-diagnosis.

The model requires a team diagnostic approach involving the expertise of a variety of professionals including a physician, neuro-psychologist, speech-language, occupational and mental health therapists, social worker, public health nurse, native liaison worker, and addictions counsellor. In addition to the physician and psychologist, members for the adult team may also include a developmental disability adult specialist, mental health therapist, justice workers, career and addictions counsellors. With the exception of the 2 physicians and neuro-psychologist, professional participation on the diagnostic teams (2 children's teams, 1 adult team) is provided in-kind by sponsoring agencies.

The team assembles in the client's community and conducts a ½ or 1 day clinic to assess, diagnose and make recommendations. Four children (2 clinic days) and one adult (1 clinic day) are diagnosed per month. Follow-up support for the families of children is provided post-diagnosis to assist the client in following through with recommendations. This follow-up support is unique to current FASD diagnostic services in North America.

Referrals to the Centre can be made by anyone involved with the client (i.e. schools, Children's Services, Human Resources and Employment, etc). To be eligible for clinic services a client must be a resident of the service area and provide confirmation of maternal alcohol consumption during pregnancy. Of the 128 children assessed by the Centre, 110 received an alcohol-related diagnosis. 18 were deferred for further follow-up at a later date. All 22 adults received an alcohol related diagnosis. (See Appendix A for diagnostic breakdowns.)

Project Evaluation

Based on the clinical assessments completed by specific team members, the Centre provides a diagnosis, recommendations for follow-up services and short-term support post-diagnosis. As it

does not maintain long-term involvement with the client, project evaluation was limited to assessing the:

- number of diagnoses completed,
- effectiveness of the process itself as judged by the clients and the team members,
- short-term impact of the diagnosis as judged by the caregivers and service providers.

Data was collected through interviews, focus-group sessions, written surveys, file and literature reviews. An assessment of the long-term impact of diagnosis on FASD clients was beyond the scope of this evaluation, but should be considered for future research.

Project Outcomes and Results

1. *The Project will **improve access** to FASD diagnostic services for all residents of the (then) Lakeland Regional Health Authority.*

Diagnostic services prior to the Centre's opening were in Edmonton or Calgary with lengthy waiting lists and all of the barriers associated with travel and difficulty in accessing post-diagnostic services. Of those clients who had previously attempted to obtain an FASD diagnosis for their child, 85% indicated that accessing the Lakeland Centre was "easier" for both the pre-clinic process and on the clinic day. Most would not have attempted to access services in the urban centres.

2. *The Project will enhance access to additional and/or more appropriate services for clients based on an accurate diagnosis of FASD.*

The 128 assessed children received recommendations for an average of 5 school or health-related follow up services. Typical recommendations were for special education funding through Alberta Learning, proper Individual Program Plan development, physician follow-up, speech and/or occupational therapy, mental health, and respite care. Adults received an average of 4.5 recommendations to services focussed on health, financial assistance, counselling, legal or personal support. The professional assessments and diagnostic reports provided by the Centre form the basis for applications for enhanced professional services.

3. *Project clients will experience an **improvement in their health status** as a result of services provided.*

When asked to respond to a variety of questions regarding personal and family wellness, clients reported the following:

- an increased knowledge about FASD (58%)
- an increased understanding of the diagnosed child and his/her behaviour (65%)
- a change in the way they interact with the diagnosed child (61%)
- an improvement in the child's behaviour at school (69%)
- satisfaction with the outcome of the diagnosis (83%) and the support they received from the Centre (82%)

Foster and adoptive parents were more likely to have followed through with service recommendations (as compared with birth parents or extended family caregivers). The

most sought after services were those that would improve the child's often troubled school experience. The recommended services least likely to have been accessed were those for counselling, respite care or for social interactions.

4. *The Project will provide accurate and useful information regarding FASD to individuals and organizations.*

A major goal of the Centre is to raise awareness of FASD and enhance current agency practice with FASD clients. This is done through a newsletter, website, and on-site training for requesting organizations. Service provider surveys indicated 76% felt that their knowledge level of FASD was adequate or extensive. 83% attributed some or all of their FASD knowledge to the Centre. 85% said they had in the past or are now working with an FASD client and 52% indicated that the Centre had positively impacted their ability to work with the client. In an 18 month period, the contract trainers conducted 75 training sessions to 2250 participants from a variety of professions including education, health, community workers, etc.

5. *The Project will successfully **pilot a service delivery model** for FASD diagnostic and support services that has been adapted for use in rural communities.*

All evaluation tasks completed throughout the project indicate that it was carefully planned, thoroughly implemented and well received by both clients and the professional community. The Centre has received nation-wide recognition for their work and has been asked to make presentations and consult to a wide variety of organizations from New Brunswick, Ottawa, Alaska, Northwest Territories and to all levels of government.

6. *The Project will **add to the knowledge base** regarding the health status of adults diagnosed with FASD.*

Prior to forming the adult team, there was no organization providing adult-specific diagnosis in North America. What was known about the effects of FASD in adulthood was limited to anecdotal reports and extrapolations from experiences with diagnosed children. The data collected by the adult teams has not been formally analysed and reported and such analysis was beyond the scope of this evaluation. Ongoing evaluation with this group post-HIF funding is being conducted and will be available upon request.

Unintended Outcomes

1. **National Recognition** - While the commitment to excellent service was a stated goal from the beginning, the extent to which the Centre has achieved national recognition for that excellence was unintended and has been surprising. It has translated into Centre staff participating in FASD discussions at national levels and receiving requests for information and advice on an almost weekly basis.
2. **Partner Support** – Expecting agencies to donate staff to work as part of the diagnostic team was not a given during times of cut-backs when the Centre first began. An early concern was that team members would be trained and then the partnering agency would withdraw its support. With the success of the Centre, the opposite has occurred and team member longevity

has become a non-issue. Some agencies have used potential participation with the Centre's teams as a recruitment incentive.

3. Team Functioning – The extent to which the diagnostic teams have learned to work so effectively together has been beyond what was expected. Centre staff have provided specific training on effective team development based on their experiences.

Barriers and Challenges

Barriers to effective service delivery and client outcomes are:

- **Ineffective agency client practices** make it difficult to make any meaningful change in the lives of FASD clients. If a post-diagnosis recommendation is made to an agency whose practice is based on ineffective methods for FASD clients, nothing will change for the client.
- The need to charge a **diagnostic fee** was questioned in the early days but has become a non-issue for most as it is viewed as a cost-effective investment in quality service delivery. However it is still a barrier for some organizations and communities who lack the resources and/or experience with the Centre.
- Due to a lack of sustainable core-funding **the need to focus on fund raising** to provide core services has become a significant drain on human resources.

Contributions to the Health System

The Centre has contributed to the Health System by providing an increased understanding of the following:

- a. The factors that contribute to an **effective integrated service** delivery model.
 - effective team member and staff selection, development and management
 - thorough community preparation prior to service delivery
 - a focus on the client/family
 - effective cultural connections
 - political activity and visibility
 - adaptability
- b. The **incentives for staff** to work collaboratively.
 - being part of an effective and innovative process
 - training and experience
 - change in routines
 - being seen as an expert
- c. The **incentives for agencies** to support staff participation.
 - known to be a partner in a visible program
 - benefit to agency's client group
 - staff training at no cost
 - increased job satisfaction and therefore staff retention
 - cross-discipline awareness

- d. The **incentives for client** participation.
- comprehensive assessment from a variety of professionals at one time
 - services provided in home community

In addition to increased understanding, the diagnostic services provided by the Centre has had a direct impact on the health of individuals in the following ways:

- a. An early diagnosis is a primary protective factor against a whole host of secondary disabilities (i.e. mental health problems, disrupted school experience, trouble with the law, inappropriate sexual behaviour, alcohol/drug problems, etc.).
- b. Information deliverables to the family physicians of each child/adult seen in clinic.
- c. The identification of previously undiagnosed medical issues of concern leads to early and more effective treatment.
- d. Assessment and diagnosis will clarify the client's disabilities and reduce the use of resources on ineffective treatments.

Implications

As FASD clients will need a variety of services throughout their entire life span, the following lessons have application for all human services professionals:

1. FASD diagnosis is important – Acknowledging the controversy between the benefits of diagnosis vs. the risk of labelling, it is clear that receiving an FASD diagnosis provides the access to additional services that will contribute to the client's quality of life. It also empowers families and clients to advocate for themselves. The cost to the system of not diagnosing will be greater as families and individuals struggle to find help and resources are wasted on ineffective services.

2. An FASD diagnosis is not a cure – There is no cure for the brain damage that can result from pre-natal alcohol consumption. This inability to cure has been seen as a barrier to some physicians who are reluctant to get involved. Diagnosis is key to obtaining more effective information and support for the client and his/her family.

3. FASD is not an "Aboriginal problem" – Contrary to the popular mythology, FASD should be an issue of concern to all individuals, governments, researchers and policy makers. Currently funding and policy is focussed primarily on Aboriginal communities, especially at a federal level. In addition to inequitable funding distribution, this focus reinforces a negative stereotype. A more equitable funding policy should be established to ensure all sectors of society have access to FASD programming.

4. Multi-disciplinary work can be done effectively in rural areas – The lack of specialized service providers in rural areas does not need to limit access to all specialized services to rural residents. Service providers should be encouraged to examine alternative models of service delivery.

5. Medical professionals are important community partners – Physicians and public health personnel are often the first contact a woman makes during pregnancy and they should be encouraged to take a more active role in FASD prevention and intervention. The

physicians in this region have had significant exposure to FASD as a result of the Centre. It is likely that medical professionals in other regions have not and would benefit from continued encouragement.

6. Community-based solutions do work but take time – A community that has not taken ownership for FASD prevention will not likely succeed at establishing this model. The Centre provides annual training to other communities wanting to establish local services, but community readiness for services will impact success.

7. Effective innovative service delivery models should be supported – To fund innovation projects and evaluate them for effectiveness and learning is to be applauded. Assisting those projects that are found to be worthwhile to find core funding would help ensure their continuation and limit the need to spend valuable resources on fund-raising. The Centre is currently examining a fee-for-service diagnostic process that would have teams completing diagnoses for non-residents. While this may be considered innovative it is also contrary to the goals and philosophy of the FASD Society and Centre staff and is only being considered as a last funding resort.

8. In order to address persistent gaps and barriers, effective service for FASD clients will require changes to departmental practice standards in all disciplines. To provide an effective FASD diagnosis is only the first step for individuals and families. It needs to be followed up with effective service delivery over the client's lifespan. Regional authorities (i.e. Child and Family Services, Persons with Developmental Disabilities, Health, School boards, etc) should be encouraged to actively pursue FASD best practices in light of current knowledge about effective service delivery to this client group. Excellent models are being developed (i.e. Southwest Alberta Child and Family Services Authority in Lethbridge) and should be examined for local application.

Final Evaluation Report

July 15, 2004

Project Name

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Project Overview

Brief History

In response to the growing awareness of Fetal Alcohol Spectrum Disorder (FASD) and its impact on local residents and communities, a group of concerned agency representatives joined together to plan the first FASD conference in this area hosted by the Bonnyville Canadian Native Friendship Centre in 1994. Following the conference, a core group began meeting regularly to develop prevention initiatives and the Lakeland FASD Committee was formed in 1995. Over the next several years, the Committee expanded to cover the entire region and focused on providing training opportunities, producing and distributing prevention materials and hosting regional conferences.

The Committee knew that more needed to be done to support individuals and families dealing with FASD but that nothing could be put in place for them until they could receive an alcohol-related diagnosis. Having heard Drs. Sterling Clarren and Anne Streisguth from the FASD diagnostic clinic at the University of Washington speak about the benefits of a multi-disciplinary team diagnosis, the Committee felt it was a model that could be used effectively in the local region and began making plans to expand to providing diagnostic services.

In 2000 the Committee sent a team of local professionals recruited from committed agencies to Seattle to receive diagnostic training using Dr. Clarren's model. After adapting the model to meet local goals and realities, the team began providing diagnostic and assessment services in November 2000. Until funding could be secured to hire coordinating staff, the management of the diagnostic team and process was handled through Children's Services staff and the team limited its work to diagnosing children identified by Children's Services.

Short term funding was obtained to do some of the administrative work of the committee and to develop proposals for core funding. Alberta Health and Wellness was approached for Health Innovation Funding in 2001 and the Centre officially opened in May 2001 with a 3-year funding commitment.

The Centre was physically housed in Cold Lake but provided services throughout the region until the Lakeland Regional Health Authority (Region 12) was absorbed into the Aspen region in 2003. Services were then limited to the eastern portion of the Aspen region (Cold Lake,

Bonnyville, Lac La Biche, St. Paul areas) from where the majority of the referrals had been coming.

Since that time, the Lakeland FASD Committee has become the Lakeland FASD Society and it currently oversees a wide variety of services provided through the Centre including:

- ***Diagnostic and Assessment Services for Children***
- ***Diagnostic and Assessment Services for Adults***
- ***Prevention activities***
- Follow-Up support Services
- Mothers-to-Be Mentorship program
- Community Alcohol/Drug Awareness Coordination
- School Based Support
- FASD Workshops
- Train-the-trainer workshops
- Mentorship Program Development training
- Diagnostic and Assessment Certified Team Training
- Community Development Training and Support
- Information Clearinghouse
- Resource Development

The Alberta Health and Wellness Health Innovation Fund (HIF) has provided direct funding for the Centre's core activities shown above in bolded italics. The remainder of the listed activities have been added to the Centre's core program over time and are funded by other organizations. The remainder of this report will focus primarily on the Health Innovation Fund portion of the Centre's activities.

Terminology

FASD - Fetal Alcohol Spectrum Disorder 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 will be used throughout this document in place of whatever terminology may have been used at the time being described.

Assessment vs. Diagnosis – Prior to or during the clinic, a variety of assessments are completed by specific service providers. Typical assessments may include (but are not limited to) expressive language, memory, IQ, neurological screening, occupational therapy, facial measurements, as well as a variety of risk factor assessments (i.e. suicide, alcohol/drug risk, depression, etc.). After a thorough review and discussion of these assessments by the team, a diagnosis is made using the diagnostic categories recognized by the Alberta Medical Association: Fetal Alcohol Syndrome (FAS), Partial FAS, Alcohol Related Neuro-developmental Disorder (ARND), and Alcohol Related Neuro-behavioural Disorder (ARNBD). If there is not enough information, or the client is too young to complete some of the assessments, the diagnosis is deferred for subsequent follow-up.

Client Statistics

Since the Centre began providing diagnostic services in 2000, 128 children and 22 adults have been assessed and received a diagnosis. A brief description is provided below with a more complete description included in Appendix A.

	Children N=128	Adults N=22
Gender	37% female 63% male	52% female 48% male
Ethnicity	20% Caucasian 24% Metis 54% First Nations 2% Other	29% Caucasian 14% Metis 52% First Nations 5% Inuit
Diagnosis	1 FAS 18 Partial FAS 81 ARND 10 ARNBD 18 Deferred	19 ARND 3 Partial FAS

Project Costs

The Health Innovation Fund provided \$630,000.00 to the Centre over three years. This funding covered the Centre's infrastructure costs as well as salaries for the executive director who is also the children's team coordinator. It also provided salaries for the adult team coordinator and the executive assistant. Additionally the HIF covered the honorarium paid to the pediatrician, neuro-psychologist fees, and all expenses connected to the clinic process (i.e. travel, documentation, etc.). All other programs provided by the Centre are funded with grants from other government departments, fee-for-service activities, or community fundraising.

Project Context and Description

Compared with other long standing health and social issues which have received the benefit of years of intervention and scientific investigation, the Fetal Alcohol Spectrum Disorder field is relatively new. The potential link between alcohol consumption during pregnancy and facial dysmorphism was first suggested in the 1960's in France. Published articles began appearing in the 1970's and were focused on effects of teratogens on fetal development. Since that time, the field has been evolving slowly as society acknowledges a problem that affects people in all economic, social and cultural groups.

Diagnostic standardization began in the 1970's based largely on the work Dr. Sterling Clarren and Dr. Ann Streisguth of the FASD Diagnostic and Prevention Network at the University of Washington in Seattle. Interventions for individuals affected by FASD began from these diagnostic beginnings as recently as the 1990's.

At a local level, when the FASD Committee first started meeting in 1994, there had begun to be an awareness that significant portions of the regional population had likely been affected by maternal alcohol consumption. Of equal concern was the high rates of alcohol consumption by

both men and women in the affluent oil industry culture of the region which pointed to significant problems for high numbers of children in the future. While there are no Canadian statistics indicating prevalence rates for FASD, US statistics show that one in 100 children have been affected by prenatal alcohol exposure. Based on their experience with local communities and schools, the Centre estimates that number to be 20% for the Lakeland area.

Awareness of FASD was not high when the Committee began meeting, even among professional service providers. There was even less awareness and acceptance among the community and political leaders. Awareness even at provincial and national levels was slow in coming. It was 1998 when the provincial government asked that each region develop an FASD committee to examine the issues throughout the communities of the region. The already established FASD Committee expanded to include the entire region.

An FASD diagnosis cannot be completed adequately by one practitioner and at that time the closest organizations providing some level of FASD assessment were in Edmonton or Calgary making a diagnosis virtually inaccessible to people living in the Lakeland region. The waiting lists were extensive (measured in years), the barriers associated with travel significant for the majority, and no follow-up support could be provided.

The 7 years of work by the FASD Committee led to the successful establishment of the Lakeland Centre for FASD which has now been in operation for 3 years. The Committee, in establishing the Centre, had established three primary goals:

1. Stable, multi-disciplinary teams will be formed to provide diagnostic services to people from the region.
2. Centre staff will support clients after the diagnosis and link them to available and appropriate services.
3. The Centre will provide clients, service providers and the general public with accurate and effective information regarding FASD.

Project level outcomes were designed based on priorities established by the HIF (indicated in italics) and in keeping with the goals of the Committee.

1. The Project will *improve access* to FASD diagnostic services for all residents of the (then) Region 12.
2. The Project will enhance access to additional and/or more appropriate services for clients based on an accurate diagnosis of FASD.
3. Project clients will experience an *improvement in their health status* as a result of services provided.
4. The Project will provide accurate and useful information regarding FASD to individuals and organizations.
5. The Project will successfully *pilot a service delivery model* for FASD diagnostic and support services that has been adapted for use in rural communities.

6. The Project will ***add to the knowledge base*** regarding the health status of adults diagnosed with FASD.
-

Approach to Project Implementation

The Committee began providing diagnostic services without full-time staff in 2000. Once funding was received from the HIF, the executive director and support staff were hired, and the Lakeland Centre for FASD came into existence.

The Centre, having received training in Seattle, had determined that a number of adaptations were necessary to make that model successful in rural areas. The major adaptation required team member agencies to donate staff time on an in-kind basis. The Seattle team was made up of full-time professionals working for the clinic. Lack of resources made this approach impossible in north eastern Alberta, so team members were recruited from local human service agencies willing to donate staff time for clinic activities. There are currently two children's diagnostic teams and they are made up of the following professionals:

- Pediatrician
- Neuro-psychologist
- Mental Health therapist
- Speech language pathologist
- Occupational therapist
- Public Health nurse
- Native liaison worker
- Addictions counsellor
- Social worker
- Team coordinator

With the exception of the neuro-psychologist and pediatrician, member participation is donated by the team member's agency.

A short time after the Centre opened, an adult services coordinator was hired and an adult team recruited to offer FASD assessment and diagnosis for adults. The Centre is still the only organization in North America that has an adult-specific team. The diagnostic process was based on the Seattle model as well, however team make-up was changed to include professionals who work with adults as listed below:

- Physician
- Neuro-psychologist
- Mental Health therapist
- Legal representative
- Persons' with Developmental Disabilities (PDD) coordinator
- Career counsellor
- Aboriginal liaison worker
- Addictions counsellor
- Team coordinator

The children's teams diagnose four children per month in two clinic days. The adult team diagnoses one adult per month in one clinic day. Extra time is taken with adult clients as the client's history and needs are often more complex.

Referrals to the Centre can be made by anyone involved with the client (i.e. schools, Children's Services, Human Resources and Employment, etc). To be eligible for clinic services a client must be a resident of the service area and be able to provide confirmation of maternal alcohol consumption during pregnancy.

The clinic process (same for child and adult clients) consists of 6 phases completed prior to and/or on the clinic day. Generally it proceeds as follows:

- **Review of data and preparation of the client** – conducted prior to the clinic day by the coordinator and team members.
- **Clinical assessments** – conducted prior to or on the clinic day by team members (i.e. neuro-psych, speech, medical, etc).
- **Team assessment: Diagnosis and service planning** – team members reviewing assessment results and determining diagnosis and recommendations.
- **Caregiver debriefing** – lead team members meet with the caregiver to provide results and recommendations.
- **Team closure** – team members review and debrief.
- **Short term follow-up support** – After the clinic, the support worker contacts the family to offer support and assist with the recommendations made by the team. This could include assisting the family and the school in developing best practices for the child, helping parents advocate for their children, connecting families to each other.

The follow-up support worker is a critical addition to the Seattle model. The Committee felt that to diagnose and then not provide follow-up support was a serious gap that would greatly diminish the potential benefit of receiving the diagnosis in the first place. The support worker position is funded by Children's Services and no funds were found to provide a similar service to adult clients. Limited support to adult clients is provided by the adult team coordinator but this has been identified as a critical gap in service.

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

Currently the Centre provides services to:

- 7 First Nations communities (Cold Lake, Kehewin, Frog Lake, Beaver Lake, Heart Lake, Saddle Lake, Whitefish Lake)
- 4 Metis Settlements (Elizabeth, Fishing Lake, Kikino, Buffalo Lake)
- 25 rural communities in the St. Paul, Lac La Biche and Bonnyville areas
- 1 city (Cold Lake)
- 1 military base (4-Wing Cold Lake)

The Centre's client-focused approach as opposed to a research focus is another adaptation from the original model. The Seattle clinic is based at the University of Washington and its

clients provide the data for FASD research. While the Seattle clinic has been the source of much of the groundbreaking empirical research done around FASD, the Lakeland FASD committee consciously chose a client-focused approach. This commitment to client care and respect is likely the largest contributing factor to the overwhelmingly positive client feedback the Centre receives. The Centre was conceived and staffed by community members and service practitioners from throughout the region. The need to conduct and publish research has not been a high priority, but a research agenda is emerging which will contribute to examining and sharing the work the Centre has done.

The service delivery model has turned out to be both appropriate and effective as well as innovative. It addresses the need for professional, timely assessment and diagnosis with an emphasis on client support and respect. Diagnosis was not being done this way anywhere else and the Centre is recognized as a best-practice model for FASD diagnosis. Centre staff and team members provide training sessions annually to other communities/organizations seeking to establish diagnostic services. It is the only FASD training centre that is recognized by the Alberta Medical Association.

Approach to Evaluation

The Centre established a system of providing diagnosis followed-up by a support process that attempted to link clients to outside agencies in programs or services recommended by the diagnostic team. While it was hoped that diagnosis and participation in services would have a long-term impact on clients it became clear that this would be difficult to evaluate as the Centre does not maintain long-term involvement with the client. Project evaluation was limited to assessing:

- the number of diagnoses completed
- the effectiveness of the diagnostic and support process itself as judged by both the clients and the team members.
- the impact of the diagnosis as perceived by the caregivers and service providers.

With the exception of client use numbers, the information gathered for the evaluation was primarily a qualitative assessment of perceptions and levels of satisfaction of project stakeholders. The specific methods used to gather the information was:

- assessment of client participation and perceptions using surveys and interviews
- assessment of staff and team member perceptions using focus groups, interviews and journaling
- assessment of community response to project activities using surveys and interviews
- literature review
- file review

The evaluator designed the interview guides and conducted all of the client interviews. These interviews were conducted over the telephone at or after six-months post-diagnosis and a two year follow-up interview was conducted with those diagnosed in the first year. This process provided feed back to the Centre on the client's perception of service impact as well as alerting them to any need for further involvement with the family.

Surveys were used to obtain feedback from community agencies beyond the diagnostic teams throughout the region. All surveys were designed and administered by the evaluator. They were sent either by email, delivered in person or by Canada Post. In addition, telephone interviews were conducted for service providers in the Cold Lake area.

All data was analyzed for recurring themes. Staff and team members were used to provide context and meaning to the findings. Annual team meetings were held in which the evaluator presented findings to date and gathered feedback and input from the team members.

Evaluation was limited to client, caregiver and professional perception of quality of the Centre's services and short-term impact. An assessment of the long-term impact of an FASD diagnosis was beyond the scope of this evaluation.

Findings/ Results

In order to determine the degree to which the Centre achieved the established outcomes the evaluator conducted document and literature reviews, focus groups with team and staff members, as well as ongoing interviews with clients and caregivers over the course of the project. Additionally, surveys were administered to agency personnel throughout the region, including Metis and First Nations communities. As mentioned previously, the responses provided insight into the respondents perception of the quality of the clinic process, changes in client and caregiver knowledge and behaviour since attending clinic, and the Centre's perceived impact on FASD practice. A discussion of the extent to which the project outcomes were met is provided below.

1. *The Project will improve access to FASD diagnostic services for all residents of the (then) Lakeland Regional Health Authority.*

When the Centre first began providing service, the former Lakeland Region went from Fort Saskatchewan east to the Saskatchewan border north of Highway 16, not including Fort McMurray. While the original plan was to provide services to residents living throughout the region, it soon became clear that the majority of referrals were coming from the eastern portion of the region. When the Lakeland Region was absorbed into the Aspen Region, it was no longer possible to provide services on a regional basis. It was decided to limit diagnostic services to the communities close to the centres of St Paul, Lac La Biche, Bonnyville, Cold Lake and the Metis and First Nations communities in that area.

This focus on core communities is especially important as the services are mobile in nature and provided in the location chosen by the client. To spread services over too large an area would have jeopardized the ability of the teams to work effectively and provide any meaningful follow-up.

As to client perception of access, of those participants who had previously tried to access a diagnosis for their child, 85% said the Centre was easier to access both pre-clinic and on the clinic day. Referring to the distance traveled to attend the clinic, 50% said it was held in their own community, 21% had to travel less than 50 k's, 18% had to travel 50-100 k's and 12% traveled more than 100 k's. 74% indicated that attending the clinic had represented "no hardship" to them.

A large number would not have attempted to obtain a diagnosis for their child in Edmonton. The process of obtaining a referral and the logistics of travel would have been an insurmountable barrier for most.

2. The Project will enhance access to additional and/or more appropriate services for clients based on an accurate diagnosis of FASD.

As part of the diagnostic process, the client is given a list of recommendations for follow-up services that would specifically benefit the client’s assessed needs. The 128 children received an average of 5 recommendations for services. The largest grouping of recommendations are for school or health related services as listed below. Additionally, clients may also have received recommendations for transitioning assistance to adult services (14%) and permanency planning (16%).

Table 2	
Service Recommendations	
Percentage of Clients Who Received:	
School-based recommendations	
Individual Program Planning	69%
Alberta Learning Code 44*	44%
Health-related recommendations	
Family physician follow-up	34%
Mental Health	33%
Respite	25%
Speech Language	23%
Occupational Therapy	13%
Addictions	13%
Medication Review	11%
* Note: Code 44 is Alberta Learning’s special education designation for children diagnosed with FASD.	

In subsequent interviews with caregivers, it was stated by the majority that the primary reason for seeking a diagnosis from the Centre was to obtain access to follow-up services. They were particularly interested in obtaining enhanced services for their children at school. It was estimated that 75% of the children diagnosed by the Centre had existing Individual Program Plans (IPP) at their school but they were, in most cases, based on incorrect diagnosis or ineffective practice for FASD children. The diagnosis provided recommended changes or additions to the IPP based on the child’s assessed abilities and disabilities. Code 44 is Alberta Learning’s Special Education designation for children diagnosed with FASD. This coding allows for specialized services and testing and in the case of significant cognitive impairment may include provisions for a classroom aide. A diagnosis from the Centre can be used to substantiate an application to Alberta Learning for funding.

Services recommended for adult clients are to address the client’s financial needs, to identify short and hopefully long-term living support for the client, and engage him/her in a competitive or, more likely, non-competitive vocational setting. Needs identified beyond that point are addressed and if progress is made in resolving them, it is considered a bonus. Recommendations to adults have been for the following:

- a. **Financial Aid (64%)**
To link the client to a funding support best suited to his/her needs and qualifications (i.e. AISH, SFI, Trusteeship, or if competitive employment is possible, vocational training).
- b. **Personal Support (45%)**
Clients who were eligible were referred to PDD (Persons with Developmental Disabilities) for programming support.
- c. **Career/Educational Counselling (68%)**
To address the vocational needs, 68% were referred to a Human Resources and Employment worker to assist the client find what is available and appropriate to his/her interests and abilities.
- d. **Medical Follow-up (95%)**
Most clients are referred to their family physician for medical follow-up, some for very specific medical conditions that were identified by the diagnostic team and previously unknown to the client.
- e. **Counselling (86%)**
86% were referred for counselling support to deal with depression, anxiety, self-esteem, etc. Common referrals are to Mental Health, Elders, psychologists, etc.
- f. **Addictions Counselling (64%)**
Clients with substance use/abuse issues are in need of addictions counselling through AADAC or other community resources. Several of the clients felt socially isolated and were referred to Friendship Centres, Elders, FCSS, etc. for social, spiritual, and/or family support.
- g. **Legal Assistance (23%)**
Some few clients receive recommendations to seek help to deal with outstanding legal issues. A small number of clients have had serious criminal convictions and are or have been incarcerated.

Currently, recommended support is primarily provided by team members' agencies throughout the region operating within their existing mandates and relate back to the general goals of establishing financial stability, short-term support to access appropriate systems, and introduction to a vocational setting. The reality for adults with FASD is that their typical deficits make it likely that they will need supported living their entire lives. There is no current system available to do this for clients who do not qualify for PDD.

Unlike adult diagnosis, the diagnosis and follow up services for children is more likely to have a long term impact as early diagnosis is a protective factor against secondary disabilities. With the diagnosis of adults, the goals and the impact are more likely to be short term, with the realization that most do not have consistent family support and that the needed long-term support is beyond the ability of the current system of care.

In general, the team's policy is to ensure that recommendations are attainable and community-based so as to increase the likelihood of client participation. However, without a client follow-up

worker it is difficult to know to what extent clients are following through with the recommendations made.

3. *Project clients will experience an improvement in their health status as a result of services provided.*

The improvement of health status was defined as an increase in perception of personal and family system wellness. Interviews were conducted with 46 caregiver families who had been through the diagnostic process and were focused around five aspects of that wellness, including:

a. Knowledge about FASD (Appendix B: Knowledge)

Rationale: Knowing that the Centre could not provide long-term support to client families, it was important to provide specific information that would help them know more about what they were dealing with and assist them to find what they would need in the future.

Client families were asked about the level of the knowledge about FASD since making contact with the Centre. The majority (58%) felt that they were more knowledgeable about FASD than before. The majority of those who felt that their knowledge level had remained the same (38%) were foster and adoptive parents who receive FASD training through their own support programs.

Client families were then asked about their awareness of community services and how to find what was needed for their children. Almost one third (31%) indicated an increase in their awareness of what was available and how to access it. Again, foster and adoptive parents receive assistance in this regard from their own systems. This number may also have been affected by the lack of services available in some communities where there is little to be aware of in the way of services for FASD children.

65% indicated an increased understanding of their child and his/her behaviour. Typical comments were, "Now I understand what makes him tick." or "I'm more relaxed now because I realize that he's not being difficult, he really can't do what I'm asking him to do." 65% is a hopeful number which should translate into more effective interaction with the child.

b. Parental Behaviour (Appendix B: Parental Behaviour)

Rationale: An increased knowledge of FASD in general and a better understanding of their child in particular would suggest a change in the caregiver's behaviour towards the child. We asked if they are doing things differently for the child and for themselves since the diagnosis.

61% indicated they were interacting with their children differently since going for the diagnosis. Being more patient, keeping directions to the child more simple, yelling less, being more structured were all cited as examples of the changes.

When asked if they were doing anything differently for themselves since going to the Centre, the majority (59%) indicated that nothing significant had changed. Many

indicated the lack of time as the main reason. Some made reference to the need for respite care but had been unable to access it as recommended.

c. Child Behaviour (Appendix B: Child Behaviour)

Rationale: With an increase in knowledge about FASD and the opportunity to do things differently for themselves and for their child, we were interested in knowing if the child's behaviour had changed both at home and at school since going for the diagnosis.

40% indicated that their child's behaviour at home had improved over-all. It is important to note that this was strictly a statement of their perception on the day the question was asked. There was no attempt made to measure, explain or verify the perceived improvement. 41% indicated no general improvement. Some of those said that the child's behaviour was not a problem before the diagnosis, while some few indicated that the child's behaviour was before, and remains still, difficult and disruptive. 14% felt that, at least for a time, the child's behaviour had worsened but had returned to normal levels. This was more likely to be the case with adolescents who may have had a negative emotional reaction to the diagnosis.

A child's inability to cope at school is a critical source of stress to caregivers of FASD children. If the child is not succeeding in school and his/her behaviour is causing negative interactions with staff and other students, the parents are less likely to indicate satisfaction with the outcome of the diagnosis. When asked if the child's behaviour at school had improved since the diagnosis, 69% answered in the affirmative. Again, this was based on the parents perception of how things were going as compared to before the Centre's involvement with them. They felt that the improvements were due to the school's increased understanding of the child gained from the diagnosis and recommendations as well as an increase in staff knowledge about FASD. The Centre has provided significant levels of in-servicing around FASD best-practices to school staff as well as student-specific recommendations as requested.

d. Outcomes vs. Hopes (Appendix B: Outcomes vs. Hopes)

Rationale: The diagnostic referral form asks parents to identify the reason they are seeking a diagnosis for their child. A section of the interview attempted to determine whether their hopes had been realized and if they were satisfied with the services they received. As continuous improvement is needed for quality assurance, they were also asked for specific input about what would have made the experience better for them and whether they would recommend a diagnosis for others who suspect FASD.

When asked in the interviews what they were hoping for from the diagnosis, the majority of caregivers indicated a desire for increased understanding of their children and to be able to access more services for them based on an accurate diagnosis. 83% said their hopes were met, that they had received what they were hoping for from the diagnostic process and subsequent services. Some few indicated they were hoping for proof that their child was not affected and one birth mother did not accept the diagnosis.

94% indicated that they would recommend that other people have their child diagnosed if FASD was suspected. The majority felt it was better to know what you're dealing with so that you can apply effective strategies.

The assistance of the follow-up support worker is recommended for the majority of clients seen at the Centre. With 128 clients to date, providing adequate follow-up service can be challenging. When asked about the level of support they had received, the majority (82%) felt that it was as much as they needed and knew that they could access the worker if they needed more. 16% felt that they could have used more help and a lucky 2% felt that they received more than they needed.

e. Service Recommendations

Rationale: As mentioned earlier, part of the diagnosis included a list of recommendations for subsequent services based on the assessments made during the diagnostic process. Notwithstanding support provided by the follow-up worker, the client is responsible for finding and connecting to the services as they choose. Finding out whether the clients actually followed through with the recommendations was important.

Several barriers to an accurate assessment of client follow-through made the results of this question less valuable than hoped. When asked about specific recommendations, clients often couldn't remember the details or didn't want to admit whether they had or had not followed-through. Some parents caring for several FASD children couldn't remember which recommendations were made for which child. Based on what they were able to provide, the following recurring themes were evident:

- Foster and adoptive parents were most likely to have followed-through with the recommendations made during the diagnosis, as compared to birth parents or extended family caregivers.
- The most sought after services were school-based. Appropriate behaviour coding, speech/language or occupational therapy recommendations were the most likely to have been followed-through with. While the results were not always as desired, (i.e. child didn't receive an aide, speech services not available in the school, etc.), school-based services were the most important to all categories of caregivers in determining overall satisfaction.
- Caregivers were less likely to have reported a positive experience with recommendations for Mental Health support (i.e. client refused to go, felt they didn't need it, etc.), respite care (i.e. were unable to access it, didn't feel they needed it, couldn't find a worker, etc.) and social club interactions (i.e. Boys and Girls club-type organizations).
- The most consistent positive comment was regarding the Centre's follow-up support worker who was described as "awesome" "great" "couldn't have done it without her," etc.

4. The Project will provide accurate and useful information regarding FASD to individuals and organizations.

Raising awareness of FASD within the communities served by the Centre has been a major priority both for the purpose of preventing future FASD births and also increasing understanding of how to work with affected individuals. A variety of methods of raising awareness have been implemented by the Centre including the following:

- A website has been in operation since 2001 and has recently be revamped. It contains general FASD information, news, updates and links to other FASD resources. The site is located at www.lakelandfas.com.
- A lending library at the Centre was established for individuals or organizations looking for FASD information. Resources include books, videos, pamphlets and fact sheets suited to lay individuals and professionals. While not accessed widely by the general public, it is used extensively by staff and team members to enhance current knowledge or for assistance in working with specific clients.
- A quarterly newsletter is distributed to parents and professionals in paper and email formats. It includes information on upcoming FASD events, best practice information, current program offerings and an update of Centre activities.
- The Centre provides training as requested ranging from short FASD overviews to multi-day intensive sessions. Limited resources have required a fee-for-service approach to this training where possible. Training topics have included prevention, symptom and risk factor identification, best practices and a description of the diagnostic services provided by the Centre. While there is still a need for “FASD 101” presentations, the Centre is focusing limited resources on helping organizations with best practice strategies and community capacity building. In an 18-month period between April 2002 and June 2004, the contract trainers conducted 75 sessions to 2250 participants. Session evaluations have been almost without exception positive.
- The Centre has been asked to consult to a wide range of organizations about FASD and the diagnostic model, travelling extensively to assist. They receive phone calls weekly from organizations across Canada looking for input and assistance.

In order to assess the impact of FASD training on organizational practices, a survey was distributed in person, by post and by email to organizations throughout the region. Twenty-three responses (50%) were received from Aboriginal communities and 31 from agencies in Bonnyville, St. Paul, Lac La Biche, Fort Saskatchewan and Vegreville. The portion of the survey dealing with knowledge of FASD is reported below. Other portions of the survey are discussed later in this report.

Table 3 – Agency Personnel Knowledge of FASD			
	Non-Aboriginal # And (%) N=31	Aboriginal # And (%) N=23	Total # And (%)
Rate knowledge of FASD			
a. limited, need to know more	8 (28)	5 (22)	13 (24)
b. adequate for my needs	18 (58)	14 (61)	32 (59)
c. extensive	5 (16)	4 (17)	9 (17)
How much knowledge attributed to Centre?			
a. none	5 (16)	4 (17)	9 (16.5)
b. some	22(71)	14 (61)	36 (67)
c. all	4 (13)	5 (22)	9 (16.5)
Are you/ have you ever worked with a confirmed or suspected FASD client?			
a. yes	26 (84)	20 (87)	46 (85)
b. no	5 (16)	3 (13)	8 (15)
Has involvement with Centre made your work with the FASD client...			
a. easier?	14 (45)	14 (61)	28 (52)
b. harder?	1 (3)	1 (4)	2 (4)
c. made no difference.	4 (13)	3 (13)	7 (13)
d. had no client-based involvement with Centre.	12 (39)	5 (22)	17 (31)

5. The Project will successfully pilot a service delivery model for FASD diagnostic and support services that has been adapted for use in rural communities.

All evaluation tasks completed throughout the project indicate that this project has been carefully planned, thoroughly implemented and well received by both clients and the professional community. While not without challenges, most have not limited the Centre's ability to implement the project as planned and have been successfully dealt with. They have been able to develop a broader project than originally envisioned without losing sight of the original vision and mission. They have received much provincial and nation-wide recognition for their work and have been asked to make presentations and consult to a wide variety of organizations from New Brunswick, Ottawa, Alaska, to the Northwest Territories and for all levels of government. Part of the success has been because they were pioneers in FASD diagnosis in rural Canada and have been able to use what they have learned to assist others.

While the ability to assist other provinces and communities to establish FASD programs has been satisfying, the main focus is on making a difference in the communities within their own service area. The previously mentioned survey asked respondents to rate the Centre on several different aspects of that difference. The results are shown below:

Table 4 – Awareness and Impact of Centre			
	Non-Aboriginal # and (%) n=31	Aboriginal # And (%) N-23	Total # And (%)
Aware of Centre’s work in your own community?			
a. not at all aware	3 (10)	5 (21)	8 (15)
b. somewhat aware	13 (42)	13 (57)	26 (48)
c. very aware	15 (48)	5 (22)	20 (37)
Impact of Centre on FASD issues in your community?			
a. none	0 (0)	3 (13)	3 (6)
b. minimal	3 (10)	9 (39)	12 (22)
c. significant	15 (48)	5 (22)	20 (37)
d. unsure	13 (42)	6 (26)	19 (35)

6. The Project will add to the knowledge base regarding the health status of adults diagnosed with FASD.

As previously mentioned, the adult-specific diagnostic team is the only one of its kind in the world. While other diagnostic organizations may diagnose adults and children, the Centre provides the only team whose entire focus is on providing assessments to adults with FASD. They have diagnosed 22 adults to date and have collected a large amount of rich data on these individuals. While it is not within the scope of this evaluation to analyse client data beyond the demographics provided in Appendix A, it is safe to say that much new information has been learned about this client group and how to work effectively with them. Health research organizations should be interested in working with the Centre to produce empirical research about this client group. Subsequent evaluation of the work with the adult clients is continuing beyond the end of the Health Innovation Funding and will be available to interested parties upon request.

Unintended Outcomes

1. National Recognition

The Centre did not seek for the national recognition that it has received. While there was a commitment to excellence from the beginning, it was about providing quality diagnosis to regional residents. The Centre is recognized as an FASD best practice model across North America, designated as such by Health Canada in 2003. It is the only centre of its kind in North America and has the only adult-specific diagnostic team in the world. The Centre provides the only FASD team diagnostic training in Canada accredited by the College of Family Physicians approved by Main Pro (7.5 points). That they would accomplish what they have in such a short time is notable, but that it would occur in a rural community makes it even more so.

2. Partner Support – Expecting agencies to donate staff to work as part of the diagnostic team was not a given during times of cut-backs when the Centre first began. An early concern was that team members would be trained and then the partnering agency would withdraw its

support. With the success of the Centre, the opposite has occurred and team member longevity has become a non-issue. Some agencies have used potential participation with the Centre's teams as a recruitment incentive.

3. Team Functioning

The way that the diagnostic teams function and the benefits to the team members has turned out to be better than expected. Member longevity and commitment to the team has been surprising. The team members consider it a privilege to participate and organizations use potential membership on the team as a recruitment and retention tool. The Centre has made presentations at national conferences about effective team development and it is a significant part of the training provided to new teams. Participants receiving training, after watching the team conduct a diagnostic session, regularly comment during evaluation that they did not know a team could work so effectively. Team members have also found that they receive heightened recognition in their own organizations for the work they are doing as part of the FASD team. One member reported that working as part of the team is the professional highlight of the month. There is a heightened level of cross-discipline training and awareness that did not exist before.

Learning

Barriers and Challenges

While the implementation went smoothly with only minor adjustments needed there were and still exist some barriers to providing the best service that could be provided for clients with FASD.

1. Human Service Agency Practice

One of the original hopes for the Centre was that both the incidence of FASD births would decline and that human service agencies would develop practice standards that are most effective in working with FASD clients, thus eliminating the need for a Centre at all. While it was recognized that the decrease of FASD births is a long-term goal, the amount of time needed to change client practice is taking much longer than anticipated.

Ineffective agency client practices make it difficult to make any meaningful change in the lives of FASD clients. If an effective diagnosis is being made and clients are being referred to agencies that continue to implement ineffective ways of doing business that ignore client abilities and disabilities, nothing will change for the client.

While Centre staff and team members working in government agencies are doing business differently, systemic change has only happened in small sporadic patches. It takes more than education to change systems. While this is not a barrier to the Centre's program, it is a barrier to effective client outcomes beyond the Centre.

2. Diagnostic Fees

As part of the existing funding structure, the Centre has had to charge a fee to complete a diagnosis. Referring agencies first questioned having to pay \$1000 (\$2000 for adult diagnosis)

but now recognize it as a cost-effective investment in ensuring that they are providing the right services to their clients. This change in perception has occurred over time but the barrier still exists for some.

3. Funding of the Centre

With the completion of the Health Innovation funding, financial sustainability will continue to be a challenging issue for the Centre. The executive director spends significant portions of time trying to obtain core funding. Health Canada does not have program dollars for non-Aboriginal FASD projects. Alberta Health defers to the RHA's who do not have extra funding for new programming outside their stated priorities. Children's Services stepped in for the short term but only for the portion of the Centre's program relevant to their services. Local community organizations are reluctant to fund "regional" programs. Taken in total, an unfortunate amount of staff time is spent fund raising. The Society is currently exploring the concept of responding to regular requests for non-resident diagnosis on a fee-for-service basis. This entrepreneurial contingency plan is contrary to the goals and philosophy of the Society but may be a necessity to fund the cost of providing ongoing services to residents.

Contributions to the Health System Level of Inquiry

One of the main objectives of the Health Innovation Fund was to fund projects that would contribute learning to the health system in general. After three years of funding the Lakeland Centre for FASD, the health system knows more about the following:

1. The factors that contribute to an effective integrated service delivery model:

a. Careful team and staff selection, development and management

- The conscious development of an effective team is critical. Team members apply to be part of the team and are interviewed. Team members are chosen (or not) for specific reasons. They feel privileged to be involved in innovative work.
- Team members work well together and are dedicated professionals. Team dynamics are critical to the success of the work.
- The team is well supported and reinforced by Centre staff and the Lakeland FASD Society.
- The work is serious but they insert as much fun and humour into it as appropriate.
- Passion for the cause is critical.

b. Thorough community preparation

- Communities must be prepared to support and participate. The Lakeland FASD Committee had laid a solid foundation in the region making the Centre a natural next step. A diagnostic centre will not "parachute" as well into unprepared communities.
- High visibility is achieved and maintained in communities throughout the service area. The Centre has been well promoted and staff members regularly "drop in" on professionals in other communities during their traveling to promote Centre services and build networks.

- Establishing an effective network of regional and community partners with a broad, integrated view is a priority.

c. A client/family centred focus.

- A commitment to client-focused services ensures staff participation. Effectively meeting client needs is more professionally motivating than maintaining bureaucratic systems. Service providers will work hard if the work is making a difference.

d. Effective cultural connections.

- Good working relationships, based on cultural knowledge and respect, are established with all communities.
- Aboriginal professionals are included as team members.
- Team members are respectful of clients from all cultures and deal with people where they are.

e. Being politically active and visible.

- Having the teams travel to other communities is seen to be (and is) equitable and therefore supported by service providers and decision makers throughout the region.
- Political visibility and partnerships with all levels of government is cultivated. This is critical for funding and support. Much has been accomplished by soliciting the support of politicians at all levels.

f. Adaptability

- Priorities are established but allowed to develop over time.
- Be aware of new opportunities that had not been anticipated.

2. The current system in most agencies talks about integrated service delivery but does not provide support or incentives for staff to do integrated work. The successful multi-disciplinary approach used by the Centre includes many incentives to the professionals participating as team as follows:

- a. The chance to work as part of an effective and innovative process that meets client needs and makes working with the client easier.
- b. Receiving cutting edge FASD training and experience that assists them in working with their own clients.
- c. Involvement in work that is a positive change from their regular routine.
- d. Being considered an expert and the resulting chance to travel and present the work they are doing at national conferences. This has increased their profile in their own organizations as well as presented new professional opportunities.

3. The benefits to the team members sponsoring agency also provide incentives to continue to support staff participation. Potential participation on the team has been used by agencies for recruiting new staff who have heard of the Centre and the team process. Potential benefits are:

- a. Being known as an agency partner in an innovative and visible process.
- b. The agency's own client group receive the benefit of integrated service delivery.
- c. Their staff receive enhanced training that they would not otherwise receive and at no cost to the sponsoring agency.
- d. Staff are working collaboratively which can contribute to greater job satisfaction and therefore staff retention.
- e. Cross-discipline awareness gained from working together has led to more effective practice and support.

4. Working with collaborative teams can seem overwhelming for clients at first, perhaps anticipating a loss of confidentiality or the intimidation of assessment by a room full of professionals. However, receiving a comprehensive assessment from a variety of professionals and leaving with written recommendations in hand is satisfying to clients after experiencing the frustration of going from "door-to-door" looking for answers. Additionally, accessing the diagnosis and services in or near their own community means a higher likelihood of participation and therefore a greater chance for real client impact.

5. In addition to supporting the services provided by the Centre, the system still needs to consider the following gaps in service for this client group:

a. Effective Follow-up Services

Ensuring that service providers who receive referrals after the diagnosis are effective in their service delivery to FASD clients will require systemic changes beyond the Centre's influence or control. The diagnostic process is integrated and effective. Integration, or even coordination of the follow-up services will take time but could be expedited by an examination of departmental practice standards at regional or provincial levels. This is a matter of education and training as well as commitment to the continued care of the client. While some service providers have come a long way in their knowledge level regarding effective services for FASD clients, there is still much that could be done.

b. Respite Care

Even though respite care is theoretically available, regional policies can make it nearly impossible to access leaving many parents stressed and near burn out. As an example, the local Children's Services authority provides no administrative support to parents qualifying for respite care making them responsible to recruit, hire, train, supervise and pay their own provider and then request reimbursement through a lengthy, complex process. Additionally, FASD children can react negatively to disrupted routines, so if a family does actually recruit and train a person, he/she will often quit, forcing the parent to

begin again. In reality, most never make it past the recruitment process and so do not receive the help they need.

c. Long Term Case Management

Adults diagnosed with FASD are in need of case managers. Those who fall within the Persons' with Developmental Disabilities (PDD) mandate may receive some level of advocacy, but the service is voluntary and dependent on the client following-up on the referral. Those who do not qualify (55% of those diagnosed by the Centre) are left to their own devices or to piece-meal assistance from agencies with mandates too specific to address the broad range of issues that exist for FASD clients. The short-term support provided by the Centre does not address the long-term (life-long) support need identified in the literature for this client group.

d. Support to Birth Mothers

Recognizing the differing support needs for caregiver types, the Centre has identified a significant gap in programming and support for birth mothers, particularly those who may be alcohol-affected themselves. Attitudinal and program changes need to occur in all of the human services.

e. Transition Planning

Children or adults with FASD have a particularly difficult time with life changes and transition planning by those around them would ease the transition and may make the difference between success and failure. The transition from childhood to adulthood, dependence to independence, should be planned well in advance. There is no formal mechanism in place at this time to address this need.

f. Life Skills/Parenting Training

Adults with FASD typically need hands-on support and training in common tasks easily accomplished by most adults. Additionally, many of them will become parents and will lack basic parenting skills. Ways to assist them with these specific training needs are currently not available.

6. In addition to contributing to system level learning, an FASD diagnosis impacts the health of individuals and thus the health system in the following ways:

- a. One of the main protective factors against secondary disabilities for FASD clients is an early diagnosis. This will save countless dollars for health practitioners as the child grows.
- b. An effective diagnosis and the resulting medical report provides more information to family physicians for follow-up patient management. It also increases physician understanding of FASD.
- c. The diagnostic teams have identified medical issues of concern in clients they have diagnosed enhancing early treatment of problems that may have gone undiagnosed and caused larger health problems later.

- d. Assessment and diagnosis will clarify the client's disabilities for caregivers and reduce the need for resources spent on ineffective interventions based on incorrect diagnosis. Learning that misbehaviour is often caused by a brain disorder not a conduct disorder and "I won't!" often means "I can't" will positively impact work with clients in every field (i.e. schools, courts, employment, etc.).

7. As a result of the work done by the diagnostic teams, a new diagnostic category has been developed (Alcohol Related Neuro-behavioural Disorder – ARNBD) which has been recognized and included in the Alberta Physician Guidelines for diagnosing FASD.

Implications

While FASD is a medical diagnosis, what is known about it has implications for more than the medical community and should be of interest to all human service agencies. A child born with brain damage caused by maternal alcohol consumption will touch every service system throughout his/her life and the potential cost of care should motivate all service providers to try to be as effective in service delivery as possible. With that as a starting point, the following are key to policy and practice planning:

1. *Diagnosis is important.* While the discussion about the benefits of diagnosis vs. the potential damage of a negative label is not limited to FASD, it has become clear that an FASD diagnosis is the key that unlocks the door to funding for additional services for the clients, follow-up support from local service providers and valuable information to the client and his/her support system. An early diagnosis is a leading protective factor against developing secondary disabilities such as mental health issues, school disruption, legal difficulties, drug/alcohol addictions, etc. An FASD diagnosis is not easy to deal with as it carries with it an implied blame. Additionally, FASD individuals may appear and function quite normally at a certain level and therefore not want to acknowledge a brain disability. A diagnosis, however, does empower individuals to advocate on their own and other's behalf and allows systems to react based on that diagnosis. As an example, a young man diagnosed by the team had felt some difficulty accepting the diagnosis but began to tolerate others reaction to it. On one occasion, while being questioned by the RCMP, he continued to ask if they knew about FASD and would not answer their questions until they called his social worker to find out about it.

2. *An FASD diagnosis is not a cure.* There is no cure for FASD. Clients will still have all the challenges they had before receiving the diagnosis. This lack of a cure has been a barrier to some physicians wanting to get involved, but there is a growing comfort level with FASD which has led to more physician referrals and families talking with their doctors about the diagnosis. Even though there is no cure, given a diagnosis, caregivers will have access to the information and supports to work more effectively. Children and adults with FASD will need supports their entire lives, so there is nothing to be gained by not seeking out and implementing new policy and practice to more effectively deal with it.

3. *FASD is not an "Aboriginal problem."* The popular mythology around FASD is that it is primarily an Aboriginal issue. While FASD is an issue of significant concern to Aboriginal leaders and communities, it should be no less of a concern to non-Aboriginal people. Any woman who drinks alcohol during pregnancy, regardless of her socio-economic status or race, is putting her child at risk of brain damage. Non-Aboriginal organizations, governments,

researchers and policy-makers are underestimating the extent to which this issue is a reality for all women.

The statistics presented in this report show a proportionately larger number of Aboriginal clients only because of the native community's willingness to deal with the issues of alcohol use and its effects in the community. Some predominately Caucasian communities are not yet prepared to address the cultural and societal implications of alcohol use and pregnancy so are less willing to promote and support FASD interventions. The Centre continues to experience the perception that given similar misbehaviour in school, the Aboriginal child has FASD and a non-Aboriginal child has Attention Deficit Disorder.

The federal government also seems to view FASD as an Aboriginal issue as the majority of funding for service programs is provided through the First Nations and Inuit Health Branch of Health Canada. FASD funding beyond that has been established primarily for research. This not only reinforces the message that FASD is an Aboriginal issue but leads to inequitable distribution of funds for regional and/or provincial programs.

Society's attitudinal shifts take time and myths serve a purpose for the majority, but governments at all levels should be encouraged to not contribute to them and be willing to fund interventions for all of its citizens.

4. Multi-disciplinary work can be done effectively in rural areas. Speaking of myths, some individuals and communities feel that urban professionals are better skilled than their rural counterparts. The Centre's experience has been that once trained, rural professionals can be as, and in many cases more, knowledgeable, committed and passionate about the work that they are doing than urban specialists. The lack of specialized service providers in rural areas does not need to limit all specialized services to rural residents. The diagnostic and assessment model used by the FASD teams could be duplicated for other health issues and provide much needed services to non-urban residents and diminish the strain on urban services. In the meantime, medical professionals should be encouraged to seek assistance from other community professionals in working with complex clients.

5. Medical professionals are important community partners. Physicians and public health personnel are often the first contact a woman makes during pregnancy and they should be encouraged to take a more active role in talking to pregnant women about alcohol consumption and to make referrals to other service providers for additional support. The physicians in this region have had significant exposure to FASD as a result of the Centre. It is likely that medical professionals in other regions have not and would benefit from continued encouragement.

6. Community-based FASD solutions do work but take time. While the Centre has provided annual training sessions for teams from other communities wanting to establish similar programs, it takes more than a good diagnostic manual to implement this model. Community development principles need to be applied to establish community-based services. In this case, an awareness and acceptance of FASD as an issue of concern in the community, a basic level of training among local professionals, a desire for the services, the support of community stakeholders and time spent with community members to raise their awareness and acceptance of the need for services. Finding the resources to deliver the services takes patience and creativity. Once diagnostic training has been received, communities need additional support post-training to successfully establish themselves.

7. *Effective innovative models of service should be supported.* To fund innovation projects and evaluate them for effectiveness and learning is to be applauded. Assisting those projects that are found to be worthwhile to find core funding would help ensure their continuation and limit the need to spend valuable resources on fund-raising. The Centre is currently examining a fee-for-service diagnostic process that would have teams completing diagnoses for non-residents. While this may be considered innovative it is also contrary to the goals and philosophy of the FASD Society and Centre staff and is only being considered as a last funding resort.

8. *In order to address persistent gaps and barriers, effective service for FASD clients will require changes to departmental practice standards in all disciplines.* To provide an effective FASD diagnosis is only the first step for individuals and families. It needs to be followed up with effective service delivery over the client's lifespan. To not do so can be compared to patients receiving a cancer diagnosis at the Cross Cancer Institute and subsequently being treated at their local hospitals for diabetes because the hospitals don't know about cancer, so diabetes treatment will do. As unreal as this example would be in the medical field, it defines the reality for most FASD clients. While there is some discussion at provincial levels of the issues around FASD service delivery, in some departments, policy and practice are left to regional governing authorities to determine. Regional authorities (i.e. Child and Family Services, Persons with Developmental Disabilities, Health, School boards, etc) should be encouraged to actively pursue FASD best practices in light of current knowledge about effective service delivery to this client group. Excellent models are being piloted (i.e. Southwest Alberta Child and Family Services Authority in Lethbridge) and should be examined for local application.

Conclusion

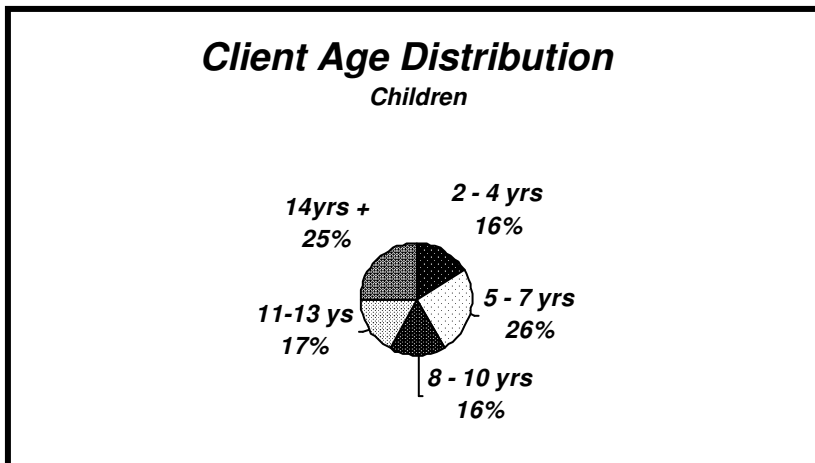
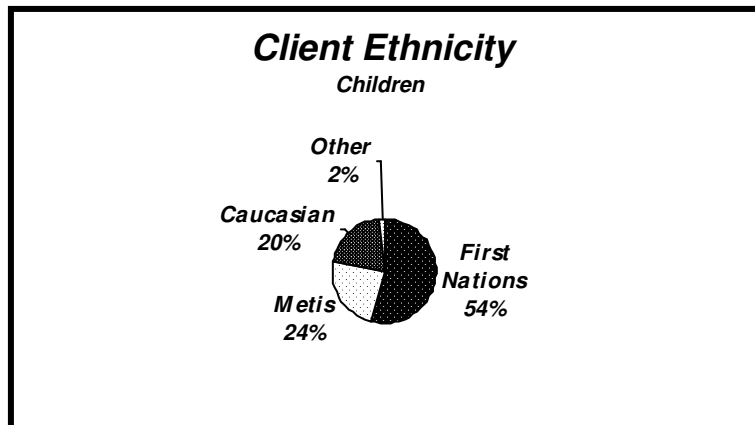
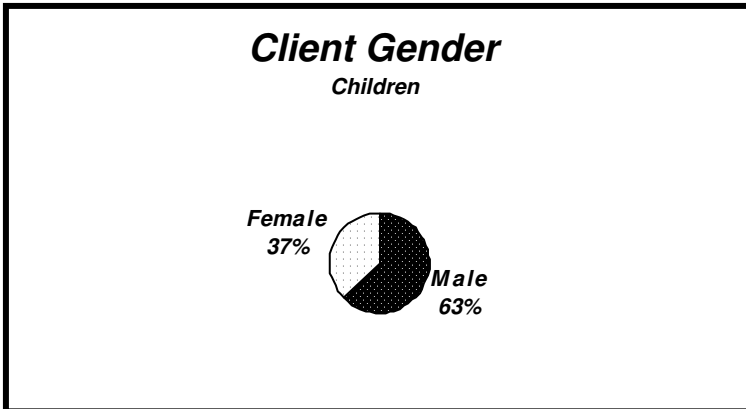
The evaluation of the Centre to date has included the effectiveness of the diagnostic process and short-term outcomes as perceived by the clients, team members and communities of the region. The results indicate that the Centre provides a quality service with measurable short term impacts. They have access to a rich data source from which could come important research. Particularly of interest would be a broader examination of long-term effects of early diagnosis. This would be of great benefit to the FASD field and should be considered as a valuable next step.

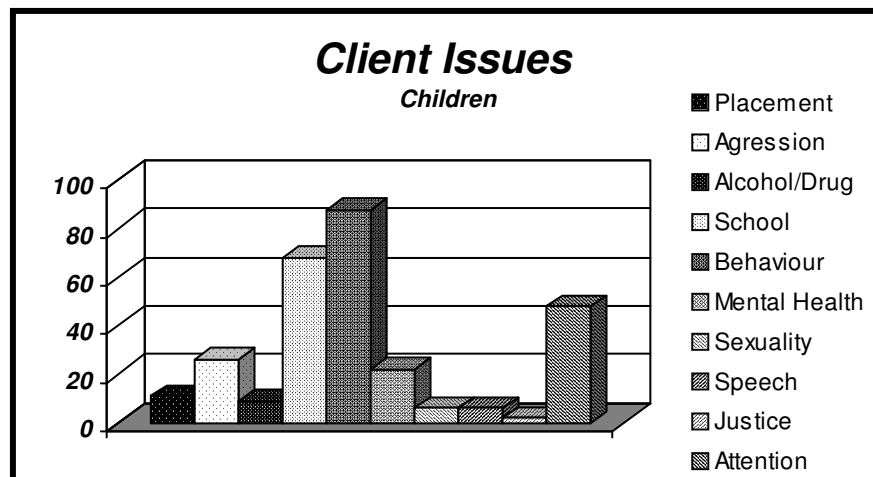
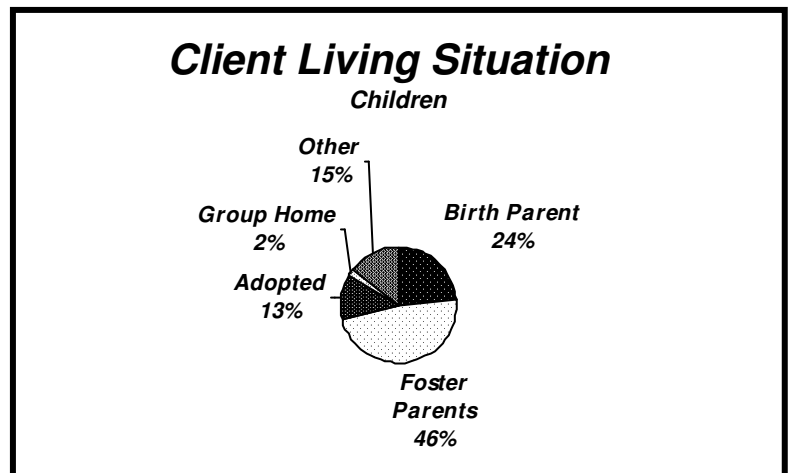
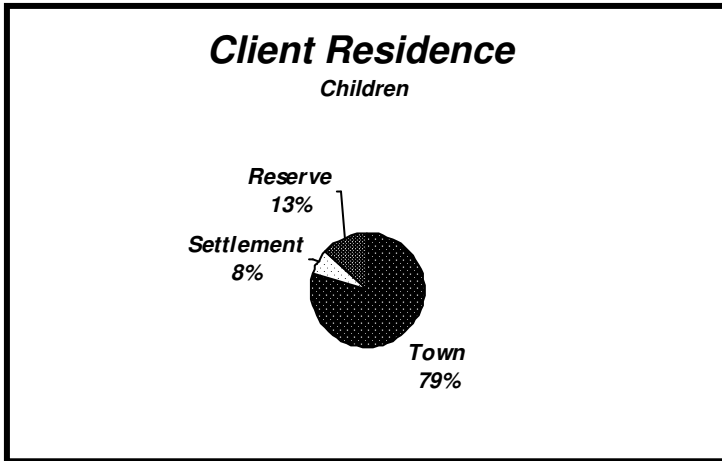
Finally, It has been my privilege to be associated with the Lakeland Centre for FASD over the past three years of this evaluation. They are courageous, visionary and committed people who, against conventional wisdom, have established an effective resource for families and individuals dealing with FASD in rural Alberta and in so doing have pioneered a valuable resource to the entire FASD professional community.

Appendix A

Client Demographics – Children’s Clinic

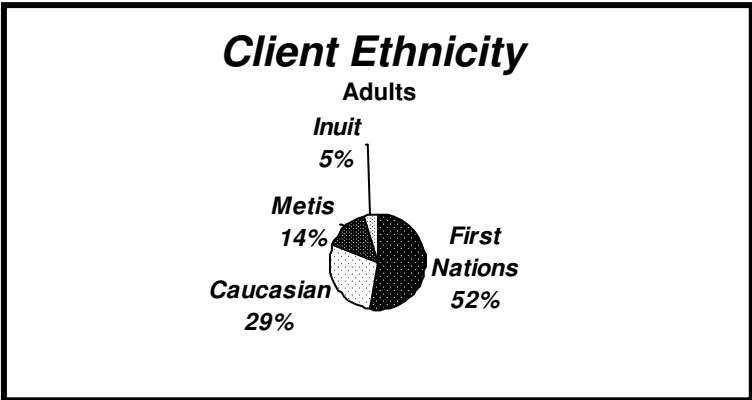
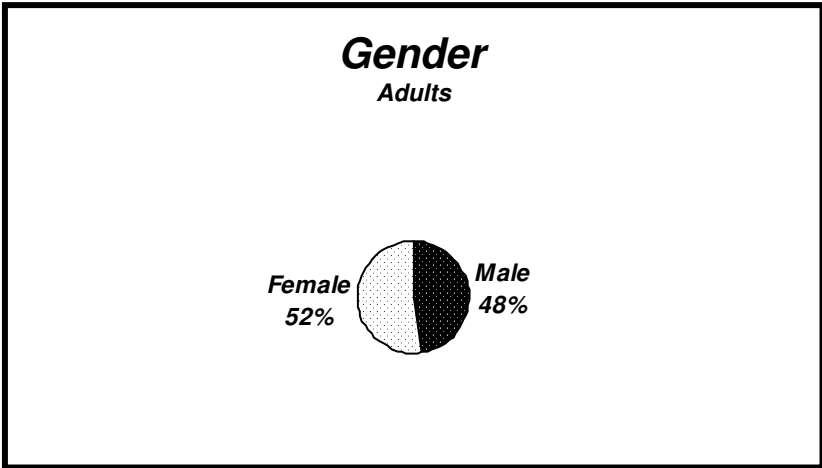
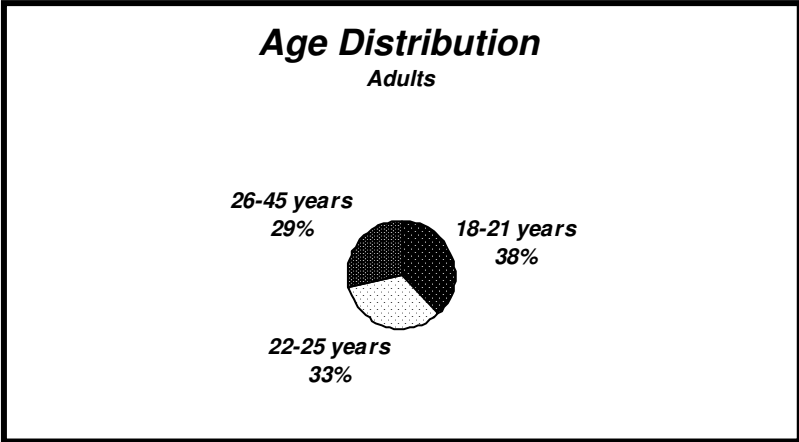
128 Children Diagnosed





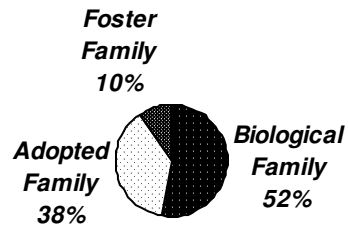
Client Demographics – Adult Clinic

22 Adults Diagnosed



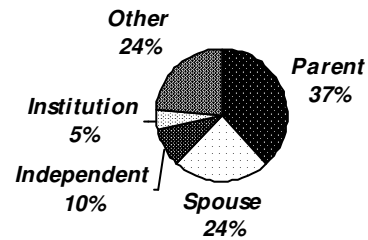
Client Origins

Adult



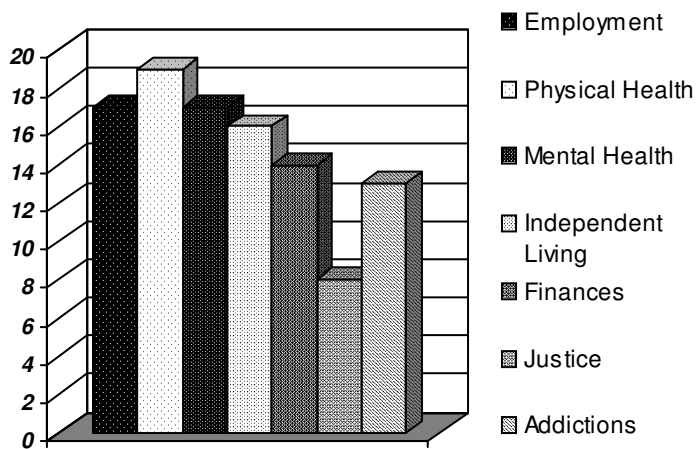
Current Living Arrangements

Adults

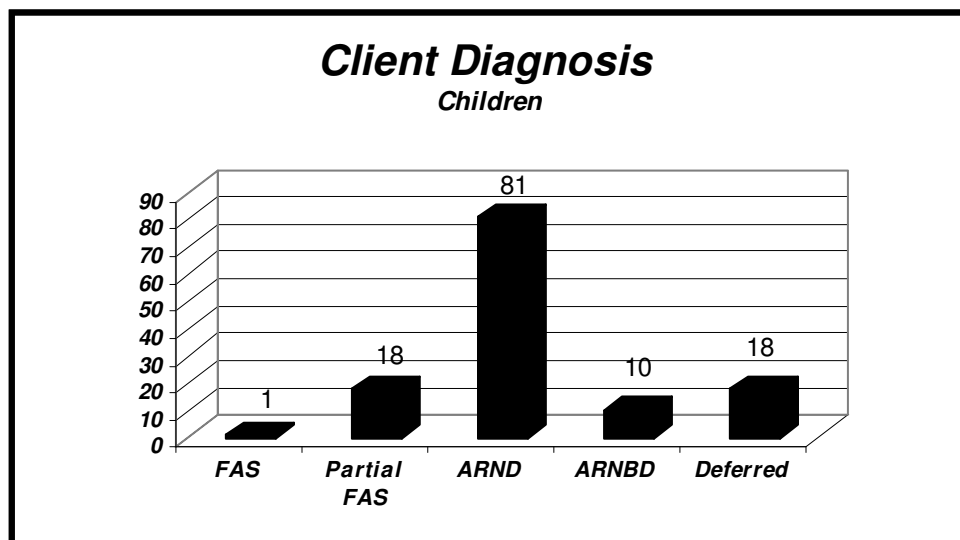
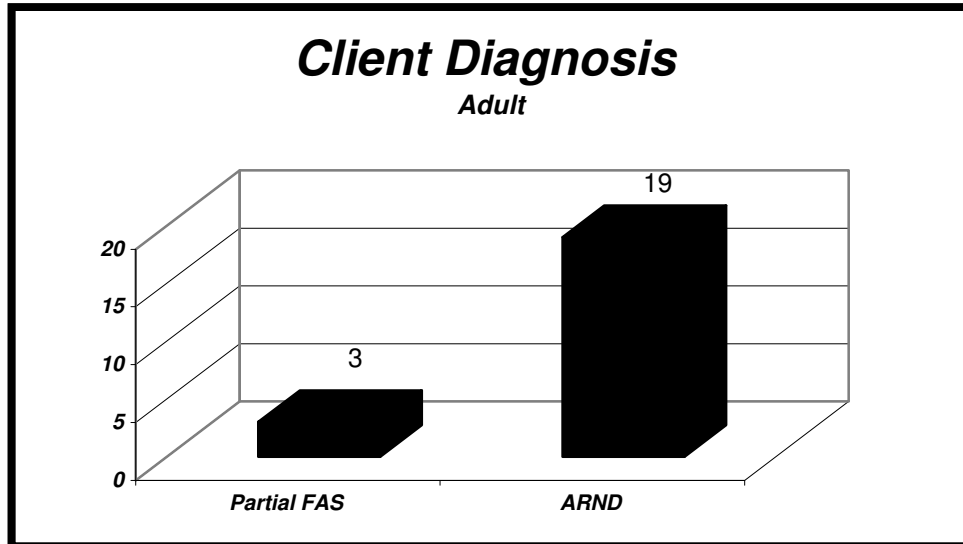


Client Issues

Adult



Client Diagnosis – Children and Adults



FAS – Fetal Alcohol Syndrome

ARND – Alcohol Related Neuro-Developmental Disorder

ARNBD – Alcohol Related Neuro-Behavioural Disorder

Deferred – Unable to make a diagnosis at that time.