



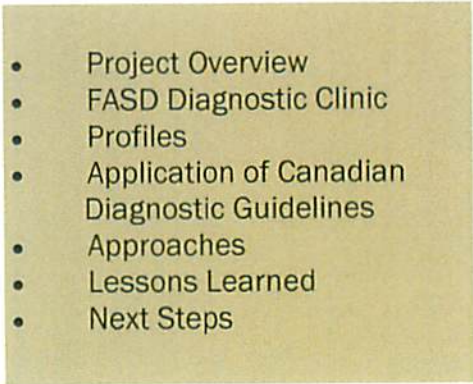
# *Creating a Foundation for FASD Diagnostic Capacity*

*A project of the FASD Stakeholders for Ontario Diagnostic Working Group*

**May 2006**

**Prepared By:**

**Geraldine Guilfoyle M.Ed.**

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- Project Overview
  - FASD Diagnostic Clinic Profiles
  - Application of Canadian Diagnostic Guidelines
  - Approaches
  - Lessons Learned
  - Next Steps

This project was made possible with funding from The Public Health Agency of Canada. The views herein do not necessarily represent the official policy of The Public Health Agency of Canada.

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## Acknowledgements

The project was conceived and planned by FASD stakeholders of Ontario Diagnostic Working Group.

**Dr. Brenda Stade, St. Michael's Hospital (Co-Chair)**

**Sheila Burns, Durham Region (Co-Chair)**

Dr. SML Kirkpatrick, Durham Region

Dr. Barry Stanley, Cedar Springs Medical Centre

Dr. Gideon Koren, The Hospital for Sick Children Motherisk

Judy Kay, Healthy Generations Family Support Program, Sioux Lookout

Doug Nugent, parent representative St. Michael's Hospital FASD Diagnostic Team

Sandy Mac Donald, Anishnawbe Health Toronto St. Joseph's Health Centre

Maureen Parks, Norwest Community Health Centre

Karen Smith, Deowadisnye Coordinator Six Nations Maternal and Child Centre

Healthy Generations Family Support Program, sponsored by Community Living Sioux Lookout was the project lead.

### Project Team Members

**Judy Kay — project lead**

Geraldine Guilfoyle — project writer

Teri Forbes — project assistant

Nancy Greaves — videoconference site coordinator

Jane Hoy— videoconference chair

Special thanks to the following FASD diagnostic clinics for their participation in the clinic survey: Northwestern Ontario Diagnostic Clinic, FASD Durham, The Hospital for Sick Children Motherisk Program, St. Michael's FASD Diagnostic Clinic, Breaking the Cycle FASD Diagnostic Clinic.

This project was made possible with funding from The Public Health Agency of Canada. The views herein do not necessarily represent the official policy of The Public Health Agency of Canada.

## WRITERS PREFACE

This report is based on the information generated during the life of a 4 month project. Response and participation by teams was circumscribed by their particular time constraints and professional commitments. The inter-disciplinary requirement for the assessment of Fetal Alcohol Spectrum Disorder provides for a rich base of clinical expertise and with it a diversity of approaches and opinions.

I have attempted to deliver a final report that reflects this diversity while at the same time remains true to the process and activities carried out during the project. Findings are a reflection of the collation of participant input rather than an agreed upon consensus by all participants. The intent is to stimulate discussion and promote mutual support in the development of diagnostic capacity. An additional study to further explore the role of the psychologist is currently being developed by Dr. Michelle Keightley as an adjunct to this project.

- Geraldine Guilfoyle

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## EXECUTIVE SUMMARY

The FASD Stakeholders for Ontario Diagnostic Working Group focuses on issues around diagnosis. In January of 2006, this group received funding through the Public Health Agency of Canada (PHAC) to assist them in the development of an Ontario Network of FASD Diagnostic Clinics. The goal of this project is to identify the strengths and challenges faced by diagnostic teams and to create a foundation of diagnostic capacity development in Ontario.

### Collaboration

Collaboration between existing FASD diagnostic teams and the working group has provided a rich collage of information sharing and reflection on the approaches, successes, lessons learned and on going challenges facing communities as they strive for excellence in the service they provide to the diversity of populations they serve.

### Diversity

Five existing FASD diagnostic clinics are profiled, each with its own unique contributions to capacity development. Diversity is evident not only in the range of specific services offered, ranging from early diagnosis to telediagnosis, but also in the models developed to provide these services. This diversity is driven by a number of factors including:

- Population served
- Geographical location
- Access to resources
- Pool of available clinical specialists

A common thread between approaches is the application of the Canadian FASD Diagnostic Guidelines as the supporting framework for assessment and diagnosis.

### Models

Three basic models emerged:

- Hospital based clinics that also provide community outreach
- Community based specialized clinics
- Networking among team members using existing service system and submitting test results to the physician for diagnosis

Each model has its strengths and limitations. Sharing of these differences provides opportunities for different teams to learn from each other and to consider new ways of overcoming their own challenges.

### **Application of Canadian FASD Diagnostic Guidelines**

While each team strives to provide the most comprehensive assessment and diagnostic service possible, there are differences in the extent to which the guidelines are applied. Composition of diagnostic team members, along with training of the team members account for most of these differences. In addition, not all teams have the same ready access to diagnostic equipment such as MRI and genetic testing. The experience of existing teams has highlighted some areas where the guidelines need refining, namely:

- Facial features as currently described may need modification for some racial groups.
- A screening checklist with a high degree of sensitivity
- More culturally sensitive neurobehavioural assessment measures

### **Lessons Learned**

FASD diagnosis requires a highly organized and inter-disciplinary approach. Inter-disciplinary team meetings to discuss each client's diagnosis allows a forum for open discussion and clarification of results and clinical opinion.

Some specific areas where the assessment and diagnosis can get mired down is in the determination of pre-natal alcohol exposure levels, and the frustration of lengthy waiting periods between referral and diagnosis. Pre-assessment contributes to efficiency. The diagnosis is challenging for families, and readiness to accept a possible diagnosis of FASD can greatly impact outcome post diagnosis. Ongoing support and education are essential to ensure optimal outcome for clients and their families.

### **Challenges**

Challenges cited by teams include insufficient funding, lack of specific diagnostic services or clinical professionals and the need for expanding the number of trained clinicians available. For example, there is currently no ministry code that allows a physician to bill OHIP for time spent in reviewing assessment documentation. Ways of overcoming these challenges include lobbying within institutions for support, using existing services, using creative approaches to training such as on-line training and peer/colleague mentoring, submitting proposals for special grants and networking between teams to problem solve and share resources where possible. Broadening the base of clinicians involved in assessment and diagnosis to include more psychiatrists, nurse practitioners and other clinical specialists is an area for future consideration.

### **Next Steps**

This report is not meant to be a definitive document on best practices in FASD diagnosis but rather a foundation for further discussion, collaboration and planning in the ongoing development of FASD diagnostic capacity. The process is complex and

requires partnerships with the colleges of clinical specialists to increase diagnostic capacity, expedite training and advance treatment and management strategies. A provincial initiative that supports the training, availability and integration of services required for start up would greatly support this process. FASD diagnosis will continue to evolve. Ongoing discussion, debate and evaluation will ensure that resources are used effectively to the best advantage of individuals and communities.

The FASD Stakeholders of Ontario Diagnostic Working Group will continue to work collaboratively with both existing and emerging FASD diagnostic teams as well as provincial and federal agencies to nurture this goal and encourages and welcomes continued dialogue and networking towards this end.

# SECTION I

## Overview of Project

## INTRODUCTION

The FASD Stakeholders for Ontario Diagnostic Working Group is pleased to present ***Creating a Foundation for FASD Diagnostic Capacity***. The information in this report was compiled through a process of collaboration between existing FASD diagnostic teams in Ontario. It is a report on a process to create a foundation for diagnostic capacity development in Ontario. The information in this report is meant as a summary and discussion platform, rather than a definitive document on best practices in FASD diagnosis. Readers are encouraged to strengthen the networking process by engaging in further dialogue with each other and by contributing additional data and information to the network as it becomes available.

## BACKGROUND

The Public Health Agency of Canada supports efforts to address the recognized need for coordination and collaboration across Ontario regarding Fetal Alcohol Spectrum Disorder (FASD). In January 2005, the first Terms of Reference for FASD Stakeholders for Ontario were crafted to provide a framework to begin establishing relationships that have moved beyond information sharing to collaboration, coordination and action. Five Working Groups were identified and each accepted a major priority of concern as a focus with the Public Health Agency of Canada continuing as the supportive agency at this time.

### Vision

FASD Stakeholders for Ontario will develop an FASD culturally based Strategic Plan and implement it across Ontario in a coordinated way.

### Mission

FASD Stakeholders for Ontario support efforts to address the recognized need for a coordinated, collaborative and complementary approach across all sectors in Ontario including but not limited to health, education, justice, etc. regarding Fetal Alcohol Spectrum Disorder (FASD) and its complexities.

FASD Stakeholders for Ontario will build capacity in Ontario by striving to realize the *FASD: National Framework for Action*, uphold its Guiding Principles, and address factors behind FASD through its identified goals and objectives.

The FASD Stakeholders for Ontario Diagnostic Working Group focuses on issues around diagnosis. In January of 2006, this group received funding through the Public Health Agency of Canada (PHAC) to assist them in the development of an Ontario Network of FASD Diagnostic Clinics. (This group will be referred to as the FASD Diagnostic Working Group)

## **GOAL**

To identify the strengths and challenges faced by diagnostic teams and to create a foundation for diagnostic capacity development in Ontario.

## **ACTIVITIES**

1. Gather information about existing clinics in Ontario and develop a report
2. Hold 2 videoconference meetings with all FASD clinics to information share re; approaches, application of diagnostic guidelines, needs of clients and team members, lessons learned and next steps for best practices.
3. Establish a communication with colleges of appropriate clinicians re multi-disciplinary teams, roles and diagnostic guidelines.
4. Establish next steps for long term network system

## **PHASE I**

A series of teleconferences were held between members of the FASD Diagnostic Working Group to plan the first videoconference. The primary purpose of the first videoconference was: *To enhance the existing FASD diagnostic teams* by providing them with an opportunity to:

- Share Approaches
- Review application of Canadian FASD Diagnostic Guidelines
- Share lessons learned
- Consult on challenges facing teams
- Consult on next steps for best practices and support of new FASD diagnostic teams

A survey was developed and sent out prior to the videoconference to gather information from each FASD diagnostic team and to develop site specific

profiles. The following teams participated in the first videoconference:

- Northwestern Ontario FASD Clinic
- St. Michael's Hospital FASD Diagnostic Clinic
- The Hospital for Sick Children Motherisk Program
- Native Child and Family Services of Toronto
- Anishnawbe Health Toronto – St. Joseph's Health Centre
- FASD Durham for Grandview Children's Centre and clinicians in private practice
- Breaking the Cycle FASD Diagnostic Clinic

## **VIDEOCONFERENCE I - HIGHLIGHTS**

The videoconference brought together for the first time all of the FASD diagnostic teams in Ontario. Each team provided an overview of how their clinic operates, who their funders are, referral and intake procedures as well as use of Canadian Diagnostic Guidelines, lessons learned and major challenges faced. A round of questions followed with each team having the opportunity to address questions to other teams. Participants valued the opportunity to meet other FASD diagnostic teams. A desire to have an ongoing discussion between teams was expressed. Time was the major constraint. With just two hours designated for the videoconference there was not enough time for in-depth discussion on the diagnostic process, follow up and case management. Participants were encouraged to continue dialoguing with each other through e-mail. A follow up to the first videoconference was the circulation of a complete contact list to facilitate ongoing discussion.

Information gleaned from the videoconference I has been integrated with information from the survey to develop profiles for each FASD diagnostic team.

# SECTION II

## FASD Diagnostic Clinic Profiles

## St. Michael's Hospital FASD Diagnostic Clinic

In the fall of 2001, St. Michael's Hospital opened a new pediatric program. A proposal to develop an FASD diagnostic clinic was developed by Dr. Brenda Stade in response to a community scan asking facilities to support such an initiative. The proposal was supported by the Hospital Administration including Dr. Tony Barozzino, Jennifer Dockery, and Jim O'Neill. Funding for training was received through Health Canada, Aboriginal Management Team. The evolution of the clinic was planned by Dr. Brenda Stade, Dr. Michael Sgro and Dr. Bill Watson. The clinic began services in November 2002. The clinic is funded through St. Michael's Hospital. The FASD diagnostic clinic is hospital based but works closely with communities. The team has a parent partner who plays a major role in supporting and promoting the program. The diagnostic team has the following resource people to draw on:

**Program Director (Dr. Brenda Stade):** Works 16 hours/week, is paid through clinic funding. Program director is the lead person to coordinate diagnostic assessment, follow-up and recommendations, research and training.

**FASD Consultants—Physician/s: Dr. Michael Sgro, Dr. Bill Watson, Dr. Jean Barwell:** - 4 physician hours a week are designated to the FASD Clinic and are paid through OHIP.

**Occupational Therapist:** Community Occupational Therapist works 1 hour every other week, is paid by Ontario Ministry of Health.

**Psychologist:** (associated with team) Dr. Pierce is a consultant to the team.

**Speech Language Services:** Community Service referral by nurse.

**Social worker:** On call depending on need, paid for through clinic funding.

**Nurse/s:** Nursing student (U of T placement) does 6 hours/week – varies throughout the calendar year. Clinic nurse for pediatric clinic provides 2 hours per month to FASD diagnostic clinic.

**Clerical:** Administrative support for pediatric clinic provides 8-12 hours/week to FASD diagnostic clinic.

**Developmental Specialist (Cathy Primeau, RN, BscN):** 4-8 hours monthly, is paid through clinic funding.

**Contact:** Dr. Brenda Stade Clinical Director,  
Clinical Director, St. Michael's Hospital FASD Clinic  
61 Queen Street 2nd Floor Paediatric Clinic, Toronto, ON M5C 2T2  
Tel: 416-867-3655 Fax: 416-867-3736 e-mail stadeb@smh.toronto.on.ca

**Family Therapist:** Dr. Barry Stanley is a consultant to the team. He follows many of the clients long term.

**Psychiatrist:** Psychiatric resident (overseen by staff psychiatrist, Dr. John Langeley) provides about 4 hours /month, is paid through OHIP.



**St. Michael's has the capacity to deliver early diagnosis.**

Infants are followed from birth to 5 years. They are seen at birth, 2 months, 6 months, 12 months, 18 months, 2 years, 2 ½ years, 3 years and prior to school entry. Infants and children at risk are evaluated to ensure they are meeting developmental milestones. Such evaluation allows implementation of needed services.



**Pre-assessment process**

St. Michael's uses a pre-assessment process to determine if criteria for full assessment are met. Specifically, if there is no alcohol exposure history then physical signs are examined. If there is no growth restriction or facial features present they will **not** go on to full assessment. An attempt is made to obtain prenatal exposure history. During pre-assessment determination is made if other tests are needed, such as psychological testing. If client meets criteria when pre-assessment is completed – a full diagnostic testing appointment is made.



**Culturally** specific supports are offered through referrals. Referrals are made to Aboriginal Legal Services and Aboriginal Families Coping with Problems.



### Outreach

St. Michael's Hospital have partnered with Native Child and Family Services of Toronto. Specifically, Native Child and Family Services of Toronto run an FASD Clinic where 4 to 6 children or adults are assessed monthly. Native Child and Family Services conduct all of the pre and post diagnostic work to meet the needs of their clients. Members of St. Michael's Hospital's FASD team attend the Native Child monthly diagnostic clinic and provide diagnostic support. Native Child and Family Services have assisted St. Michael's by providing support to Non-Native families raising Native children, or youth.



### Training

The team, primarily the Program Director has done training for Toronto Shelters (screening), and aboriginal communities (screening and diagnosis).



### Research

Several studies have emerged on the topic of FASD and prenatal exposure to other substances. These studies have included measuring development outcomes of infants exposed to alcohol and other substances; examining sensory processing abilities of children with FASD; costs and quality of life studies; homelessness and FASD research and others. One member of the FASD Clinic is one of the researchers on the investigative team that was awarded a CIHR New Emerging Team Grant to conduct the study: *Fetal Alcohol Spectrum Disorder: Perinatal Mechanisms, Treatments, and Diagnostic Neuromarkers*.

(For further information on any of these studies please contact Dr. Brenda Stade  
E-mail [stadeb@smh.toronto.on.ca](mailto:stadeb@smh.toronto.on.ca))

**Statistics 2005**

479 clients were pre-assessed with 88 going on for full assessments. Of these 65 received a diagnosis and 11 were deferred. Those who did not go on to full assessments included 96 clients who were scheduled for full assessment in 2006, and 146 clients who were working with the clinic to obtain additional information such as a clearer prenatal exposure history, results of genetic testing, and psychiatric or psychological testing. The remainder of those seen in the pre-assessment clinic represented infants and toddlers who are being followed in the FASD developmental clinic.

**Lessons Learned**

Establishing a pre-assessment clinic has greatly contributed to the efficiency and throughput. The pre-assessment clinic has decreased frustration with waiting list. It is difficult to determine pre-natal exposure levels as there may be no real documentation of history and intake forms are often not well filled out.

Major challenges facing clients include:

- Accessing services in the community
- Lack of psychological testing for those who lack funds
- Waiting list (the pre-assessment clinic has decreased frustration with the waiting list)

Major challenges facing the team is the lack of designated psychologist for the team.

## Hospital for Sick Children Motherisk Program

Motherisk provides information and guidance to pregnant women or lactating women and their health care providers regarding fetal risks associated with drug, chemical, infection, disease or radiation exposure(s) during pregnancy. The FASD diagnostic services commenced in 1994 to address increased requests for services from Motherisk. They are funded by Hospital for Sick Children. There is a weekly team meeting at Hospital for Sick Children for case conferencing. The FASD diagnostic team also provides outreach services and once monthly, the larger team from other sites joins in case conferencing. Motherisk is the longest running FASD diagnostic clinic in Ontario. The diagnostic team has the following resource people to draw on:

**Program Director:** Works 10 hours/week, paid through Hospital for Sick Children.

**Physician/Pediatrics-Toxicology:** Works 35 hours/week, paid through Hospital for Sick Children

**Psychologist:** Works 14 hours/week, paid through dedicated clinic funding. The psychologist is the lead person to coordinate follow up and recommendations.

**Speech Pathologist:** Consultations as needed, paid through Hospital for Sick Children.

**Admin. Support:** Works 14 hours/week, paid through dedicated clinic funding.

**Psychometrist:** Works 21 hours/week, paid through dedicated clinic funding.

**Geneticist:** Works as needed, paid through Hospital for Sick Children.



### Research

Motherisk researches unanswered questions on the safety of drugs, chemicals, infection, disease and radiation during pregnancy and lactation, and maintains a vital

**Contact:** Dr. Gideon Koren  
The Hospital for Sick Children, Psychology Department  
555 University Avenue, Toronto ON M5G 1X8  
Tel: 416-813-7500 Fax: 416-813-7562  
E-mail: gkoren@sickkids.ca

**Motherisk Alcohol & Substance Use in  
Pregnancy Helpline**

1-877-FAS-INFO (1-877-327-4636)

training and educational program in the area of reproductive and developmental toxicology at the undergraduate, graduate and postgraduate levels.

Motherisk conducts wide scale research on the following aspects of FASD:

1. Digital face measurements for Telediagnosis
2. Neurobehavioral phenotype of FASD
3. The role of antioxidants in preventing FASD
4. Characteristics of problem drinking women based on TWEAK and TACE
5. Measurement of FAEEs in meconium and hair as markers of intrauterine alcohol exposure



### **FOLLOW UP**

Hospital for Sick Children has the capacity to follow up post diagnosis. The extent to which this can be done is dependent on financial support.



### **TEACHING**

The FASD Diagnostic team teaches and trains throughout Canada in diagnosis and screening of FASD. On average the team delivers 6 training events a year. The team has published The Motherisk Handbook of FASD Diagnosis and an educational CD for FASD diagnosis.



### **ACCESS TO SERVICE**

Hospital for Sick Children is currently developing and validating a telediagnosis model.

**Statistics 2005**

89 clients were assessed. Of these 59 received a diagnosis and 30 were deferred.

**Lessons Learned**

The Canadian Diagnostic Guidelines are not carved in stone. They will need refinement to meet the needs of all clients. Problems arise with the how large a standard deviation is required for various assessments. Facial features as currently described may need to be modified for aboriginal children. Canada has the potential and capacity to be world leaders in this refinement. Areas to look at include:

- Developing a screening checklist with a high degree of sensitivity
- Developing a behavioral pattern checklist for parents and teachers

**Needs and Challenges of Clients and Team Members**

Major challenge facing the clients is making the diagnosis work for them.

Funding is a major issue and lack of appropriate resources is an ongoing challenge facing the diagnostic team. The wait time is 6-8 months.

## Breaking the Cycle

The Breaking the Cycle FASD Diagnostic Clinic is a component of the Breaking the Cycle (BTC) program. BTC is one of Canada's first early identification and prevention programs for pregnant women and mothers who are using alcohol or other substances, and their young children (0-6 years). Since 1995, BTC has provided a comprehensive, cross-sectoral, maternal-child program to deliver a range of integrated services (incl. addiction treatment, parenting programs, early intervention services, child care, health/medical services, mental health counseling and basic needs support) through a single-access model, with home visitation and pregnancy outreach components. BTC operates with the funding support of the Public Health Agency of Canada—Community Action Program for Children (CAPC) and Canada Prenatal Nutrition Program (CPNP), and through the in-kind contributions of the BTC partner organizations: Canadian Mothercraft Society, Hospital for Sick Children—Motherisk Program, Jean Tweed Centre, Toronto Public Health, Children's Aid Society of Toronto, Catholic Children's Aid Society, St. Joseph's Health Centre. The FASD Diagnostic Clinic which commenced services in 2003 is embedded in the range of services offered to alcohol—and substance—involved mothers and children at BTC, and includes intensive pre – and post-diagnostic services. The BTC FASD Diagnostic team is comprised of the following individuals:

**Program Manager, (Breaking the Cycle):** Paid through the Public Health Agency of Canada's Community Action Program for Children (CAPC) and Canadian Mothercraft Society, and dedicates approximately 4 hours per week to the BTC FASD Diagnostic Clinic.

**Physician/Pediatrician-Toxicologist:** paid through the Hospital for Sick Children—Motherisk Program, and dedicates approximately 4 hours per week to BTC FASD Diagnostic Clinic.

**Psychologist: (Manager, Clinical Services, Mothercraft):** Paid through Canadian Mothercraft Society, and dedicates approximately 21 hours/week.

**Case Manager (BTC Addiction Counsellor):** Paid through CAPC, the case manager coordinates pre– and post-diagnostic services, including follow up and recommendations for children and mother.

**Admin. Support: (receptionist, BTC)** Paid through Canadian Mothercraft Society, 4 hours per week of administrative support is directed to the activities of the BTC FASD

**Contact:** Margaret Leslie, Psychological Associate Breaking the Cycle FASD Clinic  
761 Queen Street West, Suite 107, Toronto, ON M6J 1G1  
Tel: 416-364-7373 ext. 204 Fax: 416-364-8008  
E-mail: mleslie@mothercraft.org

Diagnostic Clinic.

**Psychological Associate: (Director, Early Intervention Programs–Mothercraft/BTC):** Paid through Canadian Mothercraft Society, the psychological associate dedicates approximately 4 hours per week to the BTC Diagnostic Clinic.

**BTC Child Development Counsellors (2 FTEs):** Paid through CAPC, the BTC Child Development Counsellors participate in pre-diagnostic observations and assessments, and implement centre-based early intervention programs in response to clinic recommendations. They are paid through CAPC, and work 40 hours/week.

**Home based parent-infant therapists:** Paid through Canadian Mothercraft Society, the Parent-Infant Therapists participate in pre-diagnostic observation and assessment, and implement home-based early intervention in response to clinic recommendations. They are paid through the Canadian Mothercraft Society Parent-Infant Program, and work 40 hours/week.



### Early Assessment

At this time, access to the BTC FASD Diagnostic Clinic is limited to children and mothers who are clients of the BTC program. As a CAPC project, the children seen in clinic are 0-6 years of age. All BTC children for whom prenatal alcohol exposure is confirmed are referred to the FASD Diagnostic Clinic at BTC for assessment and follow-up. Full physical and neurodevelopmental follow-up occurs on an annual basis (or more frequently depending on clinic team recommendations)



### Culturally Specific Supports

BTC has strong referral relationships with culturally specific organizations and programs in the community. BTC participants are encouraged to consider culturally-specific supports when appropriate, and referrals to those agencies are facilitated by BTC when clients desire. The psychologist on the BTC FASD diagnostic team is also a member of the Anishnawbe Health FASD Diagnostic Team.

**Statistics 2005**

50 children were assessed based on confirmed maternal history of alcohol use in pregnancy. Diagnosis was deferred for all children seen due to limited neurodevelopmental/behavioural evidence (the majority of the children were under 3 years of age.) The assessments, however, serve two primary functions:

- A) they form a basis for the early intervention services recommended to children

**Statistics 2005**

50 children were assessed based on confirmed maternal history of alcohol use in pregnancy. Diagnosis was deferred for all children seen due to limited neurodevelopmental/behavioural evidence (majority of children were under 3 years of age.) The assessments, however, serve two primary functions:

- A) They document and record maternal history of alcohol use in pregnancy as well as the child's health, developmental and behavioural progress from infancy throughout childhood
- B) They document and record maternal history of alcohol use in pregnancy as well as the child's health, developmental and behavioural progress from infancy throughout childhood

**Needs and Challenges of Clients**

The biological mothers and the children are both clients of BTC, and this presents advantages as well as challenges to the diagnostic process. Because all children reside and attend the BTC FASD clinic with their biological mothers, BTC has the advantage of a full report on time and doses of intrauterine exposure, as well as all other confounders, from poverty to depression. Full physical and neurobehavioral follow-ups allows optimal study of FASD and determinants affecting it. Because all of the mothers are struggling with substance use issues or are in early recovery, however, careful attention must be given to provide sufficient support and intervention to the mothers around the child(ren)'s assessment process. For the most part, the mothers feel tremendous anxiety, fear and guilt regarding their use of substances in pregnancy and the impact on their children, and they require pre and post-assessment support in order to be able to manage their feelings in an adaptive way.

**Needs and Challenges of the Diagnostic Team**

While there is no dedicated funding for the clinic at this time, the BTC FASD Diagnostic Clinic is a successful example of how funding and community partnerships can be leveraged to achieve a viable diagnostic clinic within a comprehensive and integrated maternal-child model.

## Northwestern Ontario FASD Clinic

The Northwestern Ontario FASD Clinic consists of two sites, Sioux Lookout and Kenora, both located within the Kenora Rainy River district. This region includes a unique network of remote First Nations communities, linked by numerous social, historical and economic ties. Only a couple of the 28 northern communities in this vast region have road access. All are located on lakes and waterways and most have airports with gravel runways and regularly scheduled flights. Distance between patients and resources presents a significant challenge. In addition the First Nations populations have a high birth rate and The Sioux Lookout Zone McMaster University Physician Practice reports that developmental and behavioural problems in children are common, especially speech delay, FASD, and school problems. It has been determined that children in Northwestern Ontario are at increased risk of being born with FASD as compared to the rest of the province given the reported heavier drinking among people of childbearing age in the region. (report: Health Status of Residents Living in the Region Served by the Northwestern Health Unit (January 2003))

The Northwestern Ontario FASD Clinic commenced services in December 2004. This is a demonstration project funded by the Ministry of Health and Long-Term Care: Primary Health Care Transition Funds. Initial funding was due to end on March 31/06. It has been extended to July 31/06.

Prior to the demonstration project, most children and their families in Northwestern Ontario travelled to the Clinic for Alcohol and Drug Exposed Children (CADEC) in Winnipeg, Manitoba to access diagnostic services. For residents in Northwestern Ontario, this necessitates a drive anywhere from two to eight hours in addition to flight times. Since April 1999, a total of 130 children from Kenora-Rainy River Districts have been referred to CADEC for assessment, which represents approximately 7-8% of all referrals received by the Winnipeg Clinic.

This project is sponsored through several partnerships: Sioux Lookout First Nations Health Authority, Northwestern Ontario Health Unit, Community Living Sioux Lookout, Lake of the Woods District Hospital (Kenora), Addictions Services Kenora, Lake of the Woods Child Development Centre, Integrated Services Northwest, Kenora Association for Community Living, Wassay Gezhig Na Nahn Dah We Igamig (Kenora Area Health Access Centre)

**There are two diagnostic teams, one in Kenora and one in Sioux Lookout.**

The following is representative of resources available to each of the two clinics unless otherwise stated.

**Clinic Coordinator:** funded at 35 hours/week

**Physician:** funded one day/month

**Occupational Therapist :** funded 2 days/month

**Neuropsychologist:** funded 4 days/month

**Speech Language Pathologist:** funded 2 days/month

**Case Manager:** funded 3 days/week in Sioux Lookout and 3 days/month in Kenora. Case manager is the lead person to coordinate follow up and recommendations.

**Admin. Support:** funded 2 days/week



### Inter-disciplinary Team Meetings

There are inter-disciplinary meetings for case conferencing. Before delivery of diagnosis all team members meet to discuss findings. Team members are available individually for parent or school inquiries.



### Rural Access to Services

The Northwestern Ontario FASD Clinic is the only FASD diagnostic clinic operating outside of a large urban centre. The Kenora clinic operates out of the Kenora Health Access Centre and is located in the First Nations community of Obashkaandagaang. The Kenora Health Access Centre provides holistic services through Aboriginal traditional and contemporary health care relative to mind, body and spirit. These services are available to clients from the FASD clinic.

The Sioux Lookout First Nations Health Authority (SLHA) is one of the administering organizations of the project and provides a home base for the Sioux Lookout site. SLHA provides Aboriginal specific health service delivery, client advocacy and a child and family mental health program. Clients attending the FASD clinic can access these

services. This allows for a culturally and language appropriate service for First Nations clients. This unique partnership ensures that non-aboriginal children can also receive services.



### Follow up

Connecting families to services and providing education to families and their support system is an integral component of this project. The Northwestern Ontario FASD Clinic provides community based training for local service providers in order to assist them to support families pre and post diagnosis. This has been accomplished through face to face trainings and through videoconferences in remote northern communities.



### Research

Several members of the Northwestern Ontario FASD Diagnostic Clinic working group (Dr. Michelle Keightley, Anita Cameron, Randy White and Claudine Longboat-White) are conducting research to better understand brain injury from an Aboriginal perspective. A number of different types of brain injury have been identified to be of concern to Aboriginal communities in northwestern Ontario, including those caused by solvent abuse, pre-natal exposure to alcohol as well as the more traditionally defined Acquired Brain Injury (ABI). The group is collaborating with Aboriginal communities in northwestern Ontario to increase current awareness among primary health care providers regarding Aboriginal clients and brain injury as well as the use of traditional Aboriginal healing approaches during recovery from brain injury. In addition, they are using MRI to guide more culturally appropriate neuropsychological assessment processes.

### Statistics 2005

Total assessments = 58

Total diagnoses = 45

Sioux Lookout: 26 assessments, of these 20 received a diagnosis and 3 were deferred.

Kenora: 32 Assessments, of these 25 received a diagnosis and 3 were deferred

Note: Both sites have equivalent teams, receiving the same number of dedicated clinician hours, funded through the pilot project. (exception is case manager position)

**Major challenges facing clients:**

- Large geographical area (some case management services are done by phone)
- Language barrier
- Tests are not normed for Aboriginal children
- Inadequate physical space
- In First Nations communities, speech and language services are completely unavailable for children over the age of 6.
- Some other services are available but families may need to travel by plane to access a therapy session

**Challenges facing team:**

- Receiving intake information in a timely manner
- Funding (current funding due to expire on July 31/06)
- Building capacity

**Lessons Learned**

- Interdisciplinary team meetings to discuss findings of assessment allows a forum for open discussion and clarification of results and clinical opinion.
- There is a need for more culturally sensitive neurobehavioural assessment measures and a better understanding of how various factors such as language, cultural background and geographical isolation influence scores on standardized tests, particularly for preschool age children.
- There is a need for a better understanding of the prevalence of other physical and cognitive anomalies associated with FASD. Difficulty swallowing has been present in a number of children attending the diagnostic clinic.

**Contact Information Sioux Lookout Site**

Tannis Favot— Clinic Coordinator  
 Nodin CFI Services  
 Sioux Lookout First Nations Health  
 Authority, 54 Queen St. Box 1300  
 Sioux Lookout ON P8T1B8  
 Tel: (807) 737-4011  
 Fax: (807) 737-7532

**Contact Information Kenora Site**

Claudine Longboat-White/Ida Copenance  
 Clinic Coordinator WASSAY-GEZHIG  
 NA-NAHN-DAH-WE-IGMIG  
 Washagamis Bay First Nations  
 Box 320 Keewatin, ON P0X 1C0  
 Tel: (807) 543-1065  
 Fax: (807) 543-1126  
 E-mail: clongboatwhite@kahac.org

## Durham's FASD Assessment and Diagnostic Team Profile

Durham region has had an active FASD Committee exploring the needs of children and adults since 1995. The Committee established a plan to reduce negative outcomes for individuals with FASD by enhancing protective factors, including early diagnosis. The Committee recognized that individuals with the disability already used services, so local assessment and diagnostic services would contribute to the region's capacity to meet the complex needs of individuals in an integrated and sustainable way. It would reduce stress on the child and family and demystify the disability for agencies and clinicians.

When funding became available through Health Canada, the FASD Committee selected seven (7) area clinicians, spanning both preschool and school-age mandates, for training. Clinicians were both agency staff and from private practice. Initial training took place at the University of Washington in 2002.

After the initial training and trial assessments, the committee recommended that the diagnoses of alcohol related disabilities be integrated into the existing assessment/medical system rather than setting up a discrete FASD clinic. Lengthy waiting lists for clinical specialists for any assessment services, the potential for duplication of services, the stigma associated with an alcohol related disability, and the assumption that alcohol was the causative factor when making a referral, were rationale for this decision.

Mandates of trained clinicians were reviewed and two teams were defined and additional training provided to increase capacity. **Preschool children** were referred to Grandview Children's Centre for assessment through their multi-disciplinary team. A second team, led by a paediatrician in private practice receiving in-kind coordination from a local agency, would accept referrals for school-age children.

**Assessment Coordinator:** Assessment coordination for the **Preschool team** is done by Grandview's administrative staff as part of regular duties for booking children for a multi-disciplinary team assessment. Coordination for the **School-age team** is provided in-kind (1.5 days/month) by Resources for Exceptional Children – Durham Region. Duties include: sending out intake/history packages, referrals to case management services, collection and review of existing test material with clinical specialist, and linking families/guardian with trained clinicians who can complete further testing if required.

**Physician/pediatrician:** Children are scheduled in like other patients. Physician is paid through OHIP.

**Psychologist:** Children are scheduled with a psychologist like other patients. Fees are paid by the guardian. Other psychologist already linked with a client may be asked for standard deviations of existing test results so they can be used in the diagnostic process.

**Occupational Therapist:** Preschoolers are scheduled at Grandview like other patients. An OT is available for children < 6 through Infant Development. OT service for children <6 years is covered by Grandview or Infant Development and by guardian for older children. OTs already linked with a client may be asked for standard deviations of existing test so they can be used in the diagnostic process.

**Speech Language Pathologist:** Children are scheduled in like other patients. Service is paid through Grandview/Durham Speech and Language for preschoolers or by guardian for school-aged children. Speech pathologists already linked with a client may be asked for standard deviations of existing test so they can be used in the diagnostic process.

**Case Manager:** Case management is provided by a referring agency e.g. CAS, children's mental health services. If the client is not linked with services, the Assessment Coordinator will provide case management support while a referral is pursued. Grandview has social workers who can provide case management for preschool clients.

**Administrative Support:** Client files are the responsibility of the medical practitioners for both Grandview and the developmental paediatrician in private practice.



### Networking Model

Durham employs a community networking approach to diagnosis of FASD. The diagnostic team works inter-dependently from their regular place of work, submitting

test results to the paediatrician who makes the diagnosis.



### **Building Capacity within Existing Services**

Durham focuses on training professionals within the community so that agencies and clinicians can participate in assessments locally while avoiding the need for a special clinic for diagnosis. The FASD Committee believes this approach best meets the needs of individuals in our community. It allows for the use of existing services effectively and is a similar approach taken for the diagnosis of other disabilities. Capacity to diagnose adults is expected to be achieved by 2008.

### **Statistics 2005**

Grandview Children's Centre team and the school-age paediatrician see multiple patients for diagnosis of many disabilities and disorders.

Assessments = 12 > 5 years and 12 < 5 years received alcohol related diagnosis.

### **Needs and Challenges of Clients and Team Members**

**Time:** The school-age team isn't able to meet to discuss patients. Clinicians are spread too thin for this to be possible. It is hoped that as capacity grows, especially within the school boards, clinicians involved in an assessment will be able to discuss the final diagnosis and recommendations face to face.

**Mandate Restrictions within Agencies:** It is a challenge to get all agencies with clinicians required for assessments to buy-in to the benefit of having their staff trained and participating in multi-disciplinary assessments.

**Limits of OHIP Funding:** Expansion of diagnostic capacity will be hampered by restrictive billing codes. Doctors cannot bill for reading submissions from other clinicians or for completing the final diagnostic report and recommendations.

**Contact:** Sheila Burns FASD Coordinator, Resources for Exceptional Children  
Durham Region, 865 Westney Road South,  
Ajax, ON L1S 3M4  
Tel: (905)-427-8862 ext. #346  
Fax: (905) 427-3107  
E-mail: sburns@rfecdurham.com

# SECTION III

## Application of Canadian FASD Diagnostic Guidelines

## Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis

In 2005, a subcommittee of the Public Health Agency of Canada's National Advisory Committee on Fetal Alcohol Spectrum Disorder, reviewed, analysed and integrated current approaches to diagnosis to reach agreement on a standard for Canada. These guidelines were published in the CMAJ, Mar, 1, 2005; 172 (5 suppl; Chudley A, Conry J, Cook J, Looock C, Rosales T, LeBlanc N). These are the first Canadian guidelines for the diagnosis of FAS and its related disabilities, developed by a broad-based consultation among experts in diagnosis. (see appendix i for a copy of the guidelines)

Because of the complexity of effects caused by prenatal exposure to alcohol, with affected people exhibiting a wide range of expression, FASD requires a medical diagnosis in the context of a multi-disciplinary assessment. Application of the diagnostic guidelines requires a highly organized and inter-disciplinary approach. Canadian Diagnostic Guidelines recommend that core team members should ideally consist of the following professionals with appropriate training:

- Coordinator for case management
  - Physician specifically trained in FASD diagnosis
  - Psychologist
  - Occupational therapist
  - Speech-language pathologist
- ( see appendix ii for information on roles of different team members)

Developing capacity for diagnosis among emerging teams and enhancing the capacity of existing teams is a major thrust of this project. The following is a brief review of the diagnostic process with examples of how existing teams are currently responding to the recommendations.

### 1. Screening and Referral

Recommendations for screening and referral takes a stepped approach starting with the screening of pregnant and post partum women for alcohol use, followed by the referral of children for a possible FASD related diagnosis should they exhibit characteristic facial dysmorphology or have a combination of growth deficits and or central nervous system deficits along with known or probable significant prenatal alcohol exposure.

Participating teams in this project cited known or probable significant prenatal alcohol exposure in conjunction with neurobehavioural problems and/or learning difficulties as the most common reason for referral for assessment.

Assessment of facial dysmorphology occurs at the physical examination stage for most teams. Comprehensive intake packages have been developed to augment the referrals including:

- Intake information forms
- Complete Social Histories
- Prenatal, birth or neonatal records
- Previous Assessments (i.e. psychological, developmental, speech-language)
- Education/ school performance reports
- Photographs as an infant up to present
- Day Care/Preschool Questionnaire
- Consent form
- Authorization for release of birth records

## **2. The physical examination and differential diagnosis**

All participating teams adhere closely to the guidelines for physical examination including:

- Growth: Assess for pre or post-natal growth deficiency, below 10<sup>th</sup> percentile
- Facial Features: Facial Features Measured. (Some teams use software)
- Short palpebral fissures, at or below the 3<sup>rd</sup>-percentile (2 standard deviations below the norm)
- Smooth or flattened philtrum, 4-5 on the 5-point Likert scale of lip-philtrum guide
- Thin vermilion border of the upper lip, 4-5 on 5-point Likert scale/lip –philtrum guide
- Assess and record associated physical features and abnormalities
- Other genetic screening (hospital based teams have greater access)
- Assessment for other etiology (depends on resources available to team)

## Neurobehavioural Assessment

Neurobehavioural assessment is recommended in the following domains:

- Hard and soft neurological signs (including sensory processing- motor signs)
- Brain structure (occipitofrontal circumference, MRI etc)
- Cognition (IQ)
- Communication: receptive and expressive
- Academic achievement
- Memory
- Executive functioning and abstract reasoning
- Attention deficit/hyperactivity
- Adaptive behaviour, social skills, social communication

**Examples of tests currently used by teams for neurobehavioural assessment**

Hard and soft neurological Signs, including sensory Processing	Beery-Buktenica Test of Visual Motor Integration, Infant Beery Visual Motor Integration test of Visual Perception, Beery Visual Motor Integration Test of Motor Coordination, Carey Temperament Scales, Bayley Scales of Infant Development, Wechsler Preschool and Primary Scale of Intelligence (WPPSI), Infant/Toddler Sensory Profile, Short sensory Profile.
Brain Structure	Head circumference, MRI as clinically indicated.
Cognition (IQ)	Wechsler Intelligence Scale for Children—4th Edition (WISC IV), Wechsler Preschool and Primary Scale of Intelligence—3rd Edition (WPPSI-III), Wechsler Adult Intelligence Scale—2nd Edition (WAIS-II), Bayley Scales of Infant Development.
Academic Achievement	Wechsler Individual Achievement test—2nd Edition (WIAT-II), Wide Range Achievement Test—Revision 3 (WRAT-3) school reports, school questionnaire.
Memory	Children's memory Scale (CMS), WRAML 2, Bayley Scales of Infant Development
Executive Functioning	Behaviour Rating Inventory of Executive Function (BRIEF), Color Trails, NEPSY Tower subtest, Wisconsin Card Sorting Test (WCST)
Attention Deficit/Hyperactivity	Connors Checklist, Connor's Continuous Performance Test 2 (CPT-2), Connors Rating Scales (CRS), Achenbach, CBCL
Adaptive Behaviour Social Skills	Adaptive Behaviour Assessment System 2nd Edition (ABAS-II), Social Skills Rating System.
Communication	Clinical Evaluation of Language Fundamentals-Preschool (CELF-4), Preschool Language Scale-4 (PLS-4), Receptive-Expressive Emergent Language Test-3rd Edition REEL-3, Bayley Scales of Infant Development, Wechsler Preschool and Primary Scale of Intelligence (WPPSI).

**Treatment and Follow– Up**

Recommendations for treatment and follow up specify, education of patient and family on features of FASD as crucial. This should be done in a culturally sensitive manner. In addition a member of the diagnostic team should follow up to assure that recommendations have been addressed and diagnosed individuals and their families should be linked to community resources and services.

Currently diagnostic teams use a variety of approaches to meet these recommendations. All have education and follow up in place, but lead people for these services vary among teams. Case managers, clinic coordinators/directors and psychologists are the professionals most likely to be designated to take the lead for follow up. In addition teams that serve specific ethnic populations have taken a proactive approach to providing culturally sensitive support to families by including traditional healers/counselors in their support team. Follow up to assure that recommendations have been addressed becomes very challenging as services become remote from users.

**Maternal Alcohol History in Pregnancy**

Prenatal alcohol exposure requires confirmation by the mother, or by another reliable source or medical records. Number and types of alcoholic beverages consumed as well as pattern of drinking should be documented if available. Teams who work with at risk Moms are able to get confirmation by mother of prenatal alcohol exposure as well pattern of drinking. Other teams work with a significant number of children in foster care. Information is often less specific but generally confirmed through child welfare agency documentation and or/ supporting medical records. In general intake forms attempt to capture as much information on maternal alcohol consumption as possible.

### Diagnostic Criteria for FAS, partial FAS and ARND

The following tables provide the Canadian criteria for diagnosis.

#### Criteria for diagnosis of FAS after excluding other diagnoses

<b>GROWTH:</b> Evidence of pre-natal or postnatal growth impairment, in At least 1 of the following →	Birth weight or birth length At or below the 10 <sup>th</sup> percentile For gestational age	Height and weight at or below the 10 <sup>th</sup> percentile for age.	Disproportionately low weight-to-height ratio (= 10 <sup>th</sup> percentile)
<b>FACIAL FEATURES:</b> Simultaneous presentation of all 3 of the following →	Short palepebral fissure length, 2 or more standard deviations below the mean	Smooth or flattened philtrum, rank 4 or 5 on the lip-philtrum guide	Thin upper lip, rank 4 or 5 on the lip-philtrum guide
<b>CNS:</b> Evidence of impairment in 3 or more of the following central nervous system domains →	Hard and soft neurological signs Brain structure Cognition Social communication	Communication Academic achievement Memory Social skills	Executive functioning Abstract reasoning ADD/ADHD Adaptive behaviour.
<b>ALCOHOL EXPOSURE</b> Confirmed (or unconfirmed) maternal alcohol exposure			

### Criteria for diagnosis of P-FAS after excluding other diagnoses

<b>FACIAL FEATURES</b> Simultaneous presentation of 2 of the following facial anomalies at any age →	Short palepebral fissure length, 2 or more standard deviations below the mean	Smooth or flattened philtrum, rank 4 or 5 on the lip-philtrum guide	Thin upper lip, rank 4 or 5 on the lip-philtrum guide
<b>CNS:</b> Evidence of impairment in 3 or more of the following central nervous system domains →	Hard and soft neurological signs Brain structure Cognition Social communication	Communication Academic achievement Memory Social skills	Executive functioning Abstract reasoning ADD/ADHD Adaptive behaviour
<b>ALCOHOL EXPOSURE</b> Confirmed maternal alcohol exposure			

### Criteria for diagnosis of Alcohol- Related Neurodevelopmental Disorder (ARND) after excluding other diagnoses

<b>CNS:</b> Evidence of impairment in 3 or more of the following central nervous system domains →	Hard and soft neurological signs Brain structure Cognition Social communication	Communication Academic achievement Memory Social skills	Executive functioning Abstract reasoning ADD/ADHD Adaptive behaviour
<b>ALCOHOL EXPOSURE</b> Confirmed maternal alcohol exposure			

Diagnostic criteria are closely adhered to by existing diagnostic teams. Brain structure assessment is limited to head circumference where MRI is not routinely available for assessment. Abstract reasoning and academic achievement are omitted for younger children.

### **Harmonization of the Institute of Medicine (IOM) and 4-Digit Code approaches**

The Canadian guidelines recommend that the 4-Digit Diagnostic Code be used to describe, assess and measure objectively alcohol exposure, growth, facial features and brain damage. It is recommended that the 4-Digit Code be recorded for each assessment and may be useful for surveillance and research purposes. The terminology in the IOM criteria is recommended to describe the diagnosis.

The 4-Digit Diagnostic Code evaluation of FASD brain is based on levels of certainty, in the judgment of the clinician, that the individual's cognitive and behavioural problems reflect brain damage. The determination is based on objective evidence of substantial deficiencies or discrepancies across multiple areas of brain performance. Most diagnostic teams use the 4-Digit Diagnostic Code for their assessments, but not every team records the code for each assessment. Some harmonization between the 4-Digit Diagnostic Code and the IOM criteria is currently used. The IOM criteria are being used by some teams to describe the diagnosis and/or to describe effects that do not fall under the Canadian Guidelines.

For clarification and further reading please refer to the complete article on the Canadian Guidelines for FASD Diagnosis in the CMAJ, March 1, 2005.

# Section IV

- Training
- Diagnostic Models
- Lessons Learned

## TRAINING

Training of diagnostic teams is pivotal to the commencement of diagnostic services. A number of options for training exist for emerging teams. Location, timing and funding sources may all play a role in choice of training site.

**Training Centres** accessed by existing diagnostic teams:

- Hospital for Sick Children, Toronto
- Clinic for Alcohol and Drug Exposed Children, Winnipeg
- University of Washington, Seattle

While there is some variation between training centres in approach to diagnosis, all adhere closely to the current diagnostic criteria as outlined in the Canadian Guidelines for FASD Diagnosis. Funding for training has been provided by The Public Health Agency of Canada for a number of teams. Northwestern Ontario received its training dollars through the Ministry of Health and Long-Term Care. Teams partnering with Hospital for Sick Children have been able to receive their training through its team. Durham received its initial training at the University of Washington, Seattle which was funding through The Public Health Agency of Canada.

Cost of training varies. It ranges from \$1500/person trained to a team package at a cost of \$5000+. Time and travel are not included in these figures. University of Seattle Washington offers a 20 hour self-paced web based course for a cost of \$100 USD.

## Team Composition

FASD requires a medical diagnosis in the context of a multi-disciplinary assessment. Application of the diagnostic guidelines requires a highly organized and inter-disciplinary approach. Current guidelines recommend that the core team members consist of the following professionals with appropriate training:

- Coordinator for case management
- Physician specifically trained in FASD diagnosis
- Psychologist
- Occupational therapist
- Speech-language pathologist

The guidelines suggest several other additional members depending on context. Teams surveyed for this report, cited the following additional team members; psychomotrist, social worker, nurse, psychological associate, family therapist, developmental specialist, psychiatrist, geneticist, program director, child development counselor, home-based parent-infant therapist. Some of these participate in assessment and others in treatment and follow up. Most teams had split the functions of coordination and case management.

## Funding

Finding the dollars to support the diagnosis of FASD is a major challenge of existing and

emerging diagnostic teams. Funding sources vary widely between diagnostic units. Sources of funding include:

- Provincial Ministry of Health and Long-Term Care
- OHIP (while OHIP does cover some of the assessment costs it is inadequate). There is currently no ministry code that allows a physician to bill OHIP for time spent in reviewing assessment documentation.
- Public Health Agency of Canada Community Action Program for Children
- Operational Budgets for existing services
- Existing assessment services funded through the Ministry of Children and Youth Services.

## DIAGNOSTIC MODELS

Various models for diagnosis have developed in response to need, existing resources and the availability of funding.



### Clinics attached to Large Hospitals

Diagnostic teams operating out of existing tertiary care centres, have at their disposal expertise funded through the hospital's operating dollars. They often provide additional outreach services to community based clinics. They have a depth of expertise to draw from and can receive ongoing training and support from their sponsoring hospital. However, they are limited by the amount of dedicated clinician time allocated to the clinic. This can result in unequal access to clinicians depending on competition within facility for clinicians' services. The psychological assessment is a case in point where teams even when attached to a large centre may receive inadequate dedicated psychologist's time to complete assessment in a timely fashion. This adds to waiting lists and can be a limiting factor in through put.



### Community based clinics

These include community based clinics that provide all services under the one roof, but require their

clinicians to travel to spend a specified time commitment each month in the clinic. NW Ontario has been piloting this model for rural areas with two clinics funded through the Ministry of Health and Long-Term Care. Funding for this pilot project is due to end in July 2006. Evaluation of this project and successful proposals for long-term funding will determine the sustainability. It has the advantage of accessibility for people in rural and remote communities and is community based and driven. Team members come together to discuss assessment findings prior to diagnosis. It requires new dollars to sustain.



### **Networking Model**

Durham employs a community networking approach to diagnosis of FASD. The diagnostic team works inter-dependently from their regular place of work, submitting test results to the pediatrician who makes the final diagnosis. The assessment is coordinated by the assessment coordinator who refers the family to a case manager/service for follow up and recommendations.

Durham has 2 teams each lead by a developmental paediatrician: one for preschooler and one for school-age children. Agencies and clinicians provide in-kind service with the exception of some of psychologist's, occupational therapist and speech language pathologist hours, or are paid through existing system. It utilizes existing services and dollars. It is limited by number of trained clinicians and agencies willing to participate. It does not presently have the capacity to do team conferencing prior/post diagnosis.

### **LESSONS LEARNED**

FASD diagnosis requires an inter-disciplinary approach. Inter-disciplinary team meetings to discuss diagnosis allows a forum for open discussion and clarification of results and clinical opinion. Assessment and diagnosis can get mired down in the confirmation of pre-natal alcohol exposure levels, and the frustration of lengthy waiting periods between referral and diagnosis.

- Pre-assessment contributes to efficiency and throughput
- Difficult to determine pre-natal exposure levels
- Canadian Diagnostic Guidelines need refinement
- Community based clinics and strategies increase awareness and commitment to change
- Diagnosis opens doors for improving delivery and planning for services

- Diagnosis is challenging for families, especially bio-families and appropriate support is essential

St. Michael's Hospital has established a pre-assessment clinic that has greatly contributed to its efficiency. The pre-assessment clinic has decreased frustration with the waiting list.

It is difficult to determine pre-natal alcohol exposure levels as there is often no real documentation of history and intake forms are often not well filled out. This is sometimes a particular challenge for adoptive parents. Pre-natal histories that paid close attention to alcohol consumption would help overcome this challenge.

The Canadian Diagnostic Guidelines are not carved in stone. They will need refinement to meet the needs of all clients. Challenges arise with how large a standard deviation is required for various assessments. Areas to look at include:

- Modification of description of facial features for different racial backgrounds.
- A screening checklist with a high degree of sensitivity
- More culturally sensitive neurobehavioural assessment measures

A diagnosis of FASD can open doors for services, previously unavailable or unaffordable for families. Nevertheless, receiving a diagnosis of FASD is very challenging for families. Parents and caregivers may present in different stages of readiness in considering the role prenatal alcohol has in their child's life. Readiness at time of assessment to accept a possible diagnosis of FASD lessens the likelihood of a negative impact post diagnosis. Ongoing support and education all contribute to optimal outcome.

# Section V

- Videoconference 2
- Highlights
- Next Steps

## VIDEOCONFERENCE 2 — HIGHLIGHTS

Purpose of the second videoconference was to provide information and support to emerging FASD diagnostic teams. Agenda for the second video conference:

Welcome and Introductions—Jane Hoy , conference chair  
 Project overview— Dr. Brenda Stade  
 Overview of FASD diagnosis— Dr. Peggy Kirkpatrick  
 Summary of the FASD Diagnostic Clinic Survey—Geraldine Guilfoyle  
 Open Forum for questions from emerging teams

### Participants

Several existing diagnostic teams had representatives at the second videoconference. They served as a resource for the question period.

The following emerging teams participated in the videoconference:

Catholic Family Services - Hamilton  
 Infant Development Program - Waterloo & Wellington  
 Child Development Centre, Hotel Dieu Hospital - Kingston  
 Peel Children's Centre - Peel  
 Norwest Community Health Centre - Thunder Bay  
 Surrey Place Centre - Toronto  
 Bruce Grey Children's Services - Owen Sound  
 Five Counties Children's Centre - Peterborough  
 Children's Treatment Network of Simcoe-York - Orillia

### Question Period—Themes

#### Diagnosis

Several questions were asked related to diagnosis. Clarification was provided in the following areas:

#### Exposure

Facial features do not necessarily correlate to brain problems and brain damage can be present without facial features.

When gestational exposure is unknown or information is unreliable a score of 2 is designated on the 4-digit diagnostic code. Only when the alcohol can be confirmed absent in pregnancy is a score of 1 or no risk assigned. There are many adults who may be categorized as probably FASD affected but do not have the maternal history to assist with assessment. The amount of gestational exposure to alcohol

required for FASD affects to occur, is the subject of continuing research. A clear consensus is not available concerning the amount of alcohol that can actually be toxic to each individual fetus.

### **Anomalies**

The existence of curved pinky finger or webbed fingers is **not** a part of the diagnostic criteria for FASD. It falls under other anomalies but these features are not statistically strong enough to be included in diagnostic criteria.

### **Software**

Software for facial feature measurements while useful needs to be used with caution. Can give false positives and should be backed up by clinical examination. Software packages have been purchased for existing and emerging teams with funds made available through this project and will be distributed with the final report.

### **Benefits to diagnosis**

Existing teams confirmed that there were significant benefits to diagnosis for children and their families. It opens the door for access to services like any other brain injured individual.

### **Team Composition**

Emerging teams had questions concerning team composition. The Canadian Diagnostic Guidelines recommend the following core team members as part of the assessment process; coordinator for case management, physician specifically trained in FASD diagnosis, psychologist, occupational therapist, speech-language pathologist. It suggests several other additional members to the team depending on the particular context. Existing teams have added to their team members in various ways, such as social worker, nurse, psychomotrist, geneticist, psychiatrist, family therapist, child development counselors, parent-infant therapists. Some of these professionals assist in the assessment process, whereas others play a role in follow up and treatment plans. The addition of a parent on the St. Michael's team has contributed positively to their work, providing a supportive role for parents and raising awareness within the community.

Specialty of physician not as important as training and time commitment to developing diagnostic capacity. An FASD trained Paediatrician or psychiatrist provides added expertise to a diagnostic team. Coordination and case management is a large time component of the work of the team and needs to be addressed when setting up a diagnostic program. Access to a psychologist can be a limiting factor for some teams. Suggestion is to link into existing resources wherever possible, such as psychologists working within the school system.

### **Intake Packages**

Intake packages to assist in information gathering and assessment have been developed by existing diagnostic teams. Emerging teams are invited to request sample copies from existing teams.

### **Training**

Some emerging teams have already been trained, while others have yet to be trained. Several training options exist, including a web based program through University of Washington Seattle. Dr. Koren's team is willing to assist emerging teams with training.

**Funding**

Funding remains a major challenge for teams. There is no provincial plan to fund diagnosis. Each team needs to seek funding through whatever means are available to them. Some suggestions; lobby within your institutions, use existing services, submit proposals for special grants, network and help each other to overcome obstacles.

**NEXT STEPS**

Participants at the videoconference were asked to complete a questionnaire at the end of the videoconference. The purpose of the questionnaire was to provide feedback on the conference and suggested areas for further collaboration and support for developing FASD diagnostic capacity. All of the participating emerging teams completed a questionnaire.

**Benefits of videoconference**

Participants appreciated the opportunity to meet and hear from other existing teams. The information provided in the presentations as well as the conference packages was helpful and provided emerging teams with an overview of what is currently happening in FASD diagnosis across Ontario as well as insight into the diversity of approaches currently being used.

**Future Networking**

Participants were very eager to continue networking between existing and emerging teams. Teleconferencing and annual face to face conferences were the most often cited as best networking format. Web based communications, case conferencing, videoconference and newsletter were other suggestions.

**Needs of Emerging Teams**

Teams were asked to prioritize the areas where they needed support to develop diagnostic capacity. The following themes emerged.

**Funding/Resources**

Securing dedicated funding and specific resources to assist with capacity building and diagnosis were the most often cited urgent next steps for emerging teams. Funding for psychologist and case manager/coordinator is a requirement for some emerging teams. Need for psychology resources, guidelines for inter-disciplinary assessment and how the process works from start to finish was an area of concern. Emerging teams are looking creatively at all avenues of support. Finding ways of linking the FASD diagnostic work into the existing system of care locally as well as identifying provincial initiatives in Ontario that might lend themselves to supporting FASD work are avenues that emerging teams would like support with.

**Education/Training**

Education and training in FASD diagnosis is one of the key areas where emerging teams are seeking support for developing capacity. Specifics include; statistical training, the need for staff training across the community, the need for details regarding intake forms and screening instruments, team to team mentoring and networking in generalized areas of FASD diagnosis.

**Professionals**

Many emerging teams had concerns about the lack of availability of specific clinicians to assist with assessments. Psychologists were the most urgently required professionals cited by emerging teams. This was followed by case managers/coordinators. Pediatrician and Social Worker were also cited. Clarification was sought for role of clinic coordinator/case manager as well as information on the maintenance of clinic records.

**Buy In**

Some concerns were raised regarding achieving buy in from school boards for children over 6 years of age. Some emerging teams would like to see more engagement from key professionals in their efforts to develop diagnostic capacity.

**CONCLUDING REMARKS**

The sharing of information and approaches to FASD diagnosis that this project facilitated provides some insight into the successes and lessons learned as well as the continuing challenges faced by teams striving to provide comprehensive FASD diagnostic services to the populations they serve. The diversity in approaches is a testimony to the perseverance, commitment and resourcefulness of existing FASD diagnostic teams in making the best use of available resources to serve the needs of their particular clients. Close adherence to the Canadian Diagnostic Guidelines across a variety of approaches to diagnostic services, reflects the foundation of FASD diagnostic capacity already developed and the range of successful models for emerging teams to consider. Existing teams have generously offered to provide guidance and assistance to emerging teams.

Most clinics report that they are working on shoe string budgets, and are stretched beyond capacity with long waiting lists. The paucity of trained and available clinical specialists across the diagnostic spectrum and in particular psychological services, points to the need for a coordinated effort to increase diagnostic capacity along with a provincial initiative that supports the training and integration of services required for start up. The FASD Stakeholders of Ontario Diagnostic Working Group will continue to work collaboratively with both existing and emerging FASD diagnostic teams as well as provincial and federal agencies to nurture this goal and encourages and welcomes continued dialogue and networking towards this end.