

Creating a Foundation for FASD Diagnostic Capacity

A project of the FASD Stakeholders for Ontario Diagnostic Working Group

May 2006

Prepared By:

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

The views herein do not necessarily represent the official policy of The Public Health Agency of Canada.

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.

Acknowledgements

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

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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.

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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)

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

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555 University Avenue, Toronto ON M5G 1X8
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E-mail: gkoren@sickkids.ca

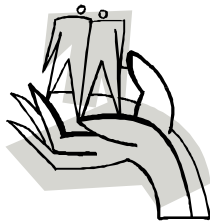
**Motherisk Alcohol & Substance Use in
Pregnancy Helpline**

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



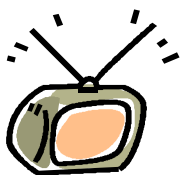
FOLLOW UP

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 Diagnostic Clinic.

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

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.

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

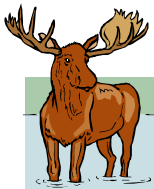
Case Manager: funded 3 days/week in Sioux Lookout and 3 days/month in Kenora. Case manager is the lead person to coordinate follow up and recommendations.

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 inquires.



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.

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

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

Contact Information Sioux Lookout Site

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Nodin CFI Services
Sioux Lookout First Nations Health
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Sioux Lookout ON P8T1B8
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Contact Information Kenora Site

Claudine Longboat-White/Ida Copenance
Clinic Coordinator WASSAY-GEZHIG
NA-NAHN-DAH-WE-IGMIG
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Box 320 Keewatin, ON P0X 1C0
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E-mail: clongboatwhite@kahac.org

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.

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

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.

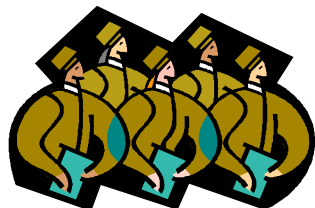
Administrative Support: Client files are the responsibility of the medical practitioners for both Grandview and the developmental paediatrician in private practice.



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

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.

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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 dysmorphism 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 10th percentile
- Facial Features: Facial Features Measured. (Some teams use software)
- Short palpebral fissures, at or below the 3rd-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

GROWTH: 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 th percentile For gestational age	Height and weight at or below the 10 th percentile for age.	Disproportionately low weight-to-height ratio (= 10 th percentile)
FACIAL FEATURES: 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
CNS: Evidence of impairment in 3 or more of the following central nervous system domains →	Hard and soft neurological signs Brain structure Cognition Social communi-	Communication Academic achievement Memory Social skills	Executive functioning Abstract reasoning ADD/ADHD Adaptive behaviour.
ALCOHOL EXPOSURE Confirmed (or unconfirmed) maternal alcohol exposure			

Criteria for diagnosis of P-FAS after excluding other diagnoses

FACIAL FEATURES 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
CNS: 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
ALCOHOL EXPOSURE Confirmed maternal alcohol exposure			

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

CNS: 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
ALCOHOL EXPOSURE 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

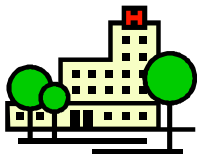
Finding the dollars to support the diagnosis of FASD is a major challenge of existing and

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

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

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.

SECTION VI

Appendices

Fetal alcohol spectrum disorder:
Canadian guidelines for diagnosis

Roles of team members

Pre-screening protocol

Sample Intake package

Sample School Questionnaire

Sample Partnership Agreement

Ontario FASD diagnostic clinics

Emerging FASD teams/participants of videoconference 2

Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis

Albert E. Chudley, Julianne Conry, Jocelynn L. Cook, Christine Look, Ted Rosales, Nicole LeBlanc

Abstract

THE DIAGNOSIS OF FETAL ALCOHOL SPECTRUM DISORDER (FASD) is complex and guidelines are warranted. 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 in Canada. The purpose of this paper is to review and clarify the use of current diagnostic systems and make recommendations on their application for diagnosis of FASD-related disabilities in people of all ages. The guidelines are based on widespread consultation of expert practitioners and partners in the field. The guidelines have been organized into 7 categories: screening and referral; the physical examination and differential diagnosis; the neurobehavioural assessment; and treatment and follow-up; maternal alcohol history in pregnancy; diagnostic criteria for fetal alcohol syndrome (FAS), partial FAS and alcohol-related neurodevelopmental disorder; and harmonization of Institute of Medicine and 4-Digit Diagnostic Code approaches. The diagnosis requires a comprehensive history and physical and neurobehavioural assessments; a multidisciplinary approach is necessary. These are the first Canadian guidelines for the diagnosis of FAS and its related disabilities, developed by broad-based consultation among experts in diagnosis.

In this document, we discuss the diagnostic approach to disabilities associated with prenatal alcohol exposure. Fetal alcohol spectrum disorder (FASD), along with its most visible presentation, fetal alcohol syndrome (FAS), is a serious health and social concern to Canadians. FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioural and learning disabilities with lifelong implications. The term FASD is not intended for use as a clinical diagnosis.

FASD is the result of maternal alcohol consumption during pregnancy and has implications for the affected person, the mother, the family and the community. Since FAS was first described in 1973,¹ it has become apparent that it is complex; affected people exhibit a wide range of expression, from severe growth restriction, intellectual disability, birth defects and characteristic dysmorphic facial features to normal growth, facial features and intellectual abilities,

but with lifelong deficits in several domains of brain function. FASD requires a medical diagnosis in the context of a multidisciplinary assessment. FASD itself is not a diagnostic term. The purpose of this paper is to review and clarify the use of the current diagnostic systems and make recommendations on their application for diagnosis of FASD-related disabilities in people of all ages. For a description of the characteristics and the natural course of FASD, consult some of the broader reviews.²⁻⁷

Epidemiology of FASD

The prevalence of FAS in the United States has been reported as 1–3 per 1000 live births and the rate of FASD as 9.1 per 1000 live births.⁸⁻¹¹ However, diagnosis may often be delayed or missed entirely.²

There are no national statistics on the rates of FASD in Canada, although studies have estimated its prevalence in small populations. In an isolated Aboriginal community in British Columbia, FASD prevalence was 190 per 1000 live births.¹² In northeastern Manitoba, an incidence of about 7.2 per 1000 live births was found.¹³ In another Manitoba study in a First Nations community,¹⁴ the prevalence of FAS and partial FAS was estimated to be 55–101 per 1000. In their survey, Asante and Nelms-Matzke¹⁵ estimated the rate of FAS and related effects at 46 per 1000 native Canadian children in the Yukon and 25 per 1000 in northern British Columbia. Based on referrals to a diagnostic clinic in Saskatchewan, the rate of FAS was estimated at 0.589 per 1000 live births in 1988–1992 and 0.515 per 1000 in 1973–1977.¹⁶ However, none of these data should be generalized to other communities, other populations or the Canadian population in general.

Risk factors

A common misconception is that FASD is associated with ethnocultural background. However, the data suggest that risk factors for prenatal alcohol exposure include higher maternal age and lower education level, prenatal exposure to cocaine and smoking, custody changes, lower socioeconomic status and paternal drinking and

drug use at the time of pregnancy;¹⁷ and reduced access to prenatal and postnatal care and services, inadequate nutrition and a poor developmental environment (e.g., stress, abuse, neglect).¹⁸

In a 5-year follow-up study of birth mothers of children with full FAS, Astley and colleagues¹⁹ found that these women came from diverse racial, educational and economic backgrounds. They were often challenged by untreated or under-treated mental health concerns, they were socially isolated, they were victims of abuse and they had histories of severe childhood sexual abuse.

Because there are no large-scale studies of risk factors and because risks are interrelated and could be different for different populations, it is difficult to provide accurate figures for relative risk. However, the most important risk factor for FASD is related to high blood-alcohol concentration: the timing of exposure during fetal development, the pattern of consumption, i.e., binge drinking (4 or more drinks per occasion) and the frequency of use. Although there seems to be no definite threshold of exposure, there appears to be a dose-response relation.^{17,20,21}

Importance of early diagnosis

An early diagnosis is essential to allow access to interventions and resources that may mitigate the development of subsequent “secondary disabilities” (e.g., unemployment, mental health problems, trouble with the law, inappropriate sexual behaviour, disrupted school experience) among affected people.²² Furthermore, an early diagnosis will also allow appropriate intervention, counselling and treatment for the mother and may prevent the birth of affected children in the future.²³ It may also prompt caregivers to seek diagnosis and support for previously undiagnosed siblings. A review of medical and behavioural management of those with FASD can be found in other sources.^{3,24} Astley and Clarren²⁵ suggest that accurate and timely diagnosis is essential to improve outcome, as misclassification leads to inappropriate patient care, increased risk of secondary disabilities, missed opportunities for prevention and inaccurate estimates of incidence and prevalence. Together, these inaccuracies could hinder efforts to allocate sufficient social and health care services to the vulnerable populations and preclude accurate assessment of primary prevention efforts.

Because of limited capacity and expertise and the need to involve several professionals in a comprehensive multidisciplinary diagnostic evaluation, only a fraction of those affected currently receive a diagnosis. Results²⁶ from the Canadian national survey regarding knowledge and attitudes of health professionals suggest that standardized guidelines for diagnosis and further professional education and training are needed for practitioners to participate in diagnosis. In response to these concerns, Health Canada’s National Advisory Committee on FASD, along with experts and practitioners in FAS diagnosis and treatment, present the following guidelines for diagnosis.

Process of guideline development

These guidelines are the result of more than 10 face-to-face consultations with Canadian and American experts in the diagnosis of FAS and its related disabilities (Appendix 1). Many of the participants are currently providing diagnostic services across Canada. Review and feedback were provided by a diverse group of individuals; professional organizations and societies; and provincial, territorial and federal levels of government. Guidelines are presented in 6 areas related to the diagnostic process: 1. screening and referral; 2. the physical examination and differential diagnosis; 3. neurobehavioural assessment; 4. treatment and follow-up; 5. maternal alcohol history in pregnancy; and 6. diagnostic criteria for FAS, partial FAS and alcohol-related neurodevelopmental disorder. We also include recommendations for harmonization of the 2 main approaches to diagnosis.

There are multiple approaches to diagnosis, and the working group sought to integrate these to achieve consistent diagnoses across Canada. Current knowledge of the complexity of the disabilities associated with prenatal alcohol exposure dictates that a comprehensive, multidisciplinary assessment is necessary to make an accurate diagnosis and provide recommendations for management. We are recommending such a multidisciplinary approach. This approach will also allow for collection of Canadian data for estimating incidence and prevalence of FASD. This information is essential to identify the need for and the development of appropriate prevention and intervention programs and services.

Background and terminology for the diagnosis of FAS

The first recognition of a variety of birth defects and developmental disabilities in offspring born to alcoholic parents is attributed to Lemoine and colleagues.²⁷ A specific pattern of birth defects following maternal alcohol exposure was described in the United States.^{1,28} The specific pattern, referred to as FAS, consists of facial abnormalities (smooth philtrum [the space between the upper lip and the nose], thin vermilion border [the exposed mucosal, or red part, of the upper lip], short palpebral fissures), impaired prenatal or postnatal growth (or both) and central nervous system or neurobehavioural disorders. Alcohol probably acts through multiple mechanisms and a range of disabilities has been observed in the absence of dysmorphic features reflecting varying degrees of damage during fetal development; undoubtedly, timing and degree of exposure are important variables that contribute to the variation. Thus, the term “suspected fetal alcohol effects” (FAE) was created.²⁹ These “effects” were further delineated by the United States’ Institute of Medicine (IOM), which published recommendations in 1996 for diagnosis of FAS in consultation with a panel of experts.⁴

The diagnostic categories presented were: FAS with and without a confirmed history of alcohol exposure, partial FAS, alcohol-related birth defects (ARBD), and alcohol-related neurodevelopmental disorder (ARND) (Table 1).

In the late 1990s, another diagnostic strategy was developed by Astley and Clarren.^{25,30} They created a 4-Digit Diagnostic Code using data from the Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network of clinics. The system uses quantitative, objective measurement scales and specific case definitions. The 4 digits in the code reflect the magnitude of expression or severity of the 4 key diagnostic features of FAS in the following order: growth deficiency; the FAS facial phenotype; central nervous system damage or dysfunction; gestational exposure to alcohol. The magnitude of expression of each feature is ranked independently on a 4-point Likert scale with 1 reflecting complete absence of the feature and 4 reflecting its extreme expression. The 4-Digit Diagnostic Code is now being used for diagnosis, screening and surveillance in clinics throughout the United States and Canada. Terminology from Astley's 2004 revision of the 4-Digit Diagnostic Code are used in this article.*

Although the approaches are different, the underlying, fundamental criteria of the IOM and the 4-Digit Diagnostic Code are similar. Some clinics are choosing to integrate the diagnostic tools and precision reflected in the 4-Digit Diagnostic Code with the diagnostic categories and language recommended by the IOM committee. Although both IOM criteria and the 4-Digit Diagnostic Code have been published, many clinicians still use the less desirable and potentially misleading gestalt approach (Table 2).

The diagnostic process

The diagnostic process consists of screening and referral, the physical examination and differential diagnosis, the neurobehavioural assessment and treatment and follow-up. Because of the complexity and the range of expression of dysfunction related to prenatal alcohol exposure, a multidisciplinary team is essential for an accurate and comprehensive diagnosis and treatment recommendations. The assessment process begins with recognition of the need for diagnosis and ends with implementation of appropriate recommendations. The multidisciplinary diagnostic team can be geographic, regional or virtual; it can also accept referrals from distant communities and carry out an evaluation using telemedicine.

The core team may vary according to the specific context, but ideally it should consist of the following professionals with appropriate qualifications, training and experience in their particular discipline:

- Coordinator for case management (e.g., nurse, social worker).
- Physician specifically trained in FASD diagnosis.
- Psychologist.
- Occupational therapist.
- Speech-language pathologist.

Additional members may include addiction counsellors, childcare workers, cultural interpreters, mental health workers, parents or caregivers, probation officers, psychiatrists, teachers, vocational counselors, nurses, geneticists or dysmorphologists, neuropsychologists, family therapists.

Comments

Clearly, funding for development, training and maintenance of multidisciplinary diagnostic teams is necessary so that major centres will have the expertise and capacity to serve their communities. To optimize the outcome of the diagnosis, the community and the family must be prepared, ready to participate in, and be in agreement with the diagnostic assessment. The diagnostic process should be sensitive to the family's and the caregiver's needs. In each community, referrals must be evaluated and their level of priority established. The family and guardian must be in agreement on the purpose of diagnosis. They must be made aware of the potential psychosocial consequences of a diagnosis of FASD (e.g., increasing a sense of guilt and anger, especially with the birth mother, or potential stigmatization of the child). The family or guardian will likely need help to move confidently through the diagnostic process. This help might include some preparatory education concerning FASD and linking them with community supports and resources.

Information from multiple sources (e.g., school records, hospital records, social services, previous assessments) should be obtained; this might involve meetings with relevant professionals who know the patient (e.g., teachers, physicians, social workers, psychologists). Other relevant documentation would include birth and pregnancy records, medical and hospital records, adoption records, academic records, achievement tests, developmental assessments, psychological and psychometric assessments, legal reports and documentation of the family history.

The comprehensive assessment by the diagnostic team provides important information about the individual's unique needs and allows interventions to be tailored to his or her strengths and challenges. The post-diagnostic report should state the basis for the diagnosis by including the history of alcohol use, the physical criteria and the psychological data that support it.

Multidisciplinary teams work with community partners and resources to develop and implement management plans to maximize the potential of the affected individual. Following assessment, a report containing recommendations should be made available to caregivers, educators, and biological families, as well as other appropriate indi-

*Astley SJ. *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code* (3rd edition). Seattle: University of Washington Publication Services; 2004.

viduals who work with the child (i.e., daycare workers, early intervention workers, social workers, etc). The team findings should be discussed with the guardian. Older children who have the cognitive ability should have the opportunity to learn about their diagnosis from the team. The team might also take on the responsibility for facilitating and providing follow-up with the family and community resources regarding outcomes of the recommendations. Ultimately, the diagnostic process will result in concrete management recommendations to improve the lives of the affected individuals, their families and the communities.

Canada is a large country with vast distances between communities, some of which are remote and isolated. Specialists providing consultation to remote areas require specialized training in FASD assessment and need to link with centres that have multidisciplinary teams to assist in the diagnostic process. A number of tools may be useful for distant diagnosis. More frequent use of telemedicine, for example, will allow assessment of children in distant communities.³¹ Other examples include the use of digital photographs^{32,33} and 3-D laser surface scanning^{34,35} sent electronically to teams in larger centres.

We recognize that there is currently a limited capacity even in some large communities in Canada to provide a multidisciplinary team-based approach to FAS diagnosis. Professionals should make the best use of available resources and expertise to provide an accurate assessment and treatment plan for affected individuals and their families, recognizing the key role of psychology.

1. Screening and referral

Recommendations

- 1.1 All pregnant and post-partum women should be screened for alcohol use with validated screening tools (i.e., T-ACE, TWEAK) by relevant health care providers. Women at risk for heavy alcohol use should receive early brief intervention (i.e., counselling).
- 1.2 Abstinence should be recommended to all women during pregnancy, as the mother's continued drinking during pregnancy will put the fetus at risk for effects related to prenatal alcohol exposure.
- 1.3 Referral of individuals for a possible FASD-related diagnosis should be made in the following situations:

Table 1: Institute of Medicine diagnostic criteria for fetal alcohol syndrome and alcohol-related effects⁴

Fetal alcohol syndrome (FAS)

1. *FAS with confirmed maternal alcohol exposure**
 - A. Confirmed maternal alcohol exposure*
 - B. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum and flat midface)
 - C. Evidence of growth retardation, as in at least one of the following:
 - low birth weight for gestational age
 - decelerating weight over time not due to nutrition
 - disproportional low weight-to-height ratio
 - D. Evidence of central nervous system neurodevelopmental abnormalities, as in at least one of the following:
 - decreased cranial size at birth
 - structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
 - neurologic hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination
2. *FAS without confirmed maternal alcohol exposure*
 - B, C, and D as above
3. *Partial FAS with confirmed maternal alcohol exposure*
 - A. Confirmed maternal alcohol exposure*
 - B. Evidence of some components of the pattern of characteristic facial anomalies
Either C or D or E
 - C. Evidence of growth retardation, as in at least one of the following:
 - low birth weight for gestational age
 - decelerating weight over time not due to nutrition
 - disproportionately low weight-to-height ratio
 - D. Evidence of CNS neurodevelopmental abnormalities, e.g.,
 - decreased cranial size at birth
 - structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
 - neurologic hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination
 - E. Evidence of a complex pattern of behaviour or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone: e.g., learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention or judgment.

care setting (e.g., TWEAK, T-ACE, CAGE, AUDIT, S-MAST, B-MAST).^{2,36-38}

There is moderate evidence^{37,38} to support the use of T-ACE and TWEAK to identify women who would benefit from intervention for alcohol use during pregnancy. If the woman cannot abstain, she should receive support and be referred to appropriate counselling and treatment. Stopping drinking at any point during the pregnancy will improve the outcome for the baby. Research is being carried out to develop gender and culturally appropriate instruments for the screening of all women during their child-bearing years.³⁸

The purpose of screening individuals at risk for the effects of prenatal alcohol exposure is to determine whether a pattern of learning and behavioural problems may be related to prenatal alcohol exposure. The screening could be conducted through the education system, the mental health system, the judicial system or social services. The purpose of screening should be to facilitate referral to a diagnostic clinic and highlight the need for referral and support for the birth mother.

The FAS Diagnostic and Prevention Network has had encouraging results in applying the FAS facial photographic screening tool in foster children and school-age children populations.³⁹ However, in the wide array of FASDs, facial dysmorphism is often absent and, in the final analysis, has little importance compared with the impact of prenatal alcohol exposure on brain function. However, it is important to note that the facial phenotype is a midline defect that is the most sensitive and specific marker for alcohol-related brain damage.

All those suspected of having brain dysfunction should

be referred to an appropriate professional or clinic for assessment (i.e., developmental pediatrics, clinical genetics, psychiatry, psychology). Because of the specificity of FASD clinics in addressing issues related to prenatal alcohol exposure, those with no prenatal alcohol exposure should be referred to an appropriate professional or clinic for assessment, treatment and follow-up.

2. The physical examination and differential diagnosis

The purpose of dysmorphology assessment is to identify those with features related to prenatal alcohol exposure and also to identify children with dysmorphic features due to other causes. Occasionally, children with prenatal alcohol effects may have another genetic syndrome as a comorbidity. When in doubt and if feasible, a genetic dysmorphology assessment is advisable.

A general physical and neurologic examination, including appropriate measurements of growth and head size, assessment of characteristic findings and documentation of anomalies (e.g., cleft palate, congenital heart defects, epicanthic folds, high arched palate, poorly aligned or abnormal teeth, hypertelorism, micrognathia, abnormal hair patterning, abnormal palmar creases, skin lesions) is required to exclude the presence of other genetic disorders or multifactorial disorders that could lead to features mimicking FAS or partial FAS (Table 3).

Some children will have significant neurologic deficits, such as deafness, blindness or seizures, and these should be

Table 2: 4-Digit Diagnostic Code criteria for FASD

Rank	Growth deficiency	FAS facial phenotype	CNS damage or dysfunction	Gestational exposure to alcohol
4	Significant Height and weight below 3rd percentile	Severe All 3 features: PFL 2 or more SDs below mean Thin lip: rank 4 or 5 Smooth philtrum: rank 4 or 5	Definite Structural or neurologic evidence	High risk Confirmed exposure to high levels
3	Moderate Height and weight below 10th percentile	Moderate Generally 2 of the 3 features	Probable Significant dysfunction across 3 or more domains	Some risk Confirmed exposure. Level of exposure unknown or less than rank 4
2	Mild Height or weight below 10th percentile	Mild Generally 1 of the 3 features	Possible Evidence of dysfunction, but less than rank 3	Unknown Exposure not confirmed present or absent
1	None Height and weight at or above 10th percentile	Absent None of the 3 features	Unlikely No structural, neurologic or functional evidence of impairment	No risk Confirmed absence of exposure from conception to birth

Note: PFL = palpebral fissure length; SD = standard deviation.

assessed and documented as essential components of the child's profile. These features do not discriminate alcohol-exposed from unexposed children. The face of FAS is the result of a specific effect of ethanol teratogenesis altering growth of the midface and brain. Those exposed to other embryotoxic agents may display a similar, but not identical, phenotypic facial development, impaired growth, a higher frequency of anomalies and developmental and behavioural

abnormalities (for a review, see Chudley and Longstaffe²⁴). However, because FAS facial criteria have been restricted to short palpebral fissures, smooth philtrum and thin upper lip, there is far less overlap with the facial phenotypes associated with other syndromes. Knowledge of exposure history will decrease the possibility of misdiagnosing FASD.

Children may be found to need other medical assessments to address co-occurring issues. For example, sleep

Table 3: Syndromes with constellations of features that overlap with those of FAS

Syndrome	Overlapping features	Features of this syndrome that differentiate it from FAS
Aarskog syndrome	Widely spaced eyes, small nose with anteverted nares, broad philtrum, mid-facial recession	Round face, downslanted palpebral fissures, widow's peak, prominent "lop" ears, specific contracture of digits on extension. Inherited as an x-linked trait. Molecular defect identified.
Brachman-deLange or Cornelia deLange syndrome	Long philtrum, thin vermilion border of upper lip, depressed nasal bridge, anteverted nares, microcephaly	Single eyebrow across eyes and forehead (synophrys), long eyelashes, downturned corners of mouth, short upper limbs particularly involving ulnar side, very short stature. Molecular defect identified.
Dubowitz syndrome	Short palpebral fissures, widely-spaced eyes, epicanthal folds, variable ptosis (droopy eyes) and blepharophimosis, microcephaly	Shallow suprorbital ridges, broad nasal tip, clinodactyly
Fetal anticonvulsant syndrome (includes fetal hydantoin and fetal valproate syndromes)	Widely-spaced eyes, depressed nasal bridge, mid-facial recession, epicanthal folds, long philtrum, thin vermilion border of upper lip	Bowed upper lip, high forehead, small mouth
Maternal phenylketonuria (PKU) fetal effects	Epicanthal folds, short palpebral fissures, long poorly formed philtrum, thin vermilion border of upper lip, microcephaly	Prominent glabella, small up turned nose, round face
Noonan syndrome	Low nasal bridge, epicanthal folds, wide spaced eyes, long philtrum	Down-slanted palpebral fissures, wide mouth with well-formed philtrum, protruding upper lip. Molecular defect identified.
Toluene embryopathy	Short palpebral fissures, mid face hypoplasia, smooth philtrum, thin vermilion border upper lip, microcephaly	Large anterior fontanelle, hair patterning abnormalities, ear anomalies
Williams syndrome	Short palpebral fissures, anteverted nares, broad long philtrum, maxillary hypoplasia, depressed nasal bridge, epicanthic folds, microcephaly	Wide mouth with full lips and pouting lower lip, stellate pattern of iris, periorbital fullness, connective tissue dysplasia, specific cardiac defect of suprvalvar aortic stenosis in many. Chromosome deletion on FISH (fluorescent in situ hybridization) probe analysis of 7q.
Other chromosome deletion and duplication syndromes	Many have short palpebral fissures, mid-facial hypoplasia, smooth philtrum.	Chromosomal analysis by standard analysis and some select syndromes by specific FISH probe analysis

disturbance is common with prenatal alcohol exposure and medical problems related to obstructive sleep apnea may have been overlooked previously. Atypical seizures may also be present and endocrinopathies may exist as a comorbid reason for growth deficiency. These individuals should be assessed by appropriate health professionals.

2a. Growth

Recommendations

2.1 Growth should be monitored to detect deficiency. Presence of pre- or post-natal growth deficiency, defined as height or weight at or below the 10th percentile (1.5 standard deviations below the mean) or a disproportionately low weight-to-height ratio (at or below the 10th percentile) using appropriate norms. To determine that a child is growth deficient requires taking into consideration confounding variables such as parental size, genetic potential and associated conditions (e.g., gestational diabetes, nutritional status, illness).

Comments

Children affected by prenatal alcohol exposure may have prenatal or postnatal growth deficits. They can be small for gestational age in utero and remain below average throughout their lives with respect to head circumference, weight and height. Many children can have normal growth parameters, but be at risk in later development for clinically significant learning, behavioural and cognitive deficits. If there is no alcohol exposure in the third trimester, the growth parameters can be normal. Gestational diabetes can lead to increased fetal size, which can mask the effects of growth retardation from prenatal alcohol exposure. Furthermore, if the infant is born into a family or a community where “normal” size is above the average for the general population, growth impairment may be masked if the child is compared with standard growth parameters rather than community norms.¹⁴ Growth deficiencies may not persist with age, and infant growth records may not be available for adults coming in for assessment for the first time. There is a need to establish growth norms for the Canadian population and subpopulations that differ from the general population.

2b. Facial features

Recommendations

2.2 The 3 characteristic facial features that discriminate individuals with and without FAS are:

- Short palpebral fissures, at or below the 3rd percentile (2 standard deviations below the mean).
- Smooth or flattened philtrum, 4 or 5 on the 5-point Likert scale of the lip-philtrum guide.^{25,39}

- Thin vermilion border of the upper lip, 4 or 5 on the 5-point Likert scale of the lip-philtrum guide.
- 2.3 Associated physical features (abnormalities such as midface hypoplasia, micrognathia, abnormal position or formation of the ears, high arched palate, hypertelorism, epicanthic folds, limb and palmar crease abnormalities and short-upturned nose) should be recorded but do not contribute to establishing the diagnosis.
- 2.4 Facial features should be measured in all age groups. If a patient’s facial features change with age, the diagnosis of the facial features should be based on the point in time when the features were most severely expressed. When diagnosing adults, it can be helpful to view childhood photographs.

Comments

A characteristic craniofacial profile associated with FAS was first described by Jones and Smith⁴⁰ in 1975 and later refined by Astley, Clarren and others.^{25,32,39} Individuals with FAS have short palpebral fissures, a thin upper lip and an



Fig. 1: Lip-philtrum guide. A 5-point pictorial scale for measuring philtrum smoothness and upper lip thinness. Features are measured independently; for example, an individual can have a rank 5 philtrum and a rank 1 upper lip.

indistinct philtrum (Fig. 1). Palpebral fissure length, philtrum and upper lip differ with race and age. Growth and facial anthropometric data are needed for the specific population, as sensitivity and specificity of the assessment will be lowered without the use of appropriate norms. Some discriminating characteristic features in FAS (i.e., upper lip or philtrum) may become less recognizable with age, making accurate diagnosis more difficult in older groups, but facial features should always be measured. More longitudinal research is needed to correlate changes in these characteristic physical findings in adolescents and adults diagnosed with FAS or partial FAS.

Palpebral fissure length (Fig. 2) is difficult to measure accurately without training. Thomas and co-workers⁴¹ have published norms for palpebral fissure length at 29 weeks gestation to 14 years. There are a number of opinions about which norms are appropriate,⁴¹⁻⁴⁴ but it is generally agreed that all are flawed in some respect.

Two graphs of palpebral fissure length are presented in Appendix 2. Some discrepancies exist. Both studies used North American white subjects; standards for other populations in Canada are not currently available. Appendix 2-1 may be more reliable when measuring palpebral fissure length using a plastic ruler (in the experience of one of the authors); Appendix 2-2 may be more reliable if slide calipers are used (in the experience of one of the authors). Percentile ranks for both graphs seem to be in agreement until age 7 years, after which Appendix 2-2 shows longer palpebral fissures in older children and adolescents than Appendix 2-1. We believe this may be due to differences in measurement technique. Because calipers are not a common tool in most medical clinics, we recommend the use of a clear flexible plastic ruler.

There is a need to establish updated norms for all ages and subpopulations. Astley and Clarren^{25,39} have developed norms for the assessment of the lip and philtrum using their pictorial guide. Lip-philtrum guides were developed for use in Caucasian and African-American populations, but no standards are currently available for other populations.

3. Neurobehavioural assessment

Recommendations

- 3.1 The following domains should be assessed:
- Hard and soft neurologic signs (including sensory-motor signs).
 - Brain structure (occipitofrontal circumference, magnetic resonance imaging, etc.).
 - Cognition (IQ).
 - Communication: receptive and expressive.
 - Academic achievement.
 - Memory.
 - Executive functioning and abstract reasoning.
 - Attention deficit/hyperactivity.

- Adaptive behaviour, social skills, social communication.
- The assessment should include and compare basic and complex tasks in each domain, as appropriate.
 - The domains should be assessed as though they were independent entities, but where there is overlap experienced clinical judgment is required to decide how many domains are affected.
 - A domain is considered “impaired” when on a standardized measure:
 - Scores are 2 standard deviations or more below the mean, or
 - There is a discrepancy of at least 1 standard deviation between subdomains. For example:
 - Verbal v. non-verbal ability on standard IQ tests,
 - Expressive v. receptive language,
 - Verbal v. visual memory, or
 - There is a discrepancy of at least 1.5–2 standard deviations among subtests on a measure, taking into account the reliability of the specific measure and normal variability in the population.
 - In areas where standardized measurements are not available, a clinical judgment of “significant dysfunction” is made, taking into consideration that important variables, including the child’s age, mental health factors, socioeconomic factors and disrupted family or home environment (e.g., multiple foster placements, history of abuse and neglect), may affect development but do not indicate brain damage.
 - Evidence of impairment in 3 domains is necessary for a diagnosis, but a comprehensive assessment requires that each domain be assessed to identify strengths and weaknesses.
 - The diagnosis should be deferred for some at-risk children (e.g., preschool-age) who have been exposed to al-

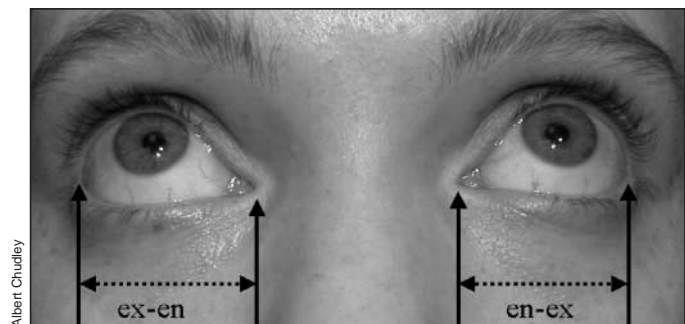


Fig. 2: Palpebral fissure length. To measure palpebral fissure length, identify the inner corner or encanthion (en) and outer corner or excanthion (ex) for each eye. Have the patient look up so that ex can be seen clearly. With a clear flexible ruler held in the horizontal plane, measure the length of each ex-en interval immediately below the eye, being careful not to touch the eye or eyelashes. Plot the result on an appropriate nomogram chart to determine the percentile or standard deviation for each eye.

cohol but may not yet demonstrate measurable deficits in the brain domains or may be too young to be tested in all the domains. However, developmental assessment should identify areas for early intervention.

Examples of tests that are most widely used to assess the domains and their criteria are provided in Appendix 3.

Comments

Research reports have documented a range of cognitive and behavioural outcomes associated with prenatal alcohol exposure. Contemporary studies have reported some of these outcomes in the absence of FAS physical features. Currently, no modal profile of abilities has been found to be unique to alcohol exposure, is observed in all those with prenatal alcohol exposure, or can be distinguished from that observed with some other neurobehavioural disorders. Furthermore, not every deficit that we may identify in a child with prenatal exposure to alcohol may be solely the result of alcohol exposure. An expert analysis of neurodevelopmental deficits caused by a range of teratogens and congenital disorders failed to result in a consensus on core deficits associated only with FASD.⁴

Research and experience has shown that features of FASD are complex and multifaceted, originating with organic brain damage caused by alcohol, but interacting with genetic and other influences. Over the lifespan of the affected person, these features may be exacerbated or mitigated by environmental experiences.

To make the diagnosis of FAS, features such as microcephaly, structural abnormalities (as may be detected on brain scans) and hard neurologic signs are taken as strong evidence of organic brain damage. We believe that low-average to borderline intelligence and soft neurologic signs alone are insufficient evidence of brain damage because they are frequently found in the general population. Features such as learning difficulties, attention deficit/hyperactivity disorder and deficits in adaptive skills, memory, higher-level language and abstract thinking are frequently seen in children with prenatal alcohol exposure, but also among those with other etiologies. These deficits can be multifactorial in etiology and can also be attributed to genetics or postnatal experiences.

The 4-Digit Diagnostic Code evaluation of the FASD brain is based on levels of certainty, in the judgement of the clinician, that the individual's cognitive and behavioural problems reflect brain damage. A higher rating may reflect a more severe expression of functional disability, asynchronous patterns across domains or certainty based on deficits in multiple domains. The determination is based on objective evidence of "substantial deficiencies or discrepancies across multiple areas of brain performance."^{25,39}

The IOM⁴ also requires "evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by famil-

ial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment," but is much less specific than the 4-Digit Diagnostic Code with regard to the criteria for determining the deficit.

We have adapted the method of the 4-Digit Diagnostic Code with regard to identifying domains and severity of impairment or certainty of brain damage. Current research shows overlap between the neurobehavioural outcomes in FAS and ARND diagnostic groups when neuropsychologic data are compared.⁴⁵ In addition, we believe that a single feature such as microcephaly is not a sufficient indicator of brain damage for the purposes of an FAS diagnosis because it may reflect genetic or ethnic differences not reflected in currently available physical norms. Our concern is that there may be an over-diagnosis of FAS if evidence of brain damage is based on a single indicator as allowed by both the 4-Digit Diagnostic Code and the IOM models. An individual showing hard neurologic signs or structural brain abnormalities (i.e., true brain damage) will likely show additional functional deficits in the listed domains. A diagnosis of full FAS will not be denied by combining the criteria for full FAS and ARND in this harmonized system.

Although the domains are considered to be separate and independent entities, there is obviously overlap. For example, a discrepancy between verbal and non-verbal scores on an IQ test (taking into account normal variability in the population) may be reflecting a specific language disability. If language is deficient, can deficits in verbal memory be considered an additional domain? Does a language deficit represent brain damage if the child has experienced a prolonged period of social deprivation? The cut-off of 2 standard deviations below the mean on standardized tests is recommended to increase confidence that abilities in the domain are impaired as a result of brain damage and are scored as "3" (significant dysfunction) on the 4-Digit Diagnostic Code. With 3 such domains, the brain rank is 3: "probable brain dysfunction."

We realize that in standard neuropsychologic practice, 1.5 standard deviations below the mean may indicate subtle impairments. Using the 4-Digit Diagnostic Code, the domains would be scored as "moderate dysfunction" and may result in a brain rank of 2: "possible brain dysfunction." These more subtle findings are an important part of the individual's profile. For the purpose of diagnosis, however, and the certainty that the scores represent injury caused by alcohol, the more extreme cut-off is recommended. The multidisciplinary team, reviewing the data and using experienced clinical judgement, is critical in making an accurate diagnosis as qualitative aspects of performance are also important. The diagnostic profile is dynamic and may change over time; thus individuals affected or suspected to be affected may require several assessments over time. Services should not be based on the diagnosis itself, but rather on the profile of brain function-dysfunction.

4. Treatment and follow-up

Recommendations

- 4.1 Education of the patient and family members on features of FASD is crucial. The potential psychosocial tensions that might be expected to develop within the family as a result of the diagnosis should also be discussed. This must be done in a culturally sensitive manner using appropriate language.
- 4.2 A member of the diagnostic team should follow-up outcomes of diagnostic assessments and treatment plans within a reasonable length of time to assure that the recommendations have been addressed.
- 4.3 Diagnosed individuals and their families should be linked to resources and services that will improve outcome. However, where services are limited in the community, an individual should not be denied an assessment for diagnosis and treatment. Often the diagnosis in the individual is the impetus that leads to the development of resources.

5. Maternal alcohol history in pregnancy

Recommendations

- 5.1 Prenatal alcohol exposure requires confirmation of alcohol consumption by the mother during the index pregnancy based on reliable clinical observation, self-report, reports by a reliable source or medical records documenting positive blood alcohol, alcohol treatment or other social, legal or medical problems related to drinking during the pregnancy.
- 5.2 The number and type(s) of alcoholic beverages consumed (dose), the pattern of drinking and the frequency of drinking should all be documented if available.
- 5.3 Hearsay, lifestyle, other drug use or history of alcohol exposure in previous pregnancies cannot, in isolation, be informative of drinking patterns in the index pregnancy. However, co-occurring disorders, significant psychosocial stressors and prenatal exposure to other substances (e.g., smoking, licit or illicit drugs) in the index and previous pregnancies should still be recorded, based on known interactive effects of these variables on the severity of pregnancy outcomes for both the mother and her offspring.

Comments

Gathering reliable information about maternal drinking is key to establishing an accurate diagnosis. Special attention must be paid to inquiring about maternal alcohol use before the woman recognized that she was pregnant. Some women do not consider that their prior drinking is important and many underreport it. Training is required in how

to obtain this information in a non-threatening, non-judgmental way.

Canadian survey data suggest that the number of women who report drinking during pregnancy has decreased. The *National Population Health Survey, 1994–1995*⁴⁶ and *National Longitudinal Survey of Children and Youth, 1994–1995*⁴⁷ reported that 17–25% of women drank alcohol at some point during their pregnancy and 7–9% drank alcohol throughout their pregnancy. According to the *National Longitudinal Survey of Children and Youth, 1998–1999*⁴⁸ 14.4% of women drank at some point during their pregnancy and 4.9% drank throughout their entire pregnancy (3% reported binge drinking during pregnancy). In the *Fall 2002 Survey of First Nations People Living on Reserve*,⁴⁹ 53% of the respondents said that cutting down or stopping alcohol use was important for women to have a healthy baby.

The evaluation of “significant alcohol exposure” is often confusing. The IOM describes significant alcohol exposure as “a pattern of excessive intake characterized by substantial, regular intake or heavy episodic drinking”²⁴ (the National Institute on Alcohol, Alcoholism, and Alcohol Abuse defines heavy alcohol use as drinking 5 or more drinks per occasion on 5 or more days in the past 30 days³⁶). Evidence of this pattern may include frequent episodes of intoxication, development of tolerance or withdrawal, social problems related to drinking, legal problems related to drinking, engaging in physically hazardous behaviour while drinking, or alcohol-related medical problems such as hepatic disease. As further research is completed and as, or if, lower quantities or variable patterns of alcohol use are associated with alcohol-related birth defects (ARBD) or ARND, these patterns of alcohol use should be incorporated into the diagnostic criteria.⁴

6. Diagnostic criteria for FAS, partial FAS and ARND

Recommendations

- 6.1 The criteria for the diagnosis of fetal alcohol syndrome, after excluding other diagnoses, are:
 - A. Evidence of prenatal or postnatal growth impairment, as in at least 1 of the following:
 - a. Birth weight or birth length at or below the 10th percentile for gestational age.
 - b. Height or weight at or below the 10th percentile for age.
 - c. Disproportionately low weight-to-height ratio (= 10th percentile).
 - B. Simultaneous presentation of all 3 of the following facial anomalies at any age:
 - a. Short palpebral fissure length (2 or more standard deviations below the mean).
 - b. Smooth or flattened philtrum (rank 4 or 5 on the lip-philtrum guide).

- c. Thin upper lip (rank 4 or 5 on the lip-philtrum guide).
 - C. Evidence of impairment in 3 or more of the following central nervous system domains: hard and soft neurologic signs; brain structure; cognition; communication; academic achievement; memory; executive functioning and abstract reasoning; attention deficit/hyperactivity; adaptive behaviour, social skills, social communication.
 - D. Confirmed (or unconfirmed) maternal alcohol exposure.
- 6.2 The diagnostic criteria for partial fetal alcohol syndrome, after excluding other diagnoses, are:
- A. Simultaneous presentation of 2 of the following facial anomalies at any age:
 - a. Short palpebral fissure length (2 or more standard deviations below the mean).
 - b. Smooth or flattened philtrum (rank 4 or 5 on the lip-philtrum guide).
 - c. Thin upper lip (rank 4 or 5 on the lip-philtrum guide).
 - B. Evidence of impairment in 3 or more of the following central nervous system domains: hard and soft neurologic signs; brain structure; cognition; communication; academic achievement; memory; executive functioning and abstract reasoning; attention deficit/hyperactivity; adaptive behaviour, social skills, social communication.
 - C. Confirmed maternal alcohol exposure.
- 6.3 The diagnostic criteria for alcohol-related neurodevelopmental disorder, after excluding other diagnoses, are:
- A. Evidence of impairment in 3 or more of the following central nervous system domains: hard and soft neurologic signs; brain structure; cognition; communication; academic achievement; memory; executive functioning and abstract reasoning; attention deficit/hyperactivity; adaptive behaviour, social skills, social communication.
 - B. Confirmed maternal alcohol exposure.
- 6.4 The term alcohol-related birth defects (ARBD) should not be used as an umbrella or diagnostic term, for the spectrum of alcohol effects. ARBD constitutes a list of congenital anomalies, including malformations and dysplasias and should be used with caution (Table 1).

Comments

Our definition of partial FAS differs from the published IOM criteria.⁴ Where significant prenatal alcohol exposure is known and there is significant growth retardation and significant indicative facial features but no evidence of brain involvement, a diagnosis of partial FAS could be made using the IOM criteria. It is our view that, using the term partial FAS in the absence of measurable brain deficits

could be harmful for the individual because the diagnosis of partial FAS implies brain dysfunction. If some characteristic facial features and growth impairment, without significant developmental or behavioural problems, are found in children under 6 years of age, it would be prudent to say that the child may be at risk of learning and behaviour problems at a later time due to prenatal alcohol exposure. No alcohol-related diagnosis should be made, but the child must be monitored by the family physician or health care worker and deficits should be documented using a neurodevelopmental assessment.

The term “partial” in partial FAS does not imply that these individuals are less severely impaired in day-to-day functioning than those with a diagnosis of FAS, as the deficits in brain function may be similar.

7. Harmonization of the Institute of Medicine (IOM) and 4-Digit Diagnostic Code approaches

Recommendations

- 7.1 The approach identified in the 4-Digit Diagnostic Code should be used to describe, assess and measure objectively alcohol exposure, growth, facial features and brain damage. The 4-Digit Diagnostic Code should be recorded for each assessment and may be useful for surveillance and research purposes.
- 7.2 The terminology in the IOM criteria should be used to describe the diagnosis.

Comments

Table 4 and Table 5 illustrate how we recommend harmonizing the IOM and 4-Digit Diagnostic Code criteria. The ARBD category has limited utility in the diagnosis, but we do recognize that alcohol is teratogenic and may be responsible for birth defects if exposure occurs during critical periods of development. However, in the absence of other features of FAS or brain deficits, it is difficult to attribute causation.

Future research related to diagnostic guidelines

The lack or unavailability of evidence and data in key areas limits the effectiveness of the diagnostic process, in general. Such key areas include the development of Canadian growth and anthropometric norms for all ages and ethno-cultural groups. There is also a need for the development and validation of screening tools that are specific and sensitive to prenatal alcohol exposure. These tools should be adaptable for use in various contexts, they should be culturally appropriate and they should lead to accurate referrals for diagnosis and assessment.

Emerging issues

Biomarkers

Often, women will not accurately recall the amount or frequency of alcohol consumption during pregnancy. Some women may also underestimate consumption level or deny that they drank alcohol during pregnancy. Medical records are known to be incomplete with respect to maternal alcohol history. Currently, there are no reliable means to confirm maternal drinking using biochemical markers in pregnancy. High levels of whole blood-associated acetaldehyde, carbohydrate-deficient transferrin, gamma-glutamyl transpeptidase and mean red blood cell volume may be useful markers in pregnant women.⁵⁰

Studies are underway to determine the utility of fatty acid ethyl esters in meconium as markers for prenatal exposure to alcohol.⁵¹⁻⁵³ This marker will only be useful if it can be established that fatty acid ethyl ester levels in meconium are predictive of developmental outcome. Meconium testing could alert caregivers to infants who might be at risk for alcohol effects and lead to appropriate monitoring, intervention and prevention. Ethical issues regarding informed consent surround the use of biological markers in the baby that may indicate maternal drinking.

Recent innovations have led to the development of laser surface scanning, a non-invasive method for acquiring 3-dimensional images.^{33,34} This technique is promising in the analysis of facial features associated with prenatal alcohol exposure, but, at present, is a research tool only.

Remote and rural areas

The availability of diagnostic services is limited in rural and remote areas. A community may not have access to a diagnostic team or resources and services. Until regionally based diagnostic teams are established, the use of telemedicine for distant diagnosis, consultation and training may be helpful.³¹ Recent advances using digital imag-

ing and computer-assisted analysis for the diagnosis of characteristic features of FAS have shown promise for analysis of facial features associated with prenatal alcohol exposure.^{32,33,44}

Table 5: Comparison of Institute of Medicine (IOM) and 4-Digit Diagnostic Code methods in the diagnosis of FAS

Feature	IOM	4-Digit Diagnostic Code
Facial characteristics		
Number of features required	Not specified	3 of 3
Thin (flat) upper lip	Yes	Yes
Flattened philtrum	Yes	Yes
Flat midface	Yes	No
Short palpebral fissures	Yes	Yes
Other features	?	No
Growth		
Number of features required	1	1
Low birth weight alone	Yes, percentile not specified	No
Decelerating weight over time	Yes	No
Low weight-to-height ratio	Yes	No
Low height and low weight	No	Yes, ≤ 10th percentile
Central nervous system dysfunction		
Number of features required	1 structural or neurologic feature	1 structural or neurologic feature OR 3 domains of significant impairment in function
<i>Structural features may include:</i>		
Microcephaly at birth	Yes, percentile not specified	Yes, ≤ 3rd percentile
Structural abnormalities	Yes	Yes
Hard neurologic signs	Yes	Yes
Soft neurologic signs	Yes	No

Table 4: Harmonization of Institute of Medicine (IOM) nomenclature and 4-digit diagnostic code ranks for growth, face, brain and alcohol history

IOM nomenclature	4-digit diagnostic code ranks			
	Growth deficiency	FAS facial phenotype	CNS damage or dysfunction	Gestational exposure to alcohol
FAS (with confirmed exposure)	2, 3 or 4	3 or 4	3 or 4	3 or 4
FAS (without confirmed exposure)	2, 3 or 4	3 or 4	3 or 4	2
Partial FAS (with confirmed exposure)*	1, 2, 3 or 4	2, 3 or 4	3 or 4	3 or 4
ARND (with confirmed exposure)	1, 2, 3 or 4	1 or 2	3 or 4 (2 for < 6 years)	3 or 4

Note: ARND = alcohol-related neurodevelopmental disorder; CNS = central nervous system; FAS = fetal alcohol syndrome.

Source: Developed by Kwadwo Asante and Julianne Conry

*Any final 4-digit code that can be made with these combinations of numbers and that is not also an FAS code signifies partial FAS. Combinations of face 2 that include two significant facial features also meet criteria for partial FAS.

Adult diagnosis

Diagnosis of adults creates special challenges in all aspects of the diagnosis. Physical features may change over time, there may be catch-up growth, and cumulative environmental influences may distort the evaluation of brain function. The adult's history may include additional traumatic head injury, alcohol and drug abuse, and mental health problems. Although tests for the various domains are readily available, clinicians working with the adult FASD population find that the tests are often not sensitive to real-life issues. In addition to the data required for the diagnosis, an assessment must include additional components such as functional literacy and numeracy, employability and quality of life, which fall within the domain of adaptive skills. The clinician should not rely solely on the self-report of the individual who is alcohol-affected; the history and abilities of the individual must be verified by a reliable source.

Conclusion

The assessment for prenatal alcohol exposure is a diagnosis for the affected person, the birth mother and possibly affected siblings. Rather than labeling, a diagnosis provides a blueprint for early intervention. Treatment planning and implementation, specifically targeted toward the unique needs of the individual and the family, form a large part of the diagnosis.

These guidelines and recommendations have been developed in parallel and in consultation with a United States committee charged with the same task.⁵⁴ The challenges for prevention and diagnosis of FASD and intervention to assist those affected by this disorder are evolving and dynamic. Research is ongoing to determine whether tools, such as novel brain imaging techniques, biomarkers and DNA micro-array techniques, might enhance accurate and reliable alcohol-related diagnoses and treatment.

We hope that these guidelines and recommendations will be used to facilitate training of health professionals, improve access to diagnostic services and facilitate referral for intervention or treatment for all people and families living with this disability.

This article has been peer reviewed.

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Appendix 1: Participants* in meetings and teleconferences to develop Canadian guidelines for the diagnosis of FAS and its related disabilities

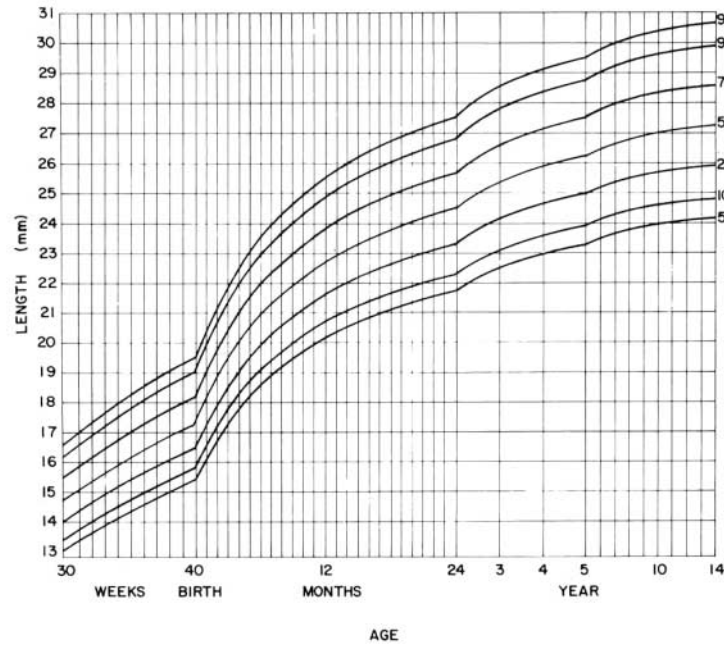
Participant	City	Province	Profession	# Consultations
Albert Chudley	Winnipeg	Man.	Physician, Clinic for Drug and Alcohol Exposed Children	12
Al Kircher	Winnipeg	Man.	Psychologist	1
Andrea Moser	Ottawa	Ont.	Correctional Services Canada	1
Anne Fuller	Vancouver	BC	BC Ministry of Children and Family Development	1
Annette Lemire	Edmonton	Alta.	Health and Wellness	2
Arthur Blue	Brandon	Man.	Native Psychologists in Canada	1
Ben Giddard	Calgary	Alta.	Physician, Alberta Children's Hospital	1
Billie Jean Benisty	Ottawa	Ont.	Health Canada	2
Bob Armstrong	Vancouver	BC	Physician, BC Women's and Children's Hospital	2
Bonnie Baxter	Vancouver	BC	Speech/Language Pathologist	1
Brad Bell	Whitehorse	YT	Health and Social Services	1
Brian Marder	Edmonton	Alta.	Career Counsellor	1
Bryce Lark	Whitehorse	YT	Health and Social Services	1
Carol Gregson	Iqaluit	Nun.	Nunavut Dept of Health	1
Carol Woodworth	Vancouver	BC	Speech/Language Pathologist, Asante Centre for FAS	1
Cathie Royle	St. John's	Nfld.	Child Youth and Family Programs, Dept. Health and Community Services	2
Christine Lilley	Vancouver	BC	Psychologist, BC Women's and Children's Hospital	1
Christine Look	Vancouver	B.C.	Physician, BC Women's and Children's Hospital	11
Claudette Landry	Fredericton	N.B.	Public Health, Dept. Health and Wellness	2
Dan Dubovsky	Washington	DC	FAS Specialist, FAS Center of Excellence	2
Darlene MacDonald	Ottawa	Ont.	Health Canada	2
Darren Joslin	Edmonton	Alta.	Health and Wellness	2
Dawn Ridd	Winnipeg	Man.	Manitoba Health	1
Del Nyberg		BC	BC Health	2
Diane Fast	Vancouver	BC	Psychiatrist, BC Women's and Children's Hospital	1
Donna Ludvigsen	Edmonton	Alta.	Health and Wellness	1
Edward Cross	Kahnawake	Que.	Education Specialist	2
Elaine Orrbine	Ottawa	Ont.	Canadian Association of Pediatric Health Centres, Canadian Pediatric Chairs	1
Ellen Fantus	Toronto	Ont.	Psychologist, Toronto Hospital for Sick Children	1
Faye Brooks	Ottawa	Ont.	Canadian Nurses Association	1
Faye Stark	Fort Providence	NWT	Health and Social Services	1
Fjola Hart-Wasekeeskaw	Ottawa	Ont.	Aboriginal Nurses Association of Canada	2
Fred Boland	Kingston	Ont.	Psychologist, Queen's University	6

Appendix 1: continued

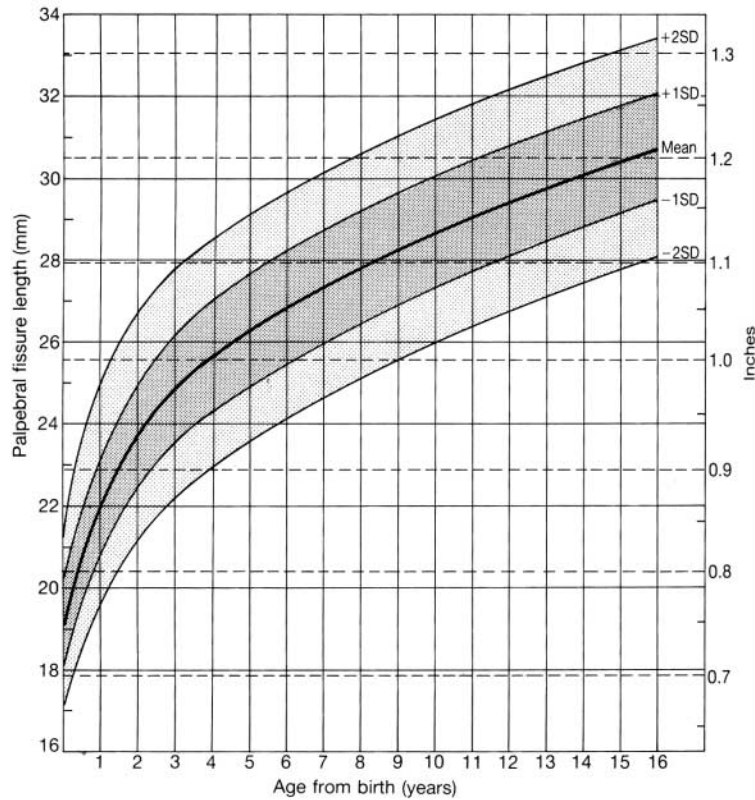
Gail Andrew	Edmonton	Alta.	Physician, Glenrose Rehabilitation Hospital	4
Gideon Koren	Toronto	Ont.	Physician, Toronto Hospital for Sick Children	6
Graham Robinson	Ottawa	Ont.	RCMP	1
Guy Bourbon	Ottawa	Ont.	Solicitor General	1
Hasu Rajani	Cold Lake	Alta.	Physician, Lakeland Centre for FAS	2
Holly Mackay	Ottawa	Ont.	Health Canada	1
Irena Nulman	Toronto	Ont.	Physician, Toronto Hospital for Sick Children	3
Jacquelyn Bertrand	Atlanta	GA	Psychologist, Centers for Disease Control and Prevention	1
Jan Lutke	Vancouver	BC	BC FAS Support Network	1
Janice Birney	Ottawa	Ont.	Indian and Northern Affairs Canada	1
Jasjeet Sidhu	Atlanta	GA	Medical Epidemiologist, Centers for Disease Control and Prevention	1
Jo Nanson	Saskatoon	Sask.	Psychologist	4
Joanne Rovet	Toronto	Ont.	Psychologist, Toronto Hospital for Sick Children	2
Joanne Weinberg	Vancouver	BC	Neuroscientist	1
Jocelynn Cook	Ottawa	Ont.	Health Canada	11
Jocylene Gauthier	Whitehorse	YT	Health and Social Services	
John Arnett	Winnipeg	Man.	Psychologist	1
John Godel	Campbell River	BC	Physician	1
John Service	Ottawa	Ont.	Canadian Psychological Society	1
Julie Conry	Vancouver	BC	Psychologist, Asante Centre for FAS	11
Karen Archbell	Toronto	Ont.	Ontario Dept of Health	1
Kathleen Montpetit	Montreal	Que.	Occupational Therapist, Shriner's Hospital	2
Kathleen Montpetit	Montreal	Que.	Occupational Therapist, Shriner's Hospital	1
Kathy Horne	Edmonton	Alta.	Psychologist, Glenrose Rehabilitation Hospital	1
Kathy Jones	Winnipeg	Man.	Psychologist, West Region First Nation Child and Family Centre	1
Kelly Stone	Ottawa	Ont.	Director, Health Canada	3
Kwadwo Asante	Vancouver	BC	Physician, Asante Centre for FAS	4
Leigh Wincott	Thompson	Man.	Physician, Thompson Diagnostic Clinic for FAS	2
Leslie Grob	Regina	Sask.	Saskatchewan Health	2
Margaret Clarke	Calgary	Alta.	Physician, Alberta Children's Hospital	3
Marie Adele Davis	Ottawa	Ont.	Canadian Pediatric Society	1
Marilou Reeve	Ottawa	Ont.	Youth Justice	1
Marilyn Van Bibber	Vancouver	BC	BC FAS Resource Network	1
Mary Cox-Millar	Winnipeg	Man.	Coordinator, Clinic for Drug and Alcohol Exposed Children	1
Mary Ellen Baldwin	Calgary	Alta.	Psychologist, Alberta Children's Hospital	1
Mary Johnston	Ottawa	Ont.	Health Canada	4
Mary Lynch	Saint John	NB	New Brunswick Family Services	1
Mercedes Mompel	Toronto	Ont.	Health and Long-term Care	1

Appendix 1: continued				
Michelle Dubik	Winnipeg	Man.	Healthy Child Manitoba	2
Nadine Huggins	Ottawa	Ont.	Health Canada	3
Nancy Taylor	Halifax	NS		1
Nicole Chatel	Yellowknife	NWT	Stanton Territorial Health Authority	1
Nicole LeBlanc	Moncton	NB	Physician, Georges Dumont Hospital	5
Nikki Bansil	Ottawa	Ont.	Canadian Medical Association	1
Pamela Massad	Ottawa	Ont.	Health Canada	1
Patricia Blakely	Saskatoon	Sask.	Physician, Kinsmen Children's Centre	4
Patricia MacPherson	Montague	PEI	Canadian Correctional Services Research Centre	1
Pearl Park	Calgary	Alta.	Speech/Language Pathologist, Alberta Children's Hospital	1
Peter Waas	LaCombe	Alta	Psychologist	3
Rachelle Deneault	Whitehorse	YT		1
Richard Snyder	Saskatoon	Sask	Physician, Kinsmen Children's Centre	1
Roxana Vernescu	St John's	Nfld.	Psychologist, Memorial University	1
Samantha Nadjiwan	Ottawa	Ont.	First Nations Child and Family Caring Society of Canada	1
Sandy Clarren	Seattle	WA	Psychologist, University of Washington	1
Sandy Steinwender	Iqaluit	Nun.	Health and Social Services	1
Sharon Bartholomew	Ottawa	Ont.	Health Canada	2
Soo-Hong Uh	Vancouver	BC	Scientist, BC Vital Statistics	2
Sterling Clarren	Seattle	WA	Physician, University of Washington	1
Suzanne Guay	Ottawa	Ont.	National Parole Board	1
Ted Rosales	St. John's	Nfld.	Physician, Memorial University	12
Terry Benoit	Winnipeg	Man.	Physician, Clinic for Drug and Alcohol Exposed Children	1
Tim Oberlander	Vancouver	BC	Physician, BC Women's and Children's Hospital	1
Val Massey	Edmonton	Alta.	Psychologist, DV Massey and Associates	1
Valerie Flynn	Ottawa	Ont.	Health Canada	2
Vyta Senikas	Ottawa	Ont.	Society of Obstetricians and Gynecologists of Canada	1
Wendy Sky Delaronde	Kahnawake	Que.	Nurse	1
Yaya deAndrade	Vancouver	BC	Psychologist, BC Women's and Children's Hospital	1
Yeshodara Naidoo	Ottawa	Ont.	Health Canada	1

Appendix 2: Guides for measurement of palpebral fissure length



Appendix 2-1: Relation between palpebral fissure length and age in both sexes of American white children aged 29 weeks to 14 years.⁴¹



Appendix 2-2: Palpebral fissure length for both sexes, birth to 16 years.⁴²

Appendix 3: Examples of tests that are most widely used to assess the domains

** Psychologists, speech-language pathologists and occupational therapists were consulted regarding their widely used tests. Tests for brain function are regularly updated and the most current versions should be used where appropriate*

Hard and soft neurologic signs (including sensory-motor)

Hard neurologic signs are assessed by the physician according to usual standards.

Soft neurologic signs include motor signs that can be elicited on the physical examination, with referral for occupational therapy assessment where appropriate.

Tests of motor functioning include:

- Movement Assessment Battery for Children
- Brunuinks-Oseretsky Scales of Motor Development
- Alberta Infant Motor Scale
- Peabody Developmental Motor Scales
- Quick Neurological Screening Test-II

Tests for visual-motor functioning include:

- Developmental Test of Visual-Motor Integration or Bender Gestalt (simple)
- Rey Complex Figure Test and Recognition Trial (complex)

Tests of perception include:

- Gardner Test of Visual Perceptual Skills
- Gardner Test of Auditory Perceptual Skills

Tests of sensory function include:

- Dunn Sensory Profile
- University of Washington Sensori-motor Checklist
- Congenital sensory-neural hearing loss as evaluated by audiologist
- Congenital vision anomalies as evaluated by an ophthalmologist

Tests and observations of articulation, phonology and motor speech if indicated:

- Goldman-Fristoe –2 Test of Articulation
- Phonological Awareness Test

Brain structure

Documented measurements of the head circumference (occipitofrontal circumference below the 3rd percentile) adjusted for age and gender (during the physical examination at any age including head circumference at birth) and other evidence of functional or structural CNS dysfunction based on a neurologic examination or findings on imaging techniques (computed tomography scan, magnetic resonance imaging, electroencephalogram). Neurologic problems may include seizures not due to a postnatal insult or other signs such as impaired motor skills, neurosensory hearing loss, memory loss or poor eye–hand coordination.

Cognition
Tests of intellectual functioning include:

- Wechsler Intelligence Scale for Children-III (WISC-IV not yet tested for usefulness with the FASD population)
- Stanford-Binet- Fourth Edition (SB5 not yet tested for usefulness with the FASD population)
- Wechsler Preschool and Primary Scale of Intelligence-III
- Differential Ability Scales
- Bayley Scales of Infant Development

Communication

Test batteries of language functioning usually combine both receptive and expressive language functions, as well as single-word and complex functions (sentences and paragraphs). Elicited versus recognition ability (multiple-choice) should be distinguished.

- Peabody Picture Vocabulary Test-III
- Expressive Vocabulary Test
- Preschool Language Scale (3 or 4)
- Reynell Developmental Language Scales
- Test of the Auditory Comprehension of Language-3
- Token Test
- Listening Test
- Test of Word Knowledge
- Clinical Evaluation of Language Fundamentals (Preschool, CELF-3, CELF-4)

These measures are complemented by a language sample analysis that includes: length of utterance, use of complex sentences and word retrieval.

Social Language Observations

- Narrative skill (PLS-E story retell); Renfrew Bus Story, Frog Where are You
- (Note: Language pragmatics are considered in the domain of social/adaptive skills.)

Appendix 3: continued

Academic achievement

Tests commonly used include:

- Wechsler Individual Achievement Test-II (most widely used)
- Gray Oral Reading Test
- Woodcock Johnson Achievement Battery
- Wide Range Achievement Test-3 (note: needs to be supplemented by a test that includes reading comprehension)
- Note: Avoid relying on group administered achievement test data.

Preschool children present a challenge in this domain; however, concept knowledge as assessed by the Preschool Language Scale, Bracken Test of Basic Concepts and Boehm Basic Concept Scale can be used.

Memory

Assessment should include comparisons between visual and auditory memory; short-term memory, delayed recall, and working memory.

Tests commonly used include:

- Children's Memory Scale-III
- Wechsler Memory Scale-III
- Wide Range Assessment of Memory and Learning
- Rey Complex Figure Test (recall)
- Developmental Neuropsychological Assessment (NEPSY) memory subtests
- Stanford-Binet Fourth Edition memory subtests
- California Verbal Learning Test
- Working memory composites from Wechsler scales

Executive functioning and abstract reasoning

- Delis-Kaplan Executive Function System
- Behaviour Rating Inventory of Executive Function (BRIEF): parent and teacher versions
- Verbal Abstract Reasoning and Problem Solving
 - Test of Problem Solving (Elementary and Adolescent)
 - Semantic Relationships (CELF-3) and Similarities and Differences (LPT-R, TLC-expanded)
 - Observation (e.g., answering how and why questions, explanations, inferences)
 - (Note: observations made on the IQ test may also apply here)
- Visual Abstract Reasoning and Problem Solving
 - Executive function subtests on the NEPSY
 - Wisconsin Card Sorting Test

Attention deficit/hyperactivity

Tests commonly used include:

- Observation
- Conners' Rating Scale
- Child Behaviour Checklist
- Continuous Performance Test-2

Adaptive behaviour, social skills, social communication

Assessment of social and adaptive skills is considered most important, but the available standardized instruments do not adequately tap the unusual adaptive problems found in FASD.

- Observation and interview, school reports and previous assessments
 - Vineland Adaptive Behaviour Scale: often used, but inadequate at higher ages
 - Adaptive Behaviour Assessment System: easier to administer and seems to correlate well with other measures and observation
 - Informal assessment of language pragmatics (not standardized), social communication
-

Role of Interdisciplinary FASD Diagnostic Team Members (guideline)

Clinic Coordinator

Conducts most the work up to the day of assessment and including the day of the assessment. Promotes the clinic. Conducts intake. Prepares and maintains the client file. Gathers background information, such as birth records, and fulfils consents and statement of understanding. Explains assessment process to the family. Conducts preparatory education with the family. Organizes assessment day. Organizes and assists with communication amongst team members. Assembles and mails out the diagnostic report. Leads team conference for determination of diagnosis. Maintains database.

Casemanager/Community Liaison

Conducts most of the work with the client and the family on the day of the assessment and after the assessment. Supports family on assessment day and debriefs with the family about the assessment process. Reviews the diagnostic report with family. Assists the family with follow up recommendations, referrals and community supports and resources. Educates family about FASD. Supports the family to implement recommendations. Provide consultation with schools or daycares. Assist the development of an ongoing plan. Assist with explaining disability to child.

Physician

Conducts a general medical exam. Measures facial features: palpebral fissure, lip and philtrum. Weighs and measures patient. Reviews prenatal alcohol and drug history. Reviews medical background and medications. Makes recommendation regarding medical or health issues and liaises with family doctor. Contributes to the discussion around the diagnosis. Meets with the family to deliver the diagnosis.

Occupational Therapist

Assessment of: fine and gross motor skills, visual-perceptual and visual motor skills, activities of daily living and sensory processing. Make recommendations regarding further assessment, treatment approaches or referral to community occupational therapy services. Contributes to the discussion around the diagnosis

Speech and Language Pathologist

Assessment of: receptive skills, expressive skills, clarity of speech and pragmatics. Make recommendations regarding further assessment, treatment approaches or referral to community speech and language therapy services. They may conduct a hearing screening and refer for further assessment. Contributes to the discussion around diagnosis.

Psychologist

Assessment of: development, cognition, problem solving, motor skills, executive function, memory, attention, social and adaptive skills, academic sampling. Makes recommendations regarding further assessment, treatment approaches or referral to community psychosocial supports. Contributes to the discussion around diagnosis. Meets with the family to deliver the diagnosis.

*All team members: -review background information and the findings of the FASD assessment. - Participate in the team conference where all information is reviewed and diagnosis determined- contribute to the discussion around the diagnosis and follow up recommendations

PRE-ASSESSMENT PROTOCOL

St. Michael's Hospital FASD Clinic uses the following protocol to streamline their diagnostic process.

Pre- Assessment

Criteria for referral to full diagnostic clinic:

- Presence of 3 characteristic facial features with growth deficit, with or without known prenatal alcohol exposure
- Evidence of prenatal exposure to alcohol (require confirmation based on clinical records, self-report, reliable observation) with suspected or confirmed CNS dysfunction

Pre-Assessment: two major Outcomes:

- 1) Meets Criteria:
 - Referral to Full Diagnostic assessment
 - Referral for additional assessments – genetic testing, psychiatric assessment etc.
- 2) Does not meet criteria:
 - Search for alcohol exposure history, further psychological testing and/or
 - Referral to other services – general developmental clinic, psychiatry, community services.

Pre-Assessment streamlines the diagnostic assessment and provides client satisfaction as they are in the system. Even if the information is insufficient for assessment in the full diagnostic clinic, the client is being helped either through assistance in information gathering or through referral to other services.

In 2005 St. Michael's did pre-assessments on 460 clients.



Leading with Innovation
Serving with Compassion

ST. MICHAEL'S HOSPITAL

Dear Patients/Parents,

Please complete this form to the best of your ability. We realize you will not have the answers to all of the questions. All information requested in this form is important in allowing us to provide you (your child) with the most accurate diagnosis and most appropriate referrals for care. Thank you for taking the time to complete it.

We will contact you within 2 to 3 months of receiving the completed form. If you have not heard from us by 2 months please call Blanche DaCosta at 416-867-3655.

Please return the form to:

Dr. Brenda Stade, RN
St. Michael's Hospital
Level 2 Nursery, 15 Cardinal Carter Wing
30 Bond Street, Toronto On M5B 1W8

(416) 864-6060 ext. 8275

Patient Name: _____

New Patient Information Form

Patient Identification

Patient's OHIP N^o. _____ Female Male Race _____

Patient's Name _____ Birth Date _____ Age _____
First Middle Last

Patient's Address _____

City _____ Province _____ Postal Code _____

Patient's Telephone: Home (_____) _____ Work (_____) _____

Caretaker Identification

Name of Patient's Primary Caretaker _____

Relationship to Patient: Birth Adoptive, or Foster Parent Other (specify _____)

Caretaker's Address _____

City _____ Province _____ Postal Code _____

Telephone: Home (_____) _____ Work (_____) _____

Name of Patient's Legal Guardian (s) _____

Person Completing the Form

Name of Person completing this form _____

Relationship to Patient: Birth Adoptive, or Foster Parent Caseworker, Medical
Care Provider Other Relationship (please specify _____)

Referred by (e.g., who or what organization told you about the clinic?) _____

Who Should Correspondence be sent To?

Name _____

Relationship to Patient: Birth Adoptive, or Foster Parent Other (specify _____)

Address _____

City _____ Province _____ Postal Code _____

Telephone: Home (_____) _____ Work (_____) _____

Birth Measurements

1. Birth Weight lbs/oz _____ or gms _____
Birth Length inches _____ or cm _____
Birth head Circumference inches _____ or cm _____
Gestational Age (*length of pregnancy*) weeks _____ or months _____

Please provide additional height, weight and head measures if available

2. Date _____ Weight lbs _____ or kg _____
Age _____ Height inches _____ or cm _____
Head Circumference inches _____ or cm _____
3. Date _____ Weight lbs _____ or kg _____
Age _____ Height inches _____ or cm _____
Head Circumference inches _____ or cm _____
4. Date _____ Weight lbs _____ or kg _____
Age _____ Height inches _____ or cm _____
Head Circumference inches _____ or cm _____
5. Date _____ Weight lbs _____ or kg _____
Age _____ Height inches _____ or cm _____
Head Circumference inches _____ or cm _____

- Birth Parents' Heights** Birth Mother inches _____ or cm _____
Birth Mother inches _____ or cm _____

- *This information may be available from the patient's physician or school nurse. If growth charts are available and can be photocopied and attached to this form, you need not fill out this section.*

Physical Appearance and Health

1. Photographs of the patient's face are very helpful to us.

The most helpful show the patient's full face towards the camera in good light without much facial expression (no big smile or frown). Pictures between ages 1 and 12 years are best.

- Are such photographs available? ___ yes ___ no
- Is one or two included with the form? ___ yes ___ no
- Can others be brought into the clinic? ___ yes ___ no

Please staple photo(s) here

Photo may be bigger than this space

1. Was the patient born with (or later discovered to have) any birth defects (things like cleft lip, congenital heart defects, club foot, etc)? ___ yes ___ no ___ unknown

If yes, please describe _____

1. Has this patient ever had

	yes	no	unknown		yes	no	unknown
Allergies	___	___	___	Chronic illness of the heart	___	___	___
Multiple ear infections	___	___	___	Chronic illness of the kidneys	___	___	___
Chronic sinusitis	___	___	___	Chronic illness of the joints/limbs	___	___	___
Chronic hearing loss	___	___	___	Chronic illness of the stomach/	___	___	___
Visual problems (wear glasses)	___	___	___	bowels	___	___	___

1. Has this patient ever had

A.) Operations (since birth) ___ yes ___ no ___ unknown

Describe Operation

Surgeon's Name

Patient's Age

B.) Any other hospitalization ___ yes ___ no ___ unknown

Reason for Hospitalization

Hospital/Doctor

Patient's Age

C.) Physical abuse ___ yes ___ no ___ unknown Age(s) _____

Was this evaluated by a physician? ___ yes ___ no ___ unknown Age(s) _____

D.) Sexual abuse ___ yes ___ no ___ unknown Age(s) _____

Was this evaluated by a physician? ___ yes ___ no ___ unknown

Neurological Issues

1. Has this patient ever had

a. Seizures

___ yes ___ no ___ unknown

Type _____

Age when seizures started _____

Name(s) of medication(s) given? _____

b. Loss of specific motor skills such as standing, walking, running, etc.

___ yes ___ no ___ unknown

If yes, please describe _____

c. Bed wetting or soiling after 8 years of age

___ yes ___ no ___ unknown

2. Has the patient ever had a head injury leading to unconsciousness or evaluation by a physician? ___ yes ___ no ___ unknown

If yes, please describe _____

3. Has the patient ever had a CT scan or MRI scan of the brain?

___ yes ___ no ___ unknown

If yes, was it described to be abnormal? ___ yes ___ no ___ unknown

Attention Deficit and Hyperactivity

1. Has the patient ever been evaluated for attention deficit/hyperactivity disorder (ADD or ADHD)? ___ yes ___ no ___ unknown

If yes

When was the evaluation done? Age _____ Date _____

Was the patient diagnosed with ADD or ADHD? ___ yes ___ no ___ unknown

Was the patient ever treated for ADD or ADHD? ___ yes ___ no ___ unknown

What medications have been tried?

<u>Drug</u>	<u>Dose</u>	<u>Ages</u>	<u>Response</u>
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Mental Health Issues

Has the patient ever been evaluated by a psychiatrist, psychologist, or mental health counselor? ___ yes ___ no ___ unknown

If yes, please list each psychiatrist, psychologist, or mental health counselor?

A. Type of professional _____

Reason for assessment _____

Type of therapy (i.e. behavioral, individual counseling, group counseling, family counseling, medicine)

Age at the time of therapy _____ Did the therapy help? ___ yes ___ no ___ unknown

If yes, how did it help? _____

B. Type of professional _____

Reason for assessment _____

Type of therapy (i.e. behavioral, individual counseling, group counseling, family counseling, medicine)

Age at the time of therapy _____ Did the therapy help? ___ yes ___ no ___ unknown

If yes, how did it help? _____

1. Has the patient ever been evaluated for mood problems (depression, anxiety, etc) or phobia (fear)? ___ yes ___ no ___ unknown

If yes

When was the evaluation (s) done? Age(s) _____ Date(s) _____

What medication have been tried and how well did they work?

<u>Drug</u>	<u>Dose</u>	<u>Response</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Early Development

- 1. Were there any problems related to early development (sitting, crawling, walking, talking, response to parents/caregivers or others in his or her environment)?

YES ___ NO ___

If YES Please explain:

2. At what age did the patient sit up? _____

3. At what age did the patient crawl? _____

4. At what age did the patient walk? _____

5. At what age did the patient begin talking? _____

For parents/caregivers who have no information about the very early years, were there problems with development when you're your child entered your home?

- 3. What behavioral problems does the patient have?

School Issues

1. List ALL schools the patient has attended and the grades of attendance

<u>School</u>	<u>City</u>	<u>Grades Attended</u>	<u>Received Special Education, Resource Room Tutoring, etc.</u>		
			<u>yes</u>	<u>no</u>	<u>unknown</u>
<hr/>	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
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<hr/>	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>

2. What learning problems does the patient have?

3. What behavioral problems does the patient have?

___	___	___	Tobacco	_____	_____
___	___	___	Medications	_____	_____
___	___	___	X-rays	_____	_____

Information about the Patient's Biological Parents

Birth mother's name _____ Birth date _____
First Middle Last

Mothers Race white black Aboriginal Ancestry French Canadian Hispanic
 Asian unknown other (specify) _____

Educational level attained (last year of school completed) _____ Age at birth of patient _____

Does she have a history of learning problems? _____

Birth mothers address _____
Street City Province Postal Code

When was the last contact with the birth mother? _____

Birth father's name _____ Birth date _____
First Middle Last

Fathers Race white black Native Canadian French Canadian Hispanic
 Asian unknown other (specify) _____

Educational level attained (last year of school completed) _____ Age at birth of patient _____

Does he have a history of learning problems? _____

Birth fathers address _____
Street City Province Postal Code

When was the last contact with the birth father? _____

Medical History of the Biological Family

Has anyone in this patient's biological family ever had any of the following conditions?
 Check all that apply.

	Birth Mother	Birth Father	Mother's Family	Father's Family	Siblings of patient
Alcoholism	_____	_____	_____	_____	_____
Birth Defects	_____	_____	_____	_____	_____
Stillbirths	_____	_____	_____	_____	_____
Miscarriages	_____	_____	_____	_____	_____
Mental Retardation	_____	_____	_____	_____	_____
Other developmental disabilities	_____	_____	_____	_____	_____
Learning disorders	_____	_____	_____	_____	_____
Attention deficit	_____	_____	_____	_____	_____
Hyperactivity	_____	_____	_____	_____	_____
Epilepsy	_____	_____	_____	_____	_____
Neurologic disease	_____	_____	_____	_____	_____
Child abuse	_____	_____	_____	_____	_____
Sexual abuse	_____	_____	_____	_____	_____
Depression	_____	_____	_____	_____	_____
Suicide	_____	_____	_____	_____	_____
Mental illness	_____	_____	_____	_____	_____
Vision problems	_____	_____	_____	_____	_____
Hearing problems	_____	_____	_____	_____	_____
Chronic illness	_____	_____	_____	_____	_____
Tourette syndrome	_____	_____	_____	_____	_____
Delinquency	_____	_____	_____	_____	_____
Any specific genetic condition	_____	_____	_____	_____	_____
Other	_____	_____	_____	_____	_____

Pregnancies of Birth Mother

Please list all of the birth mother's pregnancies including miscarriages and abortions in the order of their occurrence:

Year	Length of Pregnancy	First name of child if applicable	Live Born Child		Normally Developed		If not "normally" developed, please explain <i>Include FAS/FAE diagnosis, if known</i>
			yes	no	yes	no	
_____	_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____	_____	_____

Pregnancy, Labour, and Delivery of this Patient

1. Did the birth mother experience any difficulties during pregnancy? yes no unknown

If yes, please describe: _____

2. Did the birth mother receive prenatal care? yes no unknown

3. Were there any complications during the labour or delivery? yes no unknown

If yes, please explain: _____

4. Was the delivery: Natural By C-Section Unknown

Reason for C-Section, if performed _____

5. Where was the patient born? Hospital _____ City _____ Province _____

6. Apgar scores _____ at 5 minutes _____ at 10 minutes

7. How many days did the infant stay in the birth hospital? _____

8. Did the patient have any of the following problems while still in the birth hospital?

	Yes	No	Unknown		Yes	No	Unknown
Feeding problems	_____	_____	_____	Infections	_____	_____	_____
Apnea / breathing difficulties	_____	_____	_____	Jaundice	_____	_____	_____
Supplemental oxygen required	_____	_____	_____	Convulsions	_____	_____	_____

List of Professionals Currently Involved in Patient's Care

Primary Physicians Name _____ Phone _____
Address _____

Other Physicians Name _____ Phone _____
Specialty _____
Address _____

Name _____ Phone _____
Specialty _____
Address _____

Name _____ Phone _____
Specialty _____
Address _____

Mental Health Consultants

(Includes Psychiatrists, Psychologists, and Counselors)

Name _____ Phone _____
Specialty _____
Address _____

Name _____ Phone _____
Specialty _____
Address _____

School

Name _____ Phone _____
Address _____
Contact Person (*teacher, nurse, counselor, etc.*) _____

Other

Name _____ Phone _____
Profession _____
Address _____

Placements

List all of the placements the patient had had from birth through today.

Type of placement (i.e., foster, adoptive, etc.)	Duration of Placement	Age of patient when placement started
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

How long has the patient been in your care? _____

What to bring to Clinic

If the patient has had any of the following assessments, please bring them to Clinic on the day of your appointment. This information is VERY important to the patient's diagnostic evaluation.

_____ Medical records which document the problems you have reported above.

_____ School Assessments including:

- Achievement tests
- IQ tests
- Language assessments
- Social Skills assessments
- Behavior assessments

_____ Psychological Assessments

_____ Developmental Assessments including:

- Motor Development (fine and gross motor)
- Occupational Therapy assessments
- Mental (cognitive) assessments



SCHOOL QUESTIONNAIRE FOR CHILDREN 6-18 YEARS OLD

Please return this questionnaire to the child's parent, mail to the above address or fax to the clinic.

Child's Name: _____ Birth Date: _____

Parent or Guardian's Name: _____

Address: _____

Telephone: _____

Child's current grade level or placement: _____ Size of class: _____ students.

Has the child repeated any grades? Yes No If yes, which grade(s): _____

Name of school: _____

Telephone: _____ Fax: _____

Address of School: _____

Principal or Supervisor: _____

Classroom Teacher: _____

Questionnaire completed by: _____ Date: _____

Position: _____

1. Please describe this child's present placement (include type of classroom, and remedial support or special programming): _____

SCHOOL QUESTIONNAIRE FOR CHILDREN 6-18 YEARS OLD

Are there any special provisions provided for this child? Yes No I.E.P.

Please Explain: _____

Name of the instructor who helps this student: _____

2. To you knowledge, who initiated this referral? _____

3. Please list here any specific concerns or questions: _____

4. Please list the child's strengths:

Please list the child's difficulties:

5. Describe this student's social adjustment.

With adults: _____

With other students: _____

6. Please list the dates of any previous individual or group testing this student has had done.

Psychological or psychometric: _____

Speech and language: _____

Achievement or academic: _____

SCHOOL QUESTIONNAIRE FOR CHILDREN 6-18 YEARS OLD

Other: _____

Has this child been brought to school/team meeting? Yes No Date: _____

Are there any school/team meetings or evaluations planned for this child?

Yes No Date: _____ Waiting List: _____

7. Which of the following services does your school provide; and which one(s) does this student currently receive?

Service Offered	Available at the School	Student Involved	Name of Professional (if involved)
Learning assistance			
Resource room program			
Special education assistant			
Speech and language therapy			
Guidance counseling			
Occupational or physical therapy			
School psychologist			
Social Worker			
Special class (Please describe)			
Other (Please describe)			

8. Please rate the student's performance in each of the following areas as you have observed it on a day-to-day basis. Please mark the appropriate box and provide an estimate of the student's grade level.

Skill	Maior	Minor	No Concern	Advanced	Estimated
-------	-------	-------	------------	----------	-----------

SCHOOL QUESTIONNAIRE FOR CHILDREN 6-18 YEARS OLD

	Concern	Concern		for Age	Grade Level
Reading					
Word Recognition					
Reading Rate					
Oral reading					
Silent reading					
Reading comprehension					
Language					
Word Pronunciation					
Comprehension of verbal instruction					
Oral sentence structure and fluency					
Spelling (i.e. accuracy)					
Writing					
Punctuation					
Legibility					
Volume Output					
Written language					
Math					
Computation					
Problem solving					
General knowledge					
Memory					
Art					
Motor Skills					
Gym					
Left-right confusion					
Enthusiam					

Is this student's promotion at risk? Yes No Possibly

Conners Questionnaire

Instructions: Listed below are items concerning children's behaviour or the problems they sometimes have. Read each item carefully and decide how much you think this child has been bothered by this problem at this time.

Information Obtained: _____

By: _____

SCHOOL QUESTIONNAIRE FOR CHILDREN 6-18 YEARS OLD

Month / Day / Year

Observation	Not at All	Just a Little	Pretty Much	Very Much
1. Restless or Overactive				
2. Excitable, Impulsive				
3. Disturbs other children				
4. Fails to finish things s/he starts – short attention span				
5. Constantly fidgeting				
6. Inattentive, easily distracted				
7. Demands must be met immediately – easily frustrated				
8. Cries often and easily				
9. Mood changes quickly and drastically				
10. Temper outbursts, explosive and unpredictable behaviour.				

How serious a problem with attention do you think this child has at this time?

None	Minor	Moderate	Severe

Observation	Not at all	Just a little	Pretty Much	Very Much
Hyperactivity Excessive running or climbing				

SCHOOL QUESTIONNAIRE FOR CHILDREN 6-18 YEARS OLD

Difficulty sitting still or excessive fidgeting				
Difficulty staying seated				
Motor restlessness during sleep (Parent) Motor restlessness (Teacher)				
Always on the go or acts as if “driven by a motor”				
Inattention Often fails to finish things s/he starts				
Often doesn’t seem to listen				
Easily distracted				
Difficulty sticking to play activity				
Difficulty concentrating on school work or other tasks requiring sustained attention				
Impulsivity Often acts before thinking				
Excessive shifting from one activity to another				
Has difficulty organizing work (not due to cognitive impairment)				
Needs a lot of supervision				
Frequent calling out in class				
Difficulty waiting for turn in games or group situations				
Peer Interactions Fight, hits, punches etc.				
Is disliked by other children				
Frequently interrupts other children’s activities				
Bossy; always telling other children what to do				
Teases or calls other children names				
Refuses to participate in group activities				
Loses temper often and easily				

(Adapted from DSM – IV Teacher & Parent Rating Scale)

Does this behaviour occur in non-structured activities (i.e. recess, lunch time, assembly)?

SCHOOL QUESTIONNAIRE FOR CHILDREN 6-18 YEARS OLD

How would you rate this behaviour?

None	Minor	Moderate	Severe

Please feel free to add any additional comments about this pupil: _____

Do you have any comments or suggestions regarding this questionnaire?

Thank you very much for taking the time out of your busy schedule to complete this form. Your responses will help us assess this child. If you have any questions please feel free to call me.

With parent's permission, please attach any reports that you think would be helpful.

Sincerely,

Cathy Primeau RN BScN

BREAKING the CYCLE

Consent to Release Information

I, _____ of
(PRINT FULL NAME)

(PRINT FULL ADDRESS)

authorize the partners of Breaking the Cycle, namely:

Mothercraft	Jean Tweed Centre
Children's Aid Society of Toronto	Toronto Public Health
Catholic Children's Aid Society	Hospital for Sick Children
St. Joseph's Health Centre	

to exchange information related to the services received at Breaking the Cycle which include:

- Addiction Services
- Parenting Services
- Child Development Services
- Health and Medical Services

about me and my children.

- Me Date of birth: _____
- My children Name: _____ Date of birth: _____
 Name: _____ Date of birth: _____
 Name: _____ Date of birth: _____
 Name: _____ Date of birth: _____
- Other: Name: _____ Relationship: _____ DOB: _____

Signature

Witness

Date

Verbal Consent Only

Personal information will be gathered by the partners of Breaking the Cycle and will be shared among staff of the partner agencies. Any personal information collected by Toronto Public Health is collected under the authority of the *Health Protection and Promotion Act*. It will be shared only among staff of the partner agencies for the purposes of the program ~~Breaking the Cycle~~. Questions about this collection should be directed to Karen Whitworth, Manager, Public Health Nursing and Education Services at 416-392-7641.

ONTARIO FASD DIAGNOSTIC CLINICS

1.	Claudine Longboat-White & Ida Copenance Northwestern Ontario FASD Clinic WASSAY-GEZHIG NA-NAHN-DAH-WE-IGAMIG (Kenora Area Access Centre) Washagamis Bay First Nation Box 320 Keewatin, ON P0X 1C0	Phone: 807-543-1065 FAX: 807-543-1126 E-mail: clongboatwhite@kahac.org
2.	Tannis Favot Northwestern Ontario FASD Clinic Nodin CFI Services Sioux Lookout First Nations Health Authority 54 Queen Street, Box 1300 Sioux Lookout, ON P8T 1B8	Phone: 807-737-4011 FAX: 807-737-7532 E-mail: Tannis.Favot@nodin.on.ca
3.	Dr. Brenda Stade St. Michael's Hospital Fetal Alcohol Spectrum Disorder Diagnostic Clinic 61 Queen Street, 2 nd Floor Pediatric Clinic Toronto, ON M5C 2T2	Phone: 416-867-3655 FAX: 416-867-3736 E-mail: stadeb@smh.toronto.on.ca
4.	Dr. Gideon Koren The Hospital for Sick Children, Motherisk Program 555 University Avenue Toronto, ON M5G 1X8	Phone: 416-813-7500 FAX: 416-813-7562 E-mail: gkoren@sickkids.ca
5.	Julie Debassige Native Child and Family Services of Toronto- St. Michael's Hospital Fetal Alcohol Spectrum Disorder Diagnostic Clinic 464 Yonge Street Suite 201 Toronto, ON M4Y 1W9	Phone: 416-969-8510 FAX: 416-969-9251 E-mail: jdebassige@nativechild.org
6.	FASD Coordinator Anishnawbe Health Toronto - St. Joseph's Health Centre 179 Gerrard Street East, 2 nd Floor Toronto, ON M5A 2E5	Phone: 416-360-0486 FAX: 416-920-8876 E-mail:
7.	Sheila Burns Project Coordinator FASD Durham c/o Resources for Exceptional Children- Durham Region 865 Westney Road South Ajax, ON L1S 3M4	Phone: 905-427-8862 ext. 346 FAX: 905-427-3107 E-mail: sburns@rfecdurham.com
8.	Margaret Leslie Breaking the Cycle FASD Diagnostic Clinic 761 Queen Street West Ste. 107 Toronto, ON M6J 1G1	Phone: 416-364-7373 ext. 204 FAX: 416-364-8008 E-mail: mleslie@mothercraft.org

EMERGING FASD DIAGNOSTIC TEAMS/ PARTICIPANTS VIDEOCONFERENCE 2

<p><u>Waterloo & Wellington</u> Bonnie May, Infant Development Program 99 Regina Street South Waterloo, ON N2J 4G6</p>	<p>Phone: 519-883-2223 Fax: 519-883-4288 E-mail: mbonnie@region.waterloo.on.ca</p>
<p><u>Peel</u> Linda Lee Berkowitz, Peel Infant Development Peel Children's Centre, 85A Aventura Court, Mississauga, ON L5T 2Y6</p>	<p>Phone: 905 795-3513 Fax: 905 696-0350 E-mail: lberkowitz@peelcc.org</p>
<p><u>Hamilton</u> Jenny Sherwood, M.S.W. Children's Mental Health/ Family Counselling Program Catholic Family Services of Hamilton 477 Main Street East Hamilton, Ontario L8N 1K1</p>	<p>Phone: 905-527-3823, ext. 265 E-mail: jsherwood@cfshw.com</p>
<p><u>Thunder Bay</u> Maureen Parkes FASD Coordinator Norwest Community Health Centre 525 Simpson Street Thunder Bay, ON P7C 3J6</p>	<p>Phone: 807-622-8235 E-mail: mparkes@norwestchc.org</p>
<p><u>Surrey Place</u> Karen White Surrey Place Centre 2 Surrey Place Toronto, ON M5S 2C2</p>	<p>Phone: 416-925-5141 E-mail: Karen.white@surreyplace.on.ca</p>
<p><u>Owen Sound</u> Jennifer Sells Bruce Grey Children's Services 845 2nd Avenue East Owen Sound, ON N4K 2H2</p>	<p>Phone: 519-371-4473 ext. 121 Fax: 519-371-6397 E-mail: bfowensound@bmts.com</p>

EMERGING FASD DIAGNOSTIC TEAMS/ PARTICIPANTS VIDEOCONFERENCE 2

<p><u>Peterborough</u> Sheryl Over Five Counties Children's Centre 872 Dutton Rd. Peterborough, Ontario K9H 7G1</p>	<p>Phone: 705-748-2337 ext. 359 E-mail: sover@fivecounties.on.ca</p>
<p><u>Simcoe/York/Orillia</u> Dr. Nicky Jones-Stokreef 1080 Mississaga St. West Orillia, Ontario L3V 3C8</p>	<p>Phone: 705-326-2214 ext 223 E-mail: njonesstokreef@osmh.on.ca</p>
<p><u>Kingston</u> Dr. Garth Smith Medical Director, Developmental Pediatrician, Child Development Centre, Hotel Dieu Hospital, 166 Brock St., Kingston K7L 5G2</p>	<p>Phone: E-mail: gs3@post.queensu.ca</p>