

**Journal of Population Therapeutics
and Clinical Pharmacology**

INCORPORATING FETAL ALCOHOL RESEARCH

**Journal de la thérapie des populations
et de la pharmacologie clinique**

Official journal of the FACE (Fetal Alcohol Canadian Expertise) Research Association
Online @ www.jptcp.com
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2014 FACE POSTER COMPETITION ABSTRACTS

**15TH ANNUAL MEETING OF THE FETAL ALCOHOL CANADIAN
EXPERTISE (FACE) RESEARCH NETWORK**

September 17, 2014
Peter Gilgan Centre for Research
and Learning (PGCRL)
Toronto, Ontario

The 15th Annual Meeting of the FACE Research Association was organized by the Motherisk Program of The Hospital for Sick Children and sponsored by the Brewers Association of Canada.

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2014 FACE RESEARCH NETWORK

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POSTER COMPETITION ABSTRACTS

1

Autobiographical memory development and social cognition in adolescents with fetal alcohol spectrum disorder

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Sources of Funding: Holland Bloorview Kids Rehabilitation Hospital Foundation and Canadian Institutes for Health Research (CIHR)

Conflicts of Interest: The authors declare no conflict of interest.

Student/Trainee: Presenting author Sabrina Agnihotri is a full-time Ph.D. student.

Background: Adolescents with Fetal Alcohol Spectrum Disorder (FASD) often demonstrate deficits in social cognition and emotion processing, which negatively impact the development of appropriate social skills. Consequently, they can experience social and community withdrawal and display an increased likelihood of remaining socially isolated in adulthood. Autobiographical memory (AM) has been found to be critical for the development of appropriate social behaviours; however, it has not been determined whether AM is impaired in children and adolescents with FASD and if this contributes to inadequate social skill development and social withdrawal.

Specific Objectives: The specific objectives of the study were to: (1) compare AM recall performance between adolescents living with a diagnosis of FASD

and a group of typically developing control (TDC) participants and; 2) determine whether AM recall could predict performance on tasks designed to measure social cognition (i.e. theory of mind and social problem solving).

Methods: A two-group comparison study was carried out with 18 adolescents with FASD and 18 TDC participants ages 13-17 years. The groups were compared on the number of AM details that they recalled using the Children's Autobiographical Memory Interview. Theory of mind and social problem solving were investigated using clinical and experimental measures to assess social cognitive skills. Regression analyses were completed to understand whether the number and type of AM details recalled could predict social cognitive performance.

Results: Preliminary analyses suggest that adolescents with FASD exhibit weaknesses with autobiographical memory, but not semantic memory. Specific deficits were found in recalling event details (i.e. main event details) and perceptual/sensory details from past experiences.

Conclusions: This study is the first to our knowledge that will investigate AM in adolescents with FASD. A better understanding of the function of AM throughout adolescence in youth with FASD will increase our knowledge of the underlying mechanisms that may be related to social cognitive impairments faced by these youth.

Key Words: *Autobiographical memory, social problem solving, theory of mind, adolescents*

2

"Takes a brave woman to admit it": biological mothers raising children with fetal alcohol spectrum disorder in Ontario

Coons KD, Clement AL, Pepper JM, Watson SL

Laurentian University, Ontario, Canada

Source of Funding: Social Sciences and Humanities Research Council (SSHRC) Joseph-Armand Bombardier Canada Graduate Scholarship (CGS); Laurentian University Research Fund; Consortium National de Formation en Santé

Conflict of Interest: None

Student/Trainee: Presenting author Kelly D. Coons is a full-time student (PhD)

Objective: This study examined the lived experience of biological mothers raising children with FASD in Ontario, Canada. While qualitative studies have previously examined the experience of biological mothers, continued research is needed to understand how family experiences differ, as different family types may face a wide range of challenges and react differently to the presence of a child with FASD (Olson et al., 2009).

Methods: As part of a larger, on-going project examining the family experience of raising a child with a developmental disability in Ontario, Canada, a mixed-methods study was conducted with biological mothers of children with FASD. Eleven biological mothers (including six mothers, four grandmothers, and one great-grandmother) participated in a qualitative, semi-structured interview and completed a battery of questionnaires. The study was informed by a basic interpretive approach (Merriam, 2002) and implemented the Family Adjustment and Adaptation Response (FAAR) model (Patterson & Garwick, 1994). Quantitative findings indicate that biological mothers report clinical levels of perceived parenting stress on the Parenting Stress Index-Short Form ($n(6) = 123.7$, $SD = 21.8$). Biological mothers also report moderate levels of coping, falling in the 44th percentile, on the Family Crisis Oriented Personal Evaluation Scales ($n(8) = 94.4$, $SD = 11.9$). Qualitative interviews are currently being analyzed using interpretative phenomenological analysis (IPA; Lyons & Coyle, 2010). Preliminary findings indicate that biological mothers experience feelings of guilt and shame associated with their child's FASD. Mothers also discuss complex feelings of grief and relief upon receiving a diagnosis of FASD for their child. Findings from interviews with grandmothers also highlight the multi-generational impact of FASD.

Results: Results indicate that biological mothers are still feeling highly stigmatized by those around them.

Conclusions: Continued discussion of issues for biological mothers will help to raise awareness of FASD and promote the recognition of social determinants of health that influence FASD.

Key Words: *Mixed methods, biological mothers, fetal alcohol spectrum disorder*

3

The beautiful challenge: families raising children with fetal alcohol spectrum disorder in Ontario

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Source of Funding: Social Sciences and Humanities Research Council (SSHRC) Joseph-Armand Bombardier Canada Graduate Scholarship (CGS); Laurentian University Research Fund; Consortium National de Formation en Santé

Conflict of Interest: None

Student/Trainee: Presenting author Kelly D Coons is a full-time student (PhD).

Background: Limited research has been conducted on the experience of families raising children with Fetal Alcohol Spectrum Disorder (FASD; Watson, Coons, & Hayes, 2013). Current trends in family disability research have transitioned from deficit-based models of coping to strength-based aspects of family functioning (Summers, Behr, & Turnbull, 1989).

Methods: Employing a basic interpretive approach (Merriam, 2002), informed by the Family Adjustment and Adaptation Response (FAAR) model (Patterson & Garwick, 1994), a mixed-methods study was conducted with caregivers of children with FASD in Ontario, Canada. Eighty-four parents and caregivers from adoptive, foster, and biological families participated in a qualitative, semi-structured interview and completed a battery of quantitative questionnaires.

Results: Results from the qualitative component of the study are presented here. Using interpretative phenomenological analysis (IPA; Lyons & Coyle, 2010), ten superordinate themes, with several constituent sub-themes, were determined related to facilitators and barriers to successful family adaptation. For example, parents identified strategies they found helpful, including educating themselves about FASD, using routine, consistency, and repetition, taking things day to day, and picking their battles. Parents also discussed their use of both formal and informal supports, such as significant others, family members, and friends as important sources of informal support. Participants also identified support groups, respite services, and important professionals who were supportive in a formal capacity; however, families often reported that access to services and individuals who were educated about FASD was lacking.

Conclusions: Understanding what families do in order to transform from a family in crisis to a family that is successfully adapting is important when implementing appropriate family supports. Furthermore, many stressors for families do not originate internally within the family, but are often the result of limited support in the greater community.

Key Words: *Qualitative, families, experience*

4

The Two-Eyed Seeing (TES) diagnostic wheel

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Source of Funding: NCPC, National Crime Prevention Canada, funded the initial development of the Medicine Wheel Tool Kit

Conflict of Interest: No commercial sponsorship has been received to support this program

Background/Objectives: FASD is a complex condition that affects all aspects of an individual's development and relationships in their family and community. It is a condition that is embedded in a generational and social-cultural context. This context may affect the expression of the primary condition as well as the secondary disabilities that often follow. These secondary disabilities, such as mental illness, may actually be part of the trajectory of the primary condition and are essential to the affected individual's neurobehavioral profile. None of the widely used FASD diagnostic systems, 4-Digt Diagnostic, Canadian Guidelines, IOM (Institute of Medicine, CD, Center of Disease Control, offer a framework to consider the generational or social-cultural context of the condition. Nor do they provide a lens to examine secondary conditions common to adolescents or adults. Consideration of these factors in a FN community system may lead to improved FASD service delivery that is culturally safer for clients and their families.

Methods/Approaches: The Eastern Door Center was established in 2006 in a FN community in New Brunswick. At the core of the center was a multi-disciplinary diagnostic team that included a traditional healer from the community. This healer expressed concerns that the FASD diagnostic systems did not consider essential information that might affect an individual's behavior and development. He noted that we did not consider such issues as grief, social status, or family generational factors. This led to discussions with other elders in the community and the

development of a diagnostic tool that would combine a traditional medical perspective with a traditional aboriginal healing perspective.

Results: The Two-Eyed Seeing diagnostic wheel was developed as a clinical tool to promote a more holistic and integrated approach to diagnosis and treatment (intervention) in an indigenous community. It is the latest tool developed in the Medicine Wheel Tool-box. Together these tools provide a FN community based approach to FASD service delivery through screening, intervention and prevention as well as diagnosis. The Two-Eyed Seeing wheel was recently refined and also revised to include the new DSM 5 scoring criteria.

Conclusions/Discussion: The TES Wheel provides a multidimensional framework for FASD diagnosis. It was developed through the collaboration of health professionals and traditional aboriginal healers and is a key tool in providing culturally safe FASD service delivery in an indigenous community system. The recent revisions to the TES Wheel may allow it to have a wider application than the FN diagnostic team where it was developed. Last year at the request of the coordinator of the New Brunswick FASD Centre of Excellence the TES Wheel was introduced to the provincial diagnostic team practitioners.

Key Words: *FASD, diagnosis, generational risk, cultural-safety*

5

For shame! Stigma against fetal alcohol spectrum disorder: examining the ethical implications for public health practices and policies

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Source of Funding: NeuroDevNet NCE

Conflict of Interest: None

Background: Fetal alcohol spectrum disorder (FASD) is the leading, non-genetic cause of developmental disability in North America. Although stigma is presumed to be an important factor of the experiences of individuals with FASD, we lack specific reflections about stigma or stigma process in this context. We undertook an interdisciplinary literature review supported by working group deliberations to describe the stigma *loading* that exists for individuals with FASD, their biological mothers and families.

Methods: We conducted a review of social sciences and biomedical literatures about stigma and mental health, neurodevelopmental disorders, and disability as well as qualitative research about the experiences of individuals with FASD. The following questions were used to guide reflection: *Are there elements of the stigma process associated with FASD that are unique from other illnesses? What elements of stigma for individuals with FASD deserve special attention from an ethical standpoint? What ways could stigma be reinforced (or diminished) through public health practices?* Results from studies were summarized and discussed by the authors to shed light on stigma loading processes.

Results: We propose a model of stigma structured around (1) the stigma load of biological mothers in the form of personal responsibility and blame; (2) felt and enacted stigma for children and parents (including foster or adoptive parents); (3) the stigma of an inevitable and fatalistic life trajectory for individuals with FASD. Current practices and policies in public health might inadvertently increase stigma.

Discussion: As a complex phenomenon, stigma in the context of FASD requires close scientific scrutiny and ethical attention. Resolving the tension between public health aims and their potential negative impact on individuals, first calls for an acknowledgment that public health interventions, are not in and of themselves intrinsically good but need to be justified by scientific evidence about outcomes and sound ethical reasoning.

Key Words: *Stigma, literature review, FASD*

6

Large ears distinguish ADHD children from non-FAS, FASD children

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Source of Funding: Partially funded by a Danish International Developmental Agency Grant

Conflict of Interest: None to declare

Background/Objectives: Individuals diagnosed with FASD or ADHD share a certain behavioral phenotype characterized by executive function difficulties and

often varying degrees of cognitive and other developmental deficits. Children with severe FASD (or FAS) have distinctive craniofacial features. However children with ADHD and many with less severe FASD putatively do not have distinctive physical features. The objectives of this study are to determine whether or not certain craniofacial features could distinguish FASD from ADHD children. We report that large ear size can distinguish children with ADHD from children with non-FAS, FASD.

Methods: Ear length and ear width were measured during clinical assessment of 59 children with non-FAS, FASD, 67 ADHD and 61 control age and sex – matched children aged 3 to 17 years. Study participants were categorized into four age groups, viz; 3-6, 7-10, 11-14 and 15-17 years. Ear length and width were measured along the greatest vertical and horizontal axes, respectively, by a self-retracting plastic tape measure marked on one side in imperial units with the inch markings in sixteenths and on the other side in metric units with the centimeter markings in elevenths. Both right and left ears were measured and the mean measurements were calculated, respectively. Ear size was estimated as a product of ear length and ear width.

Results: The product of the mean ear length and ear width was 22.9 in ADHD children, 17.9 in controls and 16.1 in FASD children. The differences were significant ($p < 0.05$) across age groups even when adjusted for head size.

Conclusions/Discussion: These results demonstrate that ear size is significantly larger in children with ADHD compared to controls and to children with FASD. Large ear size is a common clinical feature in certain neurobehavioral and neurodevelopmental syndromes (example Fragile X syndrome) that share the behavioural phenotype observed in ADHD and FASD. As alcohol is a teratogen, smaller ear size in children with FASD could be attributed to the teratogenic effect of alcohol. Further, these observations also suggest that ear morphogenesis is related to neurobehavioural and cognitive development. In conclusion ear size can be used as a clinical feature for distinguishing ADHD from FASD patients.

Key Words: *Fetal alcohol spectrum disorder (FASD), fetal alcohol syndrome (FAS), attention deficit hyperactivity disorder (ADHD), clinical assessment, neurodevelopmental and neurobehavioural disorders*

7

Developmental outcomes of children born to mothers on methadone maintenance treatment

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Source of Funding: None

Conflict of Interest: None

Background/Objectives: Methadone maintenance treatment (MMT) is the standard of care for opioid use disorders during pregnancy due to associated decreases in neonatal and obstetrical complications. However, long-term developmental effects of prenatal opioid exposure are currently under-represented in the literature. The main objective of this study was to describe development outcomes of a Canadian cohort of children exposed to antenatal methadone.

Methods: A retrospective chart review was performed of infants born to methadone-maintained women attending for integrated addiction and obstetrical care at the Toronto Centre for Substance Use in Pregnancy at St. Joseph's Health Centre. Inclusion criteria consisted of infants born between 2009 and 2011 and followed over 2 years at the regional Neonatal Follow Up Clinic. Following ethics approval, data were collected from maternal and neonatal hospital and clinic charts. Due to small sample sizes at different observation points, data were summarized using basic descriptive statistics.

Results: Twenty-three children were included with approximately one-third having >1 assessment at the clinic. The overall prevalence of gross motor abnormalities was 36.3% before 12 months and decreased to 12.5% after 12 months. Fine motor and communication abnormalities were not observed before 12 months of age but occurred in 25% and 37.5%, respectively, after 12 months of age. Abnormal social development was rare.

Conclusions/Discussion: This study of infants exposed to methadone in utero demonstrated differential developmental abnormalities with a trend of gross motor development delays appearing earlier and decreasing over the first two years; whereas, fine motor and communication delays more commonly presenting after one year of age. These results provide support for the critical role of early screening and intervention programs for this high-risk population. A larger study with a longer follow-up period is needed to further characterize the impact of in utero methadone exposure on development.

Key Words: *Methadone, development, retrospective chart review*

8

Adoptive families raising children with fetal alcohol spectrum disorder in Ontario

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Source of Funding: None

Conflict of Interest: None

Student/Trainee: J.M. Pepper is a full-time student (M.A).

Background: Existing Fetal Alcohol Spectrum Disorder (FASD) research suggests that the majority of individuals raising children with FASD are non-biological parents (Rowbottom, Merali, & Pei, 2010), however limited research has been conducted on the experience of adoptive families raising children with FASD in Canada (Watson, Coons, & Hayes, 2013). Furthermore, adoption processes vary provincially. Documentation of prenatal alcohol exposure is extremely difficult. Many adopted individuals are diagnosed post-adoption (Williams, Dubovsky, & Merritt, 2011). Ontarian resources are available for parents of adopted children with FASD, but little is known about their actual needs and available resources. Data collection is ongoing, but thirty adoptive parents with at least one child with FASD are being recruited through FASD support groups in Ontario.

Methods: Using a mixed-methods approach, informed by the Family Adjustment and Adaptation Response (FAAR) model (Patterson & Garwick, 1994), parents complete five quantitative questionnaires and a semi-structured interview. The interviews are analyzed using Interpretative Phenomenological Analysis to gain an understanding of their lived experiences (Lyons & Coyle, 2010).

Results: Data collection is in progress and full results will be available for this poster. Preliminary themes reveal barriers to adaptation including a lack of information about the adoption, frustration with the diagnostic process, and difficulty accessing services (Watson, Hayes, Coons, & Radford-Paz, 2013). Conversely, parents also discussed strategies they found helpful including using humor as a coping mechanism, the use of support groups, and picking their battles. Parents discussed the lack of understanding held by some formal supports such as medical and education professionals.

Conclusion: The present study will inform Ontarian adoption agencies of the unmet needs of families of adopted children with FASD and highlight services they consider to be most helpful. It will provide a more accurate picture of the experience of raising an adopted child with FASD in Ontario.

Key Words: *Qualitative, adoption, experience*

9

Empowering conversations to prevent alcohol -exposed pregnancies: multi-sectoral training for service providers in British Columbia, Canada

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Source of Funding: British Columbia Ministry of Health

Conflict of Interest: None

Background/Objectives: In 2013-2014, the BC Ministry of Health received one-time funding for FASD prevention. In collaboration with the BC Centre of Excellence for Women's Health, education sessions were conducted for health and social service providers across BC's six health authorities. The purpose was to expand participants' knowledge, skill, and expertise to help women avoid alcohol use during pregnancy or when planning a pregnancy. This presentation provides an overview of the initiative, including outcomes, challenges, and lessons learned.

Methods: Face-to-face practice-based learning sessions were held in six health authorities. Web based evidence-based learning resources were developed by a research team and disseminated to participants prior to training. Post training webinars further supported practical skills and learning development. Public health nurses, pregnancy outreach providers, transition housing/violence service workers, social workers, midwives, physicians, mental health and substance use service providers working in Aboriginal and other communities engaged in the training and webinars.

Results: Empowering service providers with current messaging and evidence and in motivational interviewing approaches to engage women and their support networks in the conversation around alcohol use in a range of settings and contexts was emphasized. Service providers identified barriers limiting their

ability to successfully engage with women, as well as practice areas for further support and training including working with women who may have FASD themselves, engaging partners and sharing preconception information. Although resource constraints impacted training participation, the sessions supported the broader provincial strategies to address substance use in BC, including FASD prevention and improving alcohol policy.

Conclusion/Discussion: This educational initiative successfully engaged and empowered provincial health and social service providers working with women of childbearing age in a range of sectors. Lessons learned may be relevant to other alcohol brief intervention initiatives, development of continuing education resources and programs, and research knowledge translation to support practice change.

Key Words: *Brief interventions, motivational interviewing, continuing inter-professional education*

10

Social development in fetal alcohol spectrum disorders: an analysis of social deficits and interventional approaches

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Source of Funding: None

Conflict of Interest: None

Student/Trainee: Reena Rosenwald is a Masters student full time at the Munk School of Global Affairs in the University of Toronto.

Background/Objectives: Impaired social development is a core deficit of FASD. Severe social impairments persist with age and have a negative impact on multiple aspects of functioning. This review critically evaluates the existing literature on social skill deficits and current interventions for social problems in the FASD population. We hypothesized that social problems manifest differently across stages of development and remain pronounced throughout the life course.

Methods: Empirical and review studies were ascertained via a computer-based search of PubMed and Web of Science search engine. Searches included different combinations of a main set of keywords: Fetal Alcohol Spectrum Disorders, Prenatal Alcohol Exposure, Fetal Alcohol Syndrome, social skills, social cognition, intervention, treatment, adaptive behaviour

and social behaviour. Archival searches from published review papers were also conducted.

Results: Social development including social interactions, adaptive behaviours and social cognition are impaired throughout the lifespan in the FASD population. Neonates and infants show significantly impaired arousal states and atypical or delayed developmental behaviours, while older children experience marked difficulties with interpersonal interactions. In adolescence, social impairments often manifest in delinquent and defiant behaviours that continue into adulthood. By working with the affected individual and the caregiver, successful programs are able to address the unique developmental needs of the FASD population. Although progress is reported in several programs, interventions directly targeting social skills are scarce and none have addressed issues regarding the changing trajectory of social issues with time.

Conclusions/ Discussion: Existing literature points to a distinct pattern of problematic social skills that contribute to later secondary disabilities. While early intervention is suggested to prevent compounding problems, the efficacy of current approaches is limited.

Key Words: *Social skills, integrative review, interventions*

11

The universal data form project for fetal alcohol spectrum disorder (FASD)

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¹Canada FASD Research Network, ²SigP Software

Source of Funding: Public Health Agency of Canada, NeuroDevNet

Conflict of Interest: None to declare

Student/ Trainee: No

Background/Objectives: Alcohol teratogenesis generally results in diffuse brain alterations; however, the functional patterns of disability that result vary from patient to patient. To our knowledge, there is neither one study that notes the frequency of each co-occurring functional disorder, nor identifies the common clusters of functional deficits. Similarly, there has not been any published work that informs the ability to make meaningful interpretations of the diagnoses and disorders, as well as the recommendations for the most effective interventions. The goal of this study was to develop a database that would enable the collection of FASD diagnostic data across Canada in order to analyze and clearly

document the common problems – and recommended treatments – associated with FASD. Importantly, the universal data form project provides a platform for standardized data collection.

Methods: The data form was developed using a set of common forms and data was collected from over 30 participating FASD diagnostic teams in Canada.

Results: To date, the FASDataform Project has captured over 350 client records and initial data analysis reveals interesting patterns of functional diagnoses. The top three functional deficits were in the areas of adaptive behaviour (83%), executive function and abstract reasoning (81%), and social communication (78%). The most frequent patterns of functional deficits were ‘academic achievement, executive function, communication’ (58%) and ‘cognition, executive function and adaptive behaviour’ (58%).

Conclusions/Discussion: This is the first clinical dataset for FASD that has provided identification of trends and modalities related to prevention, prevalence and diagnosis of FASD across jurisdictional lines. This data accurately reflects the pan-Canadian FASD diagnostic clinical experience. These data can be used for reporting, research and surveillance; as well as informing best practices and policy.

Key Words: *Dataform, comorbidity, treatment*

12

Updates from the Canada FASD Research Network: diagnostic guidelines project, treatment improvement protocol and research priorities

Cook JL¹, Green CR¹, Anderson S², Baldwin M-E³, Chudley A⁴, Clarren SK¹, Conry J⁵, Gillis M⁶, LeBlanc N⁷, Looock C⁸, Lutke J¹, Mallon B⁹, McFarlane A¹⁰, Rosales T¹¹

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Source of Funding: Public Health Agency of Canada and the Canadian Institutes of Health Research

Conflict of Interest: None to declare

Student/ Trainee: No

Background/Objectives: Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe

the range of disabilities and diagnoses resulting from prenatal alcohol exposure. FASD is the most common type of developmental disability worldwide. Since releasing the 2005 Canadian diagnostic guidelines for FASD, gaps and inconsistencies have emerged. The goal of this project was to update and revise the current Canadian diagnostic guidelines, including a specific focus on infant and adult diagnostic criteria, as well as improved clarity and usability of the neuropsychological assessment recommendations.

Methods: The Public Health Agency of Canada tasked the Canada Fetal Alcohol Spectrum Disorder Research Network with leading the project. A Steering Committee of International experts was created to oversee and synthesize input from the broader FASD community via surveys, workshops and consultations.

Results: The updated guidelines reflect current, evidence-based practices for diagnosis of FASD. Specific attention and consideration were given to issues including nomenclature, brain domains and dysmorphology. These guidelines will be widely disseminated to all members of the FASD community.

Conclusions/Discussion: The impact of the 2005 Guidelines was significant; projects were funded for screening and data was collected in a standardized manner. New clinics opened and experienced clinics expanded. The effect of the updated Guidelines will be more significant: science, technology and tools for FASD screening, diagnosis and interventions evolve rapidly and it is critical for updates so clinical practices remain current and services are effective and efficient. Ultimately, these guidelines will better meet the needs of affected individuals and families, increase diagnostic capacity, forge stronger alignment and linkages with partners and ultimately improve health, economic and social outcomes.

Key Words: *Diagnosis, guidelines, best practices*