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Canada

Advancing Issues Related to Fetal Alcohol Spectrum Disorder

Building from Strength Conference

November 6 and 7, 2008
Dryden,Ontario

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Sheila Burns – Chair, FASD Stakeholders for Ontario

We often try to work in the middle of a problem, instead of figuring out where its beginning is.

Jan Lutke, BC mother of many children with FASD

Presentation Overview

- Introduction
- FASD basics: What it is? What to do about it?
- Stakeholder's Working Group Priorities
  - Diagnosis
  - Intervention and Supports
  - Justice
  - Prevention
  - Urban Aboriginal
- FIANO
- Regional and National Action
- Next steps
- Conclusion and Q's and A's

Definition of FASD

- FASD is an umbrella term used to describe damage that occurs to a developing fetus exposed to alcohol during the gestation period.
- It may include physical, mental, behavioral and/or learning disabilities with life-long implications.
- In Canada, the Incidence of FASD is estimated at 1:100 live births. Sampson et al 1997

Diagnoses under the FASD umbrella

Diagnosis	Growth	Face	Brain	Alcohol
Fetal Alcohol Syndrome	x	x	x	x
Partial-FAS (pFAS)	some but not all of these			x
Alcohol Related Neurodevelopmental Disorder (ARND)	0	0	x	x

Factors Impacting the Disability

- Timing of alcohol exposure
- Dosage
- Maternal factors
  - age, stress, body mass index, nutrition, other substance use, etc.
- Fetal factors
- Genetics
- Metabolism

Key Neurological Impairments

- Memory
  - Problems storing, retrieving, and processing information
  - Gaps in learning, inconsistent learner
- Abstraction and Reasoning
  - Concrete and literal thinking
  - Poor social skills
  - Poor judgment – can't plan or anticipate
- Language
  - Processing and recall deficits
- Sensory Integration
  - Hyper/hypo sensitive

Processing Deficits

- **Translating information:** difficultly changing from one mode to another – hearing into action, seeing into writing, reading into understanding, putting emotions into words
- **Generalizing information:** transferring rules into new situations, recognizing patterns, forming associations and predicting outcomes
- **Perceiving similarities:** discriminating, weighing and evaluating, comparing and contrasting

Dysmaturity

- Chronological and developmental age are not in sync
- The uneven skill sets betray true, more limited capacity
- They present better than they can perform – they may not know what they cannot do
- Processing, memory and evaluation of information means decision-making is unreliable
- Problem-solving skills are impacted

FASD Child

Will
- be failing in school (socially and/or academically)
- be seen as untruthful as they cannot accurately explain things
- be gullible and easily taken in by peers
- present better than they perform
- take things that belong to others because they confuse ownership and don't understand the value of money
- have no friends (though may report otherwise)
- be frustrated and impulsive
- show serious signs of depression and/or anxiety

May
- have unusual eating and/or sleeping habits
- have concurrent, co-occurring or misdiagnosis

Behaviour to Brain

As we understand the disability better we are able to reframe behaviour. Behaviour is the expression of their disability and/or their struggles coping with their environment.

- Overwhelmed
- Over-stimulated
- Misunderstood
- Not understanding
- Angry at themselves
- Frustrated
- Anxious
- Needing things to slow down
- Expectations are too high
- Unable to express their emotions with words

Burnout

- Inconsistent patterns of learning and behaviour means some days expectations can be met or exceeded, other days are filled with failure
  - Fatigue and frustration
  - Stress, distress, fear and deterioration of relationships
  - Depression
- These are experienced among; affected individuals, parents, families and professionals

Vulnerable Children/Vulnerable Adults

- Children with FASD are more likely to be victims of physical and sexual abuse
- More than 80% are raised by someone other than their parents compared to approximately 4% of children with Down Syndrome and approximately 8% of children with Autism Spectrum Disorder
- According to research Streissguth et al 96
  - 95% have mental illnesses
  - Most will have substance use problems
  - Most will parent early, children they cannot care for
  - More than 80% will not be able to live independently

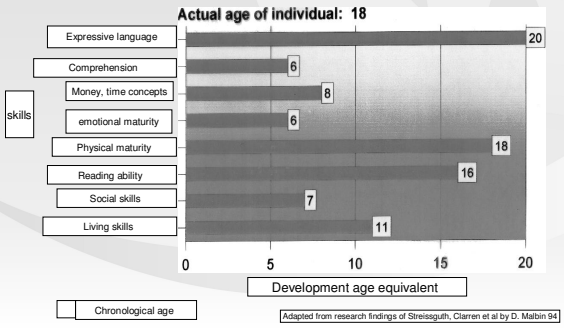
Children and Mental Health Services

- Mental health services continue to be challenged with recognizing and addressing the complex needs of children
  - Determining what is trauma, mental illness and the disability
  - FASD-sensitive approach is needed in treatment
  - Skills training to incorporate mental health and developmental disability services
- Early identification programs in the school system can catch and address delays early
  - Screening Tools for children 6-16 are being tested
- In-school support
  - Changing FASD from a behavioral to a physical exceptionality in an Individual Education Plan (IEP)
  - Opportunity to discuss and address underlying or contributing factors
  - Options to suspensions
  - Improved transition planning DC/K, 8/HS, HS/WP

Adult Justice Experience

- Research shows that individuals with FASD are vulnerable in our society and are at-risk for being involved in criminal activity or victims of crime. Streissguth et al 1996
  - Mental health and social issues associated with substance use
  - Children are placed into care for abuse or neglect
  - Financial manipulation and resulting loss of stability
  - Perpetrators and victims of crime
- Justice system needs to be aware of FASD to protect rights

Timelines and FASD



Adapted from research findings of Streissguth, Clarren et al by D. Malbin 94

Key "S" for Success

Structure: Create a structured environment that includes choices within clear and predictable routines
Supervision: more supervision is required to direct appropriate behaviour
Solving Problems: establish clear, simple strategies/guides to work through conflicts
Simplicity: Directions, verbal cues and expectations must to stated in clear, brief and simple terms
Steps: Break tasks down into small steps and teach each step through repetition and social reward
Situational Learning: Teach skills in the context in which the skills are to be used
Sensory Impairments: Be aware of triggers and adjust your approach
Set Expectations: keep expectations within the skill sets demonstrated by the child

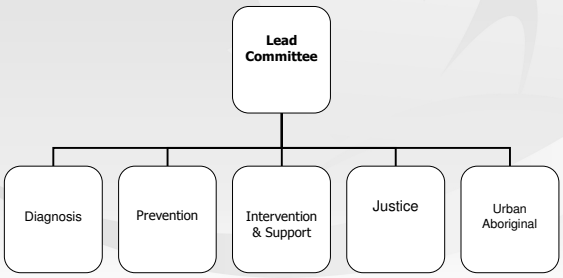
What we know

- Individuals with the disability are heavy users of our system
- Due to lack of information on their diagnosis, treatment interventions, management strategies, and education/employment plans are not appropriate
- The disability impedes the person's ability to self-advocate
- Approximately 35% of the mothers of children born with FASD have been prenatally exposed to alcohol themselves

Background - Ontario

- Discussions with community and experts were initiated to advance awareness, prevention and strategies to improve outcomes for children and adults.
- By 2005:
  - Creation of FASD Stakeholders for Ontario comprised of a Lead Committee and five working groups
  - Creation of FASD Intergovernmental Action Network of Ontario (FIANO), a network of Ontario federal and provincial government representatives

FASD Stakeholders For Ontario



Prevention Working Group

Purpose:
The Prevention Working Group will seek to share new knowledge regarding the consequences of alcohol use in pregnancy, address identified gaps in FASD prevention, and develop and promote effective strategies, resources and programs that address alcohol use in pregnancy. A priority focus is high-risk groups.

Completed Work
- Policy Forum and Conference: "Moving Systems to Improve Women's Health and Prevent FASD"
- Dissemination of training videos re: prevention; successful community based FASD public awareness campaigns; and approaches to early
- intervention for pregnant women using alcohol or substances

Current Initiatives
"Just Found Out You're Pregnant?" prevention materials and provincial media campaign available on-line at www.beststart.org

Diagnostic Working Group

Purpose:
The Diagnosis and Disability Working Group will increase both the availability of diagnostic services and accessibility to resources for individuals with Fetal Alcohol Spectrum Disorder and their families.

Highlights
- "Creating a Foundation for FASD Diagnostic Capacity" report on current models of multidisciplinary/team diagnosis in Ontario
- Informed an Incidence Study: Just how common is FASD in Ontario?
- Parent involvement in the diagnostic process

Current Initiatives
- Evaluation of telemedicine diagnosis
- Training for community based diagnostic teams and diagnostic clinics
- Tracking and posting FASD clinics or teams

Intervention & Support Working Group

Purpose:
The Intervention & Support Working Group will focus on building capacity within service sectors and systems and the general community to be able to respond appropriately to the unique and diverse needs of those living with FASD.

Completed Work
- Family Camp provided education and respite for children, youth, and parents affected by FASD
- Developed a camp guide for those interested in offering a similar camp experience

Current Initiatives
- Survey individuals, service and care providers on intervention and support
- Evaluating respite capacity in the province
- Reviewing promising practices by existing service providers
- Disseminating information on research, resources, activities, conferences and support groups

Justice Committee

Purpose:
The Justice Working Group will identify and promote appropriate options for FASD-affected individuals (witnesses, victims, offenders, and families) involved with the youth and adult justice systems, and work with justice system personnel to increase knowledge and awareness of the impact of FASD in the court system.

Completed Work
- Developed and circulated "FASD and the Justice System" CD ROM
- Launched website to inform the justice community of the impact and implications of FASD

Current Initiatives
- Promote **www.fasdjustice.on.ca** as a resource for members and users of the criminal justice and family law systems in Ontario
- Post emerging case law related to FASD for review on the website
- Research options for FASD diagnostic services for individuals in custodial settings

Urban Aboriginal Working Group

Purpose:
The Urban Aboriginal Working Group will work to ensure that culturally-based, Aboriginal owned information is being disseminated within mainstream and urban Aboriginal communities regarding appropriate protocols and interventions to be used when delivering services to Aboriginal peoples.

Completed Work
- "FASD Tool Kit for Aboriginal Families"
- Models for Housing and Program Support for Aboriginal People with Developmental Disabilities
- Guide for communities and families "Initiating and Running an FASD Clinic"

Current Initiatives
- Training and awareness for front-line mental health workers
- Dissemination of developed material

FASD Intergovernmental Action Network of Ontario (FIANO)

Purpose:

To facilitate sharing of expertise, resources and increase the profile of the portfolio in different ministries and departments.

FIANO

- FIANO is seen as parallel process, aligns priorities and makes linkages with other networks, such as the FASD Stakeholders for Ontario
- Accesses information on research which generates new directions in diagnosis, child development, interventions and support, prevention strategies for substance-using women

FIANO

- Leverages resources across many sectors without burdening one
- Sectors see implications of policy on broader system
- Movement and action can occur at different paces
- Integrates FASD into existing systems that accommodate other disabilities, mental illness, young offenders, the socially vulnerable

FIANO Accomplishments

- Cross-ministry presentation
- Collaboration and discussion with stakeholders to inform government
- Multiple ministry involvement

Regional Activities

- FASD presentations given to variety of audiences
- FASD resource mail-outs to funded projects; Ontario Early Years, Public Health Units, and stakeholders
- Supporting key FASD speaker events
- On-going support to the FASD stakeholders for Ontario and FIANO
- Implications for Ontario: Awareness of FASD Report 2007, PHAC contracted with Best Start Resource Centre to write brief report outlining the implications of the survey results in Ontario

National Activities

Highlights from 2007-2008:

- Screening and Recording Alcohol Use of Women of Child-Bearing Age and Pregnant Women - *The Society of Obstetricians and Gynaecologists of Canada*
- On-Line MD-CME Training Course - Supporting Change: Preventing and Addressing Alcohol Use in Pregnancy - *Memorial University* adapted an accredited continuing medical education module (up to 3 Mainpro M1 credits), developed by Best Start in Ontario – translated into a bilingual on-line training course. The course is available to health care and allied professionals from a range of fields at www.mdcme.ca.

National Activities

Projects in Progress:

- **FASD Training in Canada - Guiding Practice and Impact - Canadian Centre on Substance Abuse (CCSA)**
- **Developing a National Screening Tool Kit for Those (0 to 18) Identified and Potentially Affected by FASD - Canadian Association of Paediatric Health Centres (CAPHC)**
- **Economic Impact of FASD For Children In-Care in Manitoba**

National Activities

Projects in Process:

- **Early Primary Schools Outcomes of Prenatal Exposure to Alcohol and Nicotine separately and in Combination .** Preliminary data showed that while nicotine exposure by itself did not have significant impact on child outcomes, alcohol by itself did and in combination with nicotine had a significant impact in a number of domains of child development. Dr Ray Peters, Queen's University, secondary analysis of Ontario Intervention, Better Beginnings, Better Future

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- **Economic Impact of FASD in Canada**
  Current statistics: Canadian total annual cost of those 0 to 21yr is $571,010,000 B.Stade,PhD., St Michael's Hospital, Toronto, Canada

Next Steps

- Increase the profile of FASD, share best practices, and expand networks of support
- Continue to define priorities and engage broader audiences
- Strengthen the partnership between stakeholders and FIANO
- Continue to work with our National FASD colleagues
  - Building community capacity
  - Stimulating knowledge development and dissemination
  - Supporting inter-sectoral collaboration

Conclusion

- Improved understanding and interventions to reduce the incidence of FASD and better the lives of those living with the disability.

For more information:

- www.fasdontario.ca
- www.publichealth.gc.ca/fasd

Thank you