

FASD

from Policy to Research
and Research to Policy

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IHE Consensus Development Conference on

**Fetal Alcohol Spectrum Disorder
(FASD) – Across the Lifespan**

October 7 to 9, 2009, The Westin Edmonton, Edmonton, Alberta

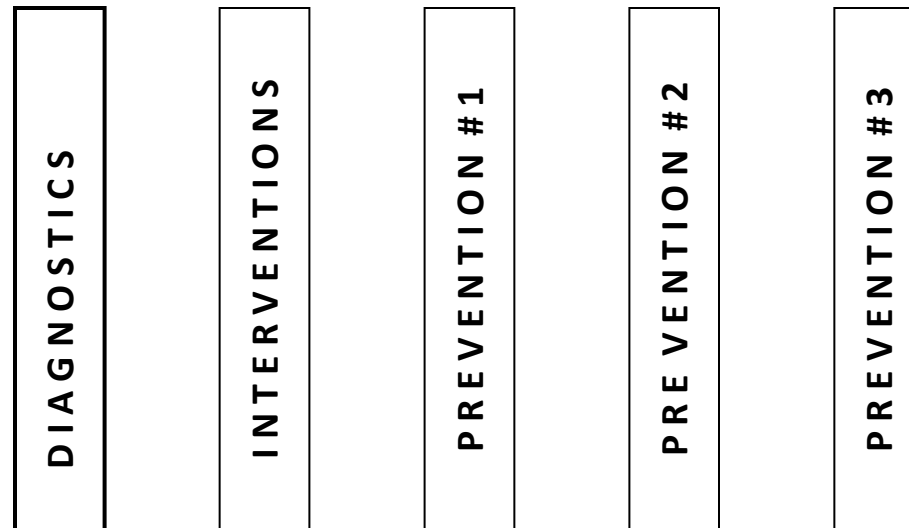


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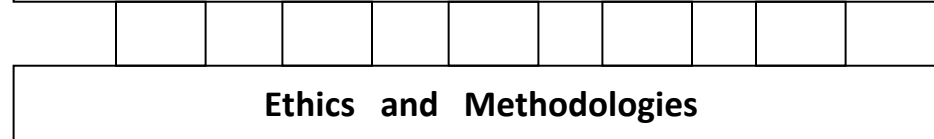
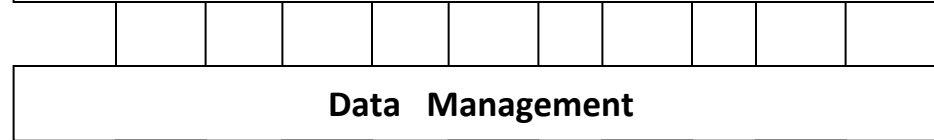
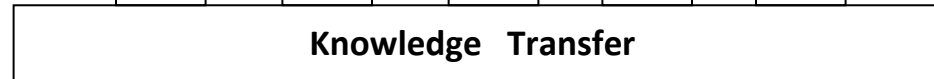
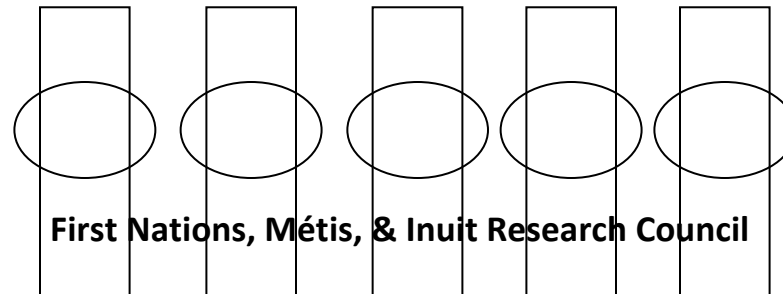
The CanFASD NW Research Network: NETWORK ACTION TEAMS (NATs)



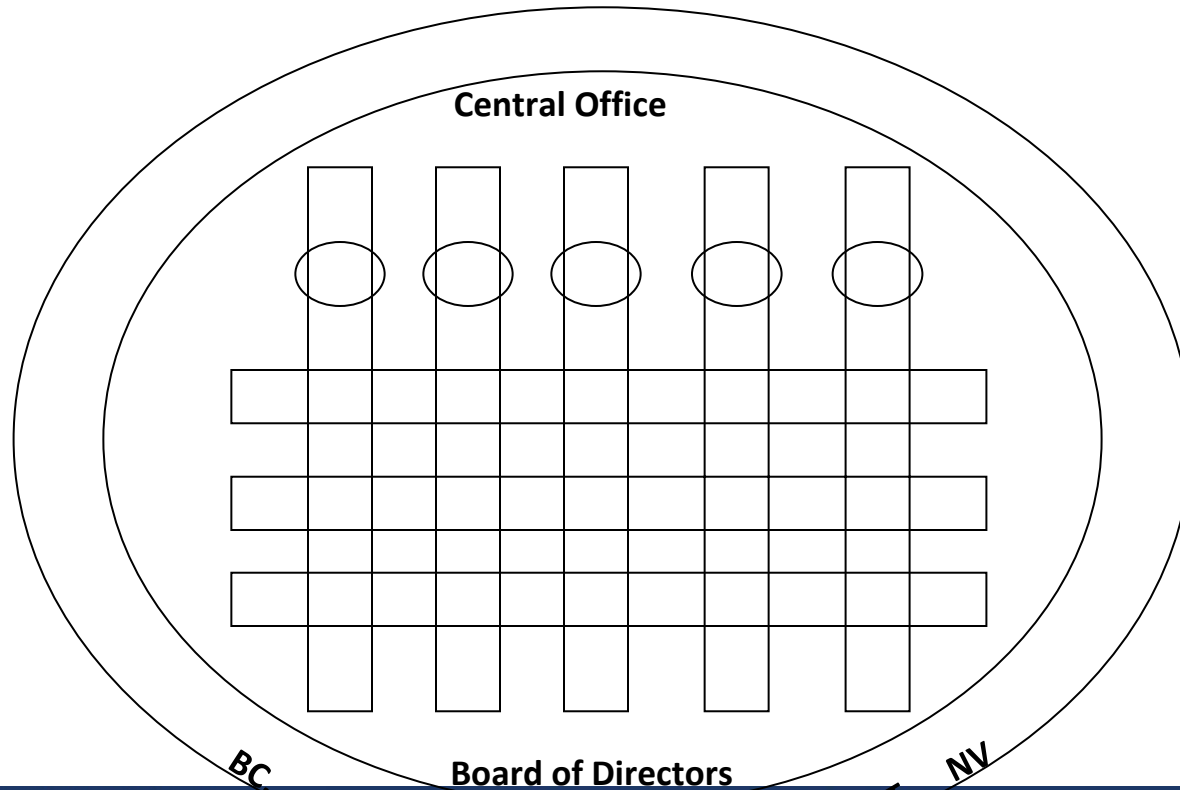
**Canada Northwest FASD Research Network
organization**

NETWORK ACTION TEAMS (NAT's)

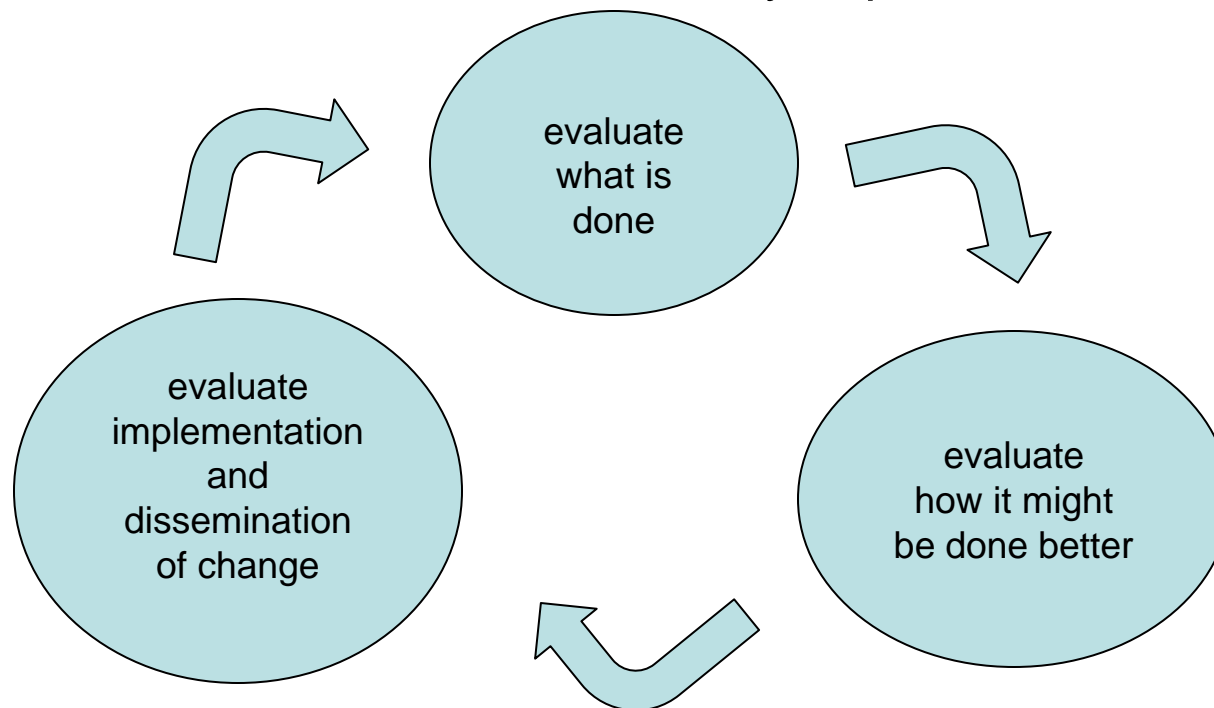
**NETWORK
IMPLEMENTATION
TEAMS (NIT's)**



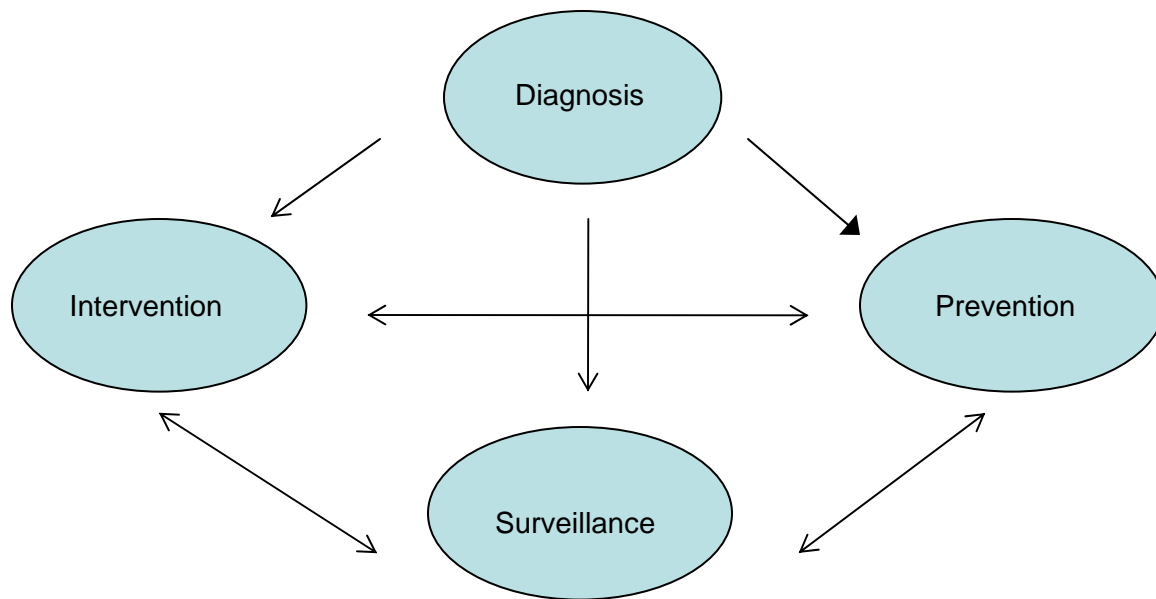
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“Clinical Research” or “Quality Improvement”?



4 aspects of Clinical Inquiry on FASD inform each other and need to be advanced synchronously.



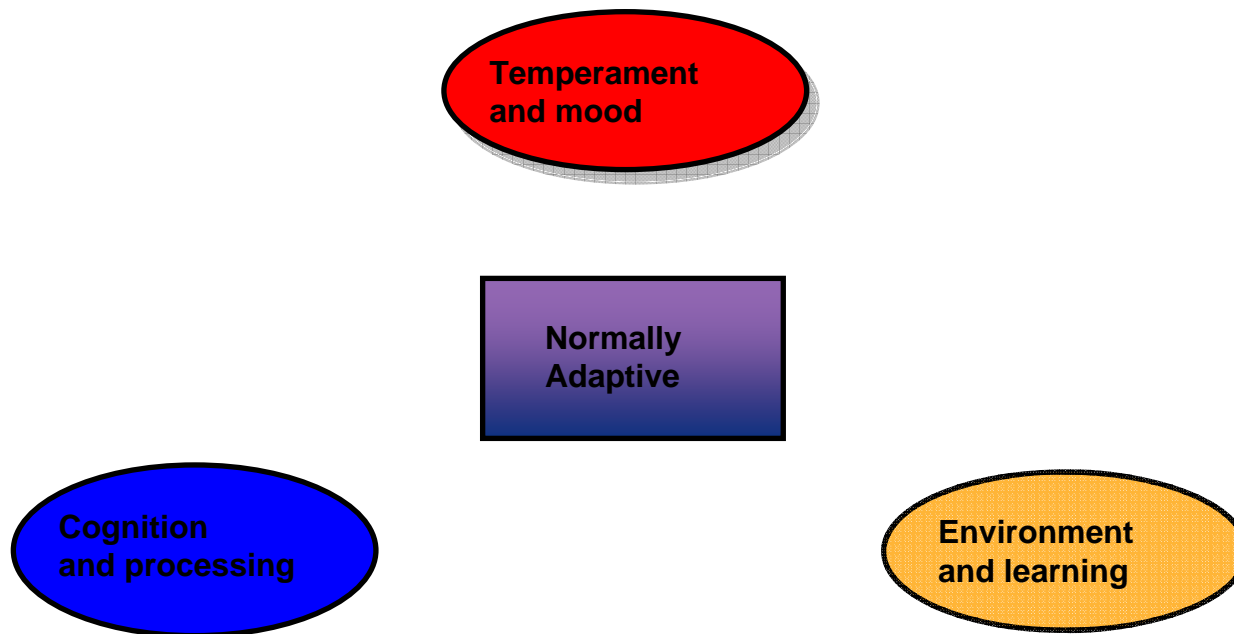
Diagnosis depends on Diagnostic Capacity

- Estimated prevalence of FAS/FASD in Canada
 - 32,000 cases - FAS
 - 340,000 cases - FASD
- Estimated annual FASD births in Canada
 - 3,200 cases
- Interdisciplinary team annual capacity in Canada
 - 1500 evaluations

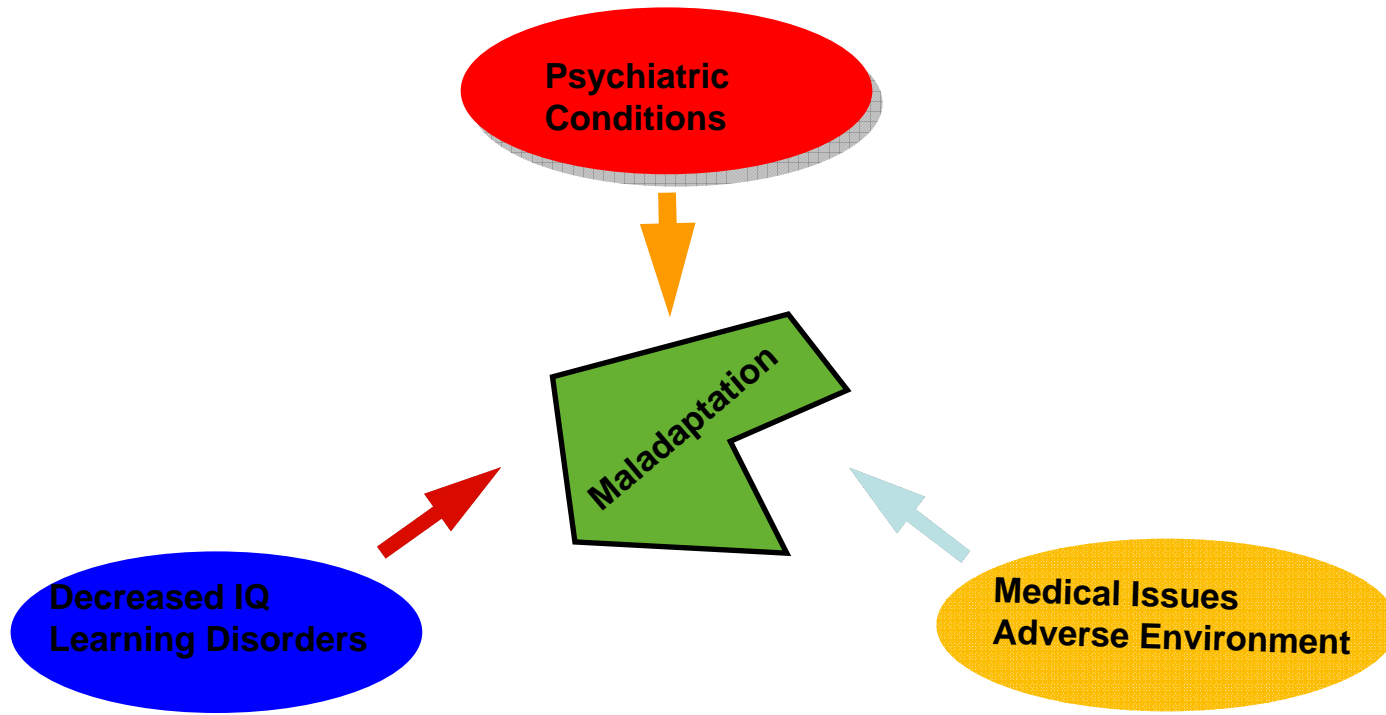
How will capacity be increased?



Normal adaptive function is the result of normal internal and external conditions



Abnormal adaptive function is the result of abnormal internal and external conditions



NOT all maladaptation is approached the same way

- Issues in Health or in the Environment
 - Societal judgment: *disease*
 - Intervention goal: *treatment or cure*
- Issues of Temperament or Mood
 - Societal judgment: *disease or disobedience*
 - Intervention goal: *treatment , cure or punishment and separation*
- Issues of Cognition and Performance
 - Societal judgment: *disability or disobedience*
 - Intervention goal: *acceptance, treatment or punishment and separation*



Traditional sites of Practice for Children with Disabilities

- **Clinical Genetics Programs**
often responsible for determining the etiology of birth defect syndromes
- **Developmental Disabilities Programs**
often responsible for providing comprehensive/coordinated care for those with birth defect syndromes.



Can these programs pick up the slack?

- **Genetics Programs**

Usually are not equipped to provide the interdisciplinary assessment needed to establish the pivotal brain dysfunction component to the diagnosis in those with FASD beyond FAS per se.

- **Developmental Programs**

Usually have clinical groups of professionals that focus on specific functional deficits rather than on etiologic conditions.

Generally these programs are rare and oversubscribed already



The first policy/research issue: Diagnostic Process and Procedures

- How should increased capacity be determined?
- Where should new programs be located?
- Who should staff them?
- Who should monitor and adjust the changes?



When capacity is increased how can we assure that?

- Clinics should be linked to prevention programs
- Clinics should be persuaded to use common forms and report common data such as:
 - The patients FASD diagnoses
 - FUNCTIONAL diagnoses
 - Treatment recommendations
 - The estimated risk that the birth mother may have for giving birth to additional children with FASD



Second policy/research issue: surveillance

- Passive retrieval systems will not yield the information that is required
- Active surveillance creates ethical considerations that must be dealt with by government
- Without this information we can not plan appropriately for services
- No feed back on the success of prevention programs
- What agency or group will take the lead here to direct the studies that are needed?



Third policy/research issue: Intervention

- Working with deficits/working with strengths
- Working with individuals or in groups
- Working with schools/society
- Working in urban/rural/remote settings

How is this work coherently fostered,
encouraged, sustained and evaluated?



Fourth Policy/Research Issue: Prevention

- Six target groups for prevention that are unique from each other:
 - WOMEN AT highest risk
 - Women with intermittent high risk behaviour
 - Women at lower risk
 - Man and women at no risk – who care about women at risk
 - Providers
 - Indirect work through women's health and social context

How is this work ***coherently*** fostered, encouraged, sustained and evaluated?

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In summary

- We do not really know how to do this work effectively and need to learn from our experiences.
- We are learning that without clear direction the work is not moving forward spontaneously.
- Persistent and sustained effort ***with a framework as well as funding*** from government will be needed to provide the clear framework for the clinical research that is needed to advance this field and provide the effective interventions needed by this population.

