#### The Gift of FASD

Impacts of FASD at the Community Level Mary Berube MSW, RSW



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





# Looking back ...

- FASD identified; generated compassion for infants with prenatal substance exposure histories
- Early prevention messaging often encouraged anger at their birth mothers











 Gradual understanding of the life-long impacts/costs for affected persons and their caregivers; FASD seen as a disability



IHE Consensus Development Conference on
Fetal Alcohol Spectrum Disorder
(FASD) – Across the Lifespan







# We are moving towards...

- Understanding the community responses that FASD and its attendant sequelae\* require
- Understanding and rethinking our responsibility/attitudes towards those who are pregnant and substance using "mothering under duress" (Poole)













?What will it take to mitigate the harm caused by the impacts of prenatal substance use? ?Who will take this on? ?What will it cost?



IHE Consensus Development Conference on

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

Fetal Alcohol Spectrum Disorder (FASD) – Across the Lifespan





# Things To Consider

- Prevention of secondary disabilities
- Community responsibilities towards persons with FASD and their families/caregivers
- Community safety
- Inclusion
- Public messaging



# Secondary Disabilities

- Education and employment challenges
- Mental health and/or substance use problems
- Problems with the law
- Victimization, homelessness
- Health/reproductive issues related to lifestyle, impulsivity, impaired judgment
- Isolation from family, community

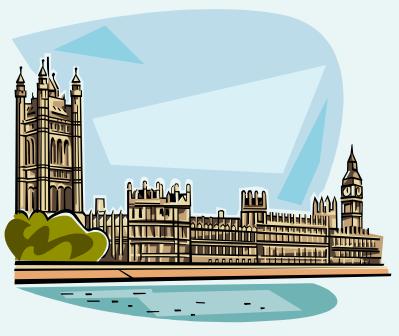


# Community Responsibilities

- Public health, diagnosis, prevention initiatives
- Social assistance for person's with disabilities
- Child welfare/child protection
- Education, employment
- Housing, health institutions, accessibility
- Substance use/mental health programming
- Justice system responses



#### Safe communities need...



- Infrastructure (capital and bureaucratic)
- Governance
- Policy design and implementation

IHE Consensus Development Conference on Fetal Alcohol Spectrum Disorder (FASD) – Across the Lifespan





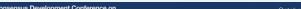
 Justice system responses to illegal activities, and victims of crimes



Fetal Alcohol Spectrum Disorder (FASD) – Across the Lifespan







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







# Community Inclusion

- Equal or appropriate opportunities for all citizens
- Accessibility to public buildings, events, opportunities
- Shared burden of caring for persons with FASD



# Public Messages

- Policy and practice that models non-discrimination and inclusion
- Valuing diversity
- Celebrating the accomplishments of persons living with disabilities





 Non-blaming public awareness campaigns; unbiased language in publications



IHE Consensus Development Conference on

Fetal Alcohol Spectrum Disorder
(FASD) – Across the Lifespan





# Prescription for community management of FASD:

HE Consensus Development Conference on







Diagnosis -for twopreferably in gestation or early infancy/childhood Woman centered substance use interventions



IHE Consensus Development Conference on Fetal Alcohol Spectrum Disorder (FASD) – Across the Lifespan





#### Harm reduction...



- Professional, multi-disciplinary teams that attend to medical issues related to FASD
- Periodic screening for hearing, vision speech/language problems, development

IHE Consensus Development Conference on Fetal Alcohol Spectrum Disorder (FASD) – Across the Lifespan







- Family centered care and advocacy to address needs of child(ren) and parents, caregivers
- Support (including grief and loss counseling, respite) for caregivers to prevent placement breakdown













- Allowances at every developmental stage for dis-maturity; anticipating and preparing for the corresponding challenges
- Recurring developmental assessments at every stage to inform case planning



# Educational placement and supports to sustain both students and teachers



IHE Consensus Development Conference on
Fetal Alcohol Spectrum Disorder
(FASD) – Across the Lifespan





- Life long, continuous advocacy and case-management for affected individual
- Parent/caregiver training for every stage of development







Planning/preparing early for future capacity for meaningful work and community engagement

IHE Consensus Development Conference on
Fetal Alcohol Spectrum Disorder
(FASD) – Across the Lifespan







 Supported employment (from search through structured day/work duties)



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





- Increased supervision/one-on-one supports to navigate the years from 12-21 (prevent disruption from school/home placements, trouble with law etc.)
- Pre-planned transitions (handoffs) from children's to adult services



- Provision of ongoing and explicit training re socialization, employment, sexual activity, life skills, accepting help
- Recognize and plan for various degrees of life-long dependency/daily living supports



- Regular screening for substance use, mental health problems, reproductive health issues, and provision of assistance to cope with relationships, parenting, family life
- Specialized intake and interventions for substance use/mental health/justice system





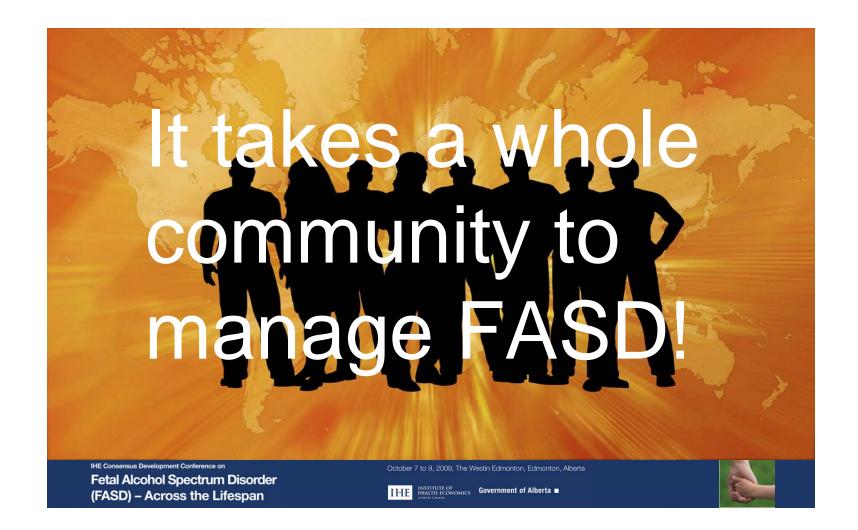
Enactment of harm reduction strategies is subject to the tides of public opinion, government ideology, bureaucratic will and available monies.

However, once interventions are entrenched in policy they are less likely to be subject to whimsical change...

Fetal Alcohol Spectrum Disorder
(FASD) – Across the Lifespan







#### **Credits**

Nanson, Jo; Roberts, Gary (2000) Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy. Health Canada

Poole, Nancy & Greaves, Lorraine (2007) Highs & Lows, **Canadian Perspectives on Women and Substance Use.** CAMH

Streissguth, Ann (1997) Fetal Alcohol Syndrome: A Guide for **Families and Communities. Brookes** 





