

WORKSHOP REPORT:

Doing it Right Too: FASD (Fetal Alcohol Spectrum Disorder) and Inuit Communities

Sponsored by: Health Canada/FNIHB and ITK

Ottawa, Aug. 13-14, 2003

Objectives

Health Canada/First Nations and Inuit Health Branch, with ITK's involvement, gathered together representatives involved in FASD work in Inuit regions, in order to provide an opportunity to:

- share and gather information about what is happening, what is working, and what is needed in Inuit regions and nationally regarding FASD issues, policies and programs
- contribute to Health Canada/FNIHB's development of an effective, efficient Inuit-specific FASD policy/program framework (Program design must be completed before funds can be released.)

Background

- *1999*: FNIHB received \$1.7 million as part of the federal government's inclusion of an FAS/FAE component in the Canada Prenatal Nutrition program
- *2000*: HC/FNIHB meetings with FN and Inuit communities, resulting in the document *It Takes a Community* as a framework and resource manual for the development, implementation and evaluation of FASD initiatives in FN and Inuit communities

Early Childhood Development (ECD) established as federal/provincial/territorial social policy priority (promotion of healthy pregnancy, birth, infancy; improved family supports; improved ECD learning and care; improved community supports).

- *2001*: Additional \$15 million for FASD efforts in on-reserve FN communities (supports for women at risk; early identification; assessment, diagnosis and training; early intervention/supports for families with FASD children). Focus on prenatal to age 6, as the initiative is part of ECD strategy for FN and Other Aboriginal children

Of the original \$16.5 million total, \$184, 017 was to go to Northern communities (Atlantic Inuit and Innu \$17, 342; NWT Inuit and FNs \$51, 344; Quebec Inuit \$28,896; Yukon FNs \$16, 873; Nunavut Inuit \$69,562)

- *October 2002*: Announcement of another \$1 million dollars for Northern allocations (total funds now available: Atlantic Inuit & Innu \$111,342; NWT FN & Inuit 330,344; Quebec Inuit 185,896; Yukon FNs \$108,873; Nunavut Inuit \$447,562)
- *May 2003*: First HC/FNIHB “Doing it Right” workshop for FN FASD experts and workers to provide input for effective and efficient expanded FASD program design; focus was on FN on-reserve communities
- *Today*: Inuit-specific “Doing it Right” workshop

Discussion

- Huge discrepancy between monies going to FN on-reserve communities and to Inuit (\$15.9 million vs. \$1.8 million); some “northern” funds go to FN groups

How do numbers of communities, needs, etc. compare?

- HC/FNIHB did not know how funding was allocated – per capita?
- What about urban Inuit? Mary Johnson of HC Population and Public Health Branch:
 - non-reserve and southern communities get federal funds from Canadian Prenatal Nutrition, Aboriginal Headstart, etc. programs – accessed by, e.g., Tunngasuvingat Inuit in Ottawa, ‘Breaking the Cycle’ programs in Toronto and Winnipeg. Not FASD-specific but inevitably related.
 - in process of developing a framework re national diagnostic and screening tools, guidelines;
 - hoping for future studies re effective approaches in various types of communities.
- Funds now with Northern Secretariat, not yet with regional health committees; can be released only when program design complete – HC/FNIHB using input from this workshop, hoping for September completion of design
- Recurring problem: deadline for using funds – March 2004; not enough time for effective use of funds by regions;

Presentations: Existing Programs or Models

Pauktuutit (Aluki Rojas):

- Past: video “Before I was Born”

Current: “Children Come First” project – community education: illustrated flipchart, accompanying manual with related activities and community discussion ideas; training workshop for community workers in Sept (Nunavut) for use of the materials; to be supplemented by video/manual and radio play. (Funding available to provide these materials/training available only to Nunavut at this time.)

- Resources culturally based, developed through a consultative participatory process
- Available in Inuktitut
- Observations: need for training and regional/community follow-up; plain-language and user-friendly (e.g., not too long); emphasis on positive messages

Nunavik Regional Board of Health and Social Services (Roselyn Ferguson):

- Shared study of people with intellectual and physical disabilities, and workplan
- Kativik School Board parenting workshops in all communities
- Recommendations: use of midwives; involve medical nursing and community wellness services during pregnancy; prevention activities during and after pregnancy; focus on early identification of at-risk families, with support and training; better coordination between all organizations/agencies

Nunavut Health and Social Services and NTI (Carol Gregson, Sandy Steinwender, Robert Imrie):

- FASD workplan includes communication network among regional representatives, Health and Social Services, Justice and RCMP
- Will be funding/participating in Pauktuutit’s training workshop
- Diagnostic/ screening tools, professional development/training needed
- Interventions and resources must be in place before diagnosis/screening is useful
- Lack of services, personnel
- Not much help available for people trying to stop drinking
- Need strategies for parent interest/involvement in order for screening, interventions to be useful

Inuvialuit Regional Corporation (Francene Ross):

- Many children undiagnosed, but diagnosis is difficult – high turnover, heavy workload in medical/educational services
- High alcohol/cocaine abuse rate, but not addressed even when women have several FASD children
- IRC emphasizing ECD centres (5 established already)

- Re FASD specifically, looking what now/what's needed/who's responsible; need to move beyond assessments and surveys
- Proposal in for funding for a one-year Harm Reduction pilot project
- RCMP, Justice have FASD initiatives
- GNWT has established funding for joint IRC/Dene steering committee
- 3rd year of very successful FASD awareness-walk

Francene also presented an overview of FASD.

Labrador Inuit Health Commission (Marjorie Flowers):

- Seven core programs delivered to communities (mental health; community health & communicable disease control; addictions; NIHB; home and community care; environmental health; child care/child development)
- FASD covered under community health & communicable disease program through Canada Prenatal Nutrition Program; impacts on all other programs

Prenatal Health and Education: public awareness sessions on FASD; t-shirts, posters, bags etc with “100% preventable, 100% permanent” slogans; support groups; nutrition information; well baby clinics; parenting programs; referrals for diagnosis (Diagnosis difficult – doctor in St. John's NF)

- 5 licensed daycares targeting special needs children; preschool and afterschool programs (at least one daycare has painted the walls a less-stimulating colour – seems to help with FASD children)
- **Alarming statistic:** Arrangements were made to have doctor come in and assess 36 children (ages 5-12) who had been community-identified as possibly FASD. 29 of these children were in fact FASD
- Child, Youth and Family Services provides respite worker for FASD children on their caseload
- FASD information session planned for September (health professionals and teachers)
- Needed: funds and human resources (doctors for more diagnoses; trained workers, etc.); training and capacity building in order to get out effective “don't drink” message; strategies for ‘hard to reach’; early diagnosis, interventions in place, and follow-up; education and support groups for parents with FASD children; more coordination among government/agencies/etc.

Discussion Groups: Core Elements of an Inuit FASD Framework:

Prevention

What's working:

Meetings, workshops, expanded national communication networks; media use; open community discussion; Pauktuutit materials; coordination between

government/departments/agencies/organizations; public education/awareness outreach

What's needed:

More communication, coordination; translated materials; counselling and support programs, including alcohol-specific to help women cut down/stop drinking; appropriate training for counsellors, CHRs, childcare workers, FASD services, etc; money; screening; identification and outreach to women at risk; family involvement and FASD education (not just women); teams; professionals out to communities, to inform/educate; involve youth

Interventions

What works:

- Interventions....but there are none in place
- Direct professional support and intervention, but it is limited: some fly-in expertise in larger communities but generally a lack of professional expertise
- Community support-level intervention (indirect): daycares, Headstart, Healthy Children: but services not consistent, varies among communities
- Consultation/support/training: currently hit-and-miss, not formal coordinated intervention
- Lack of addiction treatment centres

Barriers to intervention:

- Lack of understanding of the problem
- Lack of diagnosis
- Lack of places to refer

Helpful interventions needed:

- FASD-friendly schools and daycares: less-distracting environments (LIHC example of changing to more peaceful wall colour)
- Parent/professional partnerships – need support worker positions
- Lack of addictions treatment centres (one in Labrador, one in Nunavik); AA programs not working ; more culturally sensitive programs, land-based treatment, constructive activities and alternative supports
- No screening/diagnosis, limited treatment/intervention for FASD children
- Sexual health and alcohol effects education in schools – early intervention needed
- Parental supports for parents with FASD – cycle can continue with children

What we need:

- Healthy alternative interventions
- Agency and community networking
- Case management (team approach?)

- Local resources and programs
- National strategy for screening FASD
- Financial support
- Regional child development programs
- Support and intervention for parents

Training and capacity-building

What's working:

- Pauktuutit's flipchart/manual education package
- Learning from other regions, approaches, experiences

What we need:

- Funding for training
- Training is essential and wanted by people, needs to be ongoing, good materials, participatory process
- Training needs follow-up, including links between supervisors/service deliverers (e.g. letters of agreement?)
- Systematic implementation: priorities; community awareness; training (counsell skills in specific areas, e.g. addictions)
- Policy issues – financial and human resources
- Follow-up plans integrated with prevention and awareness activities
- Sustainability – at least a half-time coordinator in each region/sub-region for follow-up, communication, ongoing support for trained workers
- Broad training – communities, professionals, daycare workers, schools, etc. Especially important for those who remain in the communities (versus 'revolving' people)
- Important: strong evidence bases - e.g. extent/numbers of FASD problem; accountability; decision-making re screening/diagnosis

Other issues/core elements raised but not fully discussed

- Need for coordination among service providers, agencies, governments, organization, departments at community & regional levels
- Need for developing a national Inuit FASD network for information/resource development, sharing
- Funding issues: allocation formula, flow, timing, level of funding, etc
- Strategies for targeting youth

Conclusions and Next Steps

- Workshop material to be incorporated into HC/FNIHB program design
- Drafts of the report to be sent to Roda Grey at ITK, Tina Martin (FN) for comments, approval
- Translation of report into Inuktitut
- Funding needed to make Pauktuutit's materials available

RELEVANCE TO AJUNNGINIQ CENTRE WORKPLAN:

- We are now knowledgeable about what FASD initiatives are currently ongoing in all Inuit regions
- We know what is needed and can support communities/ITK in their efforts to fill the gaps
- A major identified gap – that of alcohol treatment/counselling services, and appropriate training for counsellors – fits into our environmental scan/discussion paper on alcohol-abuse services.

Much of the discussion in the workshop centred around identification/diagnosis of FASD children, and provision of effective services for such children and their parents. However, prevention efforts seem to be focused on education and awareness. As several participants noted, telling people that they need to stop drinking in order to prevent FASD is not helpful unless there are effective strategies to help them stop. The Harm Reduction outreach program that IRC/Francene Ross are hoping to provide is the only current initiative that aims to provide such alcohol-specific counselling.

Marja Korhonen, Ajunnginiq Centre, NAHO