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FETAL ALCOHOL SPECTRUM DISORDER IN RURAL AREAS

RURAL DIALOGUE SUMMARY REPORT

**Victoria, British Columbia
February 23, 2005**

Publication # 10018E
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Cat. No A-114-14/2005E-PDF
ISBN # 0-662-40399-1

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For further information on the Rural Dialogue, please call 1-888-781-2222 (toll-free number).

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1. FOREWORD

This report is a summary of discussions that took place at the Fetal Alcohol Spectrum Disorder in Rural Areas dialogue held in Victoria, British Columbia, on February 23, 2005. No limits were placed on the participants during discussions that took place in brainstorming sessions. In order to present a true report of the free-ranging discussions, recommendations made by participants that fall outside federal jurisdiction are also included. Views expressed do not necessarily represent those of the Government of Canada.

2. INTRODUCTION

This event was part of the Rural Dialogue, an ongoing, two-way discussion between the Government of Canada and Canadians from rural, remote and northern regions. Launched in 1998, the Rural Dialogue is a key citizen-engagement component of the Canadian Rural Partnership (CRP). The CRP is designed to support a horizontal approach to rural development within the Government of Canada that responds to rural, remote and northern priorities. The Dialogue process helps the Government of Canada to understand local and regional priorities, and provides rural, remote and northern citizens with an opportunity to influence government policies, programs and services that affect them.

There were 19 participants in attendance: 10 participants who work with Fetal Alcohol Spectrum Disorder (FASD) in rural areas and 9 Government of Canada representatives. During the event, representatives from the following departments provided an overview of their initiatives and resources: Human Resources and Skills Development Canada, Public Safety and Emergency Preparedness Canada (National Crime Prevention Centre) and Public Health Agency of Canada. (These are reported under section 5 of this report.) The participants also viewed "The Best Start in Life" video, and received a copy of this 11 minute long DVD as well as a workbook to help them hold meetings with youth on FASD.

The objectives of the event were:

- to share information on key initiatives undertaken, and discuss challenges and successes of communities in addressing FASD;
- to suggest ways governments and rural communities can work together to minimize future incidences of FASD and address its current impacts; and
- to learn about Government of Canada initiatives and resources available to help communities deal with FASD.

A number of the important issues that were raised during this event are linked to the following Government of Canada priorities identified in the February 2004 Speech From the Throne:

- improve access to health care professionals, expand home care and Pharmacare, and address the unique health needs of Aboriginals and the far north;
- improve the health status and living conditions (e.g. lifelong learning, better and more affordable housing, good jobs and clean water) of Aboriginals; and
- create an affordable nationwide program for early learning and childcare — a high-quality system open to all and geared towards development.

The results presented will help inform the Government of Canada on future actions, and will contribute to the proposed National Rural Framework (NRF) that will guide the actions of the federal, provincial and territorial governments. The over-arching goal of this federal-provincial-territorial collaborative effort is to ensure the long-term viability and sustainability of rural communities by creating an environment which will ensure that communities and citizens have access to social and economic opportunities.

The NRF is based on five policy areas that affect community sustainability. The issues and priorities discussed at this event are presented under the relevant policy area (section 4 of this report).

3. THE NATIONAL RURAL FRAMEWORK'S (NRF) FIVE POLICY AREAS

Sustainable Livelihoods

A range of activities, economic and social, that enable citizens to support themselves and their communities in the long-term and through changing circumstances.

Shared Environmental Stewardship

Recognition by governments and communities that all must share in the management, as well as share the benefits of our natural resources and healthy environment.

Smart Approaches to Infrastructure

Innovative, appropriate and effective means of planning, building, operating and maintaining physical, social and knowledge-based infrastructure that takes into consideration the rural context.

Engaged Population and Institutions

The active participation and collaboration of all citizens and their institutions in decisions that affect their community.

Demographic Adaptation

The ability of a community to accommodate, on an ongoing basis, the impacts or effects of changes in population, economics and services.

4. ISSUES RELATING TO THE NRF'S POLICY AREAS

The issues and priorities discussed at this event focussed on the following policy area: Smart Approaches to Infrastructure. Proposed actions and solutions that could address the issues discussed are also included in this section.

Smart Approaches to Infrastructure (Social Infrastructure)

The North Family Health Society of Prince George has started a program called “Structured for Success” that focuses on best practices with regards to working with parents in dealing with children affected by FASD. The Society works in a holistic fashion to provide treatment and services. One of the representatives from this society expressed that it was better to provide support through non-governmental organizations, like theirs, as some clients feel more comfortable not dealing with the government directly. The Society is also concentrating on participatory action research (targeting 13-19 year old girls/women at-risk) through the MIRRORS program - Mentoring Independence and Resilience. The program’s focus is on mentoring and adopting preventative measures using a holistic approach. They noted, however, that the transience of their clients presents a challenge in providing support. A “best practice” document is currently in development and will be posted on the Society’s Web site (<http://www.nfhs-pg.org>) once completed.

- Governments should increase funding to organizations providing support to rural Canadians facing FASD situations as sustainability of services is an issue.

A representative from the Fetal Alcohol Syndrome Circle in Victoria provided an overview of the organization and an update on various activities and projects. The activities of the Circle are carried out through five working subcommittees: Diagnosis; Whitecrow; Support to those with FASD; Prevention/High Risk Women; and Fundraising. The Circle, in partnership with the University of Victoria and the Vancouver Island Health Authority, is running a pilot diagnostic and support project to diagnose fifteen children, and then provides them help to access the appropriate services. A support project targeting at risk boys (13-16 years old) has just concluded, and planning is under way to hold the third annual Whitecrow family FASD camp on Victoria Island. It was noted that much work remains to be done on Victoria Island in terms of providing safe beds for pregnant women who are still active in their addictions.

- Governments should increase the core funding provided to organizations, especially those operating on a grant basis, to enable them to undertake fundraising activities to maintain FASD-related services and programs.

The New Caledonia College in Burns Lake offers an after school program for kids at-risk who can drop in to participate in activities and get snacks. Another program offered is the #1 Dads Program, which organizes sessions with dads and kids to talk about ways to deal with children affected by FASD. The College, through its programs, focuses on a continuum of support acknowledging that FASD is a life long disability requiring life long support.

The Okanagan FASD Initiatives, through four FASD teams, works on community development initiatives related to the prevention of FASD in areas of Salmon Arm, Vernon, Kelowna and Penticton. This group produced a video with kids in Kelowna and developed a “Telling our Stories” manual on living with FASD – no shame, no blame. It is actively working with Justice Canada and health agency partners in various communities. For instance, it is working with the National Crime Prevention Centre, the Royal Canadian Mounted Police (RCMP), and teachers on a restorative justice project. This group is also undertaking community asset mapping to address FASD issues using some funding provided the Public Health Agency of Canada.

The representative of the Okanagan FASD Initiatives indicated that the high cost and inconsistent curriculum of FASD educational courses offered by local colleges around British Columbia presents challenges.

- The provincial government should focus on both prevention of and support for FASD as it currently only focuses on prevention.
- Governments should develop standards for FASD courses to ensure all “experts” receive sufficient training, and ensure on the ground training (experience) is provided to those working with persons affected by FASD.
- Governments should provide ongoing funding to ensure the sustainability of FASD educational programming since this is an issue.

It was noted that issues of geographic isolation are being faced on the Queen Charlottes Islands since communities are distant from one another, and trust of outside organizations is also lacking. The representative from Old Masset Haida Health expressed that it was hard for the citizens on the Islands to establish relationships with doctors since there are no permanent ones, only some on locum. In addition there is limited access to RCMP officers, Community Health Nurses and Social Workers, and a lack of other resources since people tend to leave the Islands once they have obtained an education or acquired skills. It was also reported that the high birthrate and the three generations of FASD on the Islands has created challenging situations for health care providers. When examining FASD situations, drug addiction/problems (including access to drugs) - like the emerging crack addiction problem on the Charlottes - should also be considered.

A representative from the British Columbia Aboriginal Child Care Society (ACCS) provided an overview of the society and an update on its various activities and projects. ACCS is an independent charitable organization which received funding from Health Canada to carry out or undertake a number of projects and activities. AACS is currently undertaking an asset mapping exercise based on a community development approach which includes a healthy community approach to FASD. It is also providing training on FASD to health care providers to clarify FASD terminology and teach proven strategies for building positive relationships with children affected by FASD and creating environments that support learning. AACS holds parenting

workshops for parents affected by FASD in the areas of child development, guidance, health and nutrition. The Society also developed "The Best Start in Life" video, made by youth for youth, along with a workbook on how to organize a meeting of youth on FASD. Finally, it is currently developing a 3-day training workshop on FASD – support, roles, nutrition, asset mapping and sustainability. The AACS representative indicated that it would be hard for some people to attend the training, particularly teachers and child care workers who could not get substitutes to replace them.

Another group present at the dialogue was Whitecrow Village which travels to communities in Canada, and internationally, and brings together professionals, community agencies and families dealing with FASD. This group helps them form a common understanding and shared language, and works with communities and families to take on more responsibilities with the support from professionals. Whitecrow Village also offers an 8-day camp program for families affected by FASD that is unique as it provides theoretically framed practical experience - a necessity when working with the complexity of FASD. Through this program, knowledge of successful interventions, which are precedents in terms of identifying the necessary abilities of a community to address prevention, is provided. The young adults affected by FASD who work in this program have produced a video about it and themselves.

A number of important issues were raised by a representative of the Nanaimo FASD Working Group, which focuses on providing education and awareness of FASD to the community. She noted that people with an IQ of 70 and under are the responsibility of the British Columbia Ministry of Children and Family Development. Furthermore, she advised that the IQ level is a determinant of whether or not someone can receive services (with a 70 IQ level as the cut-off) which is a concern for children, youth and adults affected by FASD, their families and their communities. Assessment and diagnostic processes should be developed for adults with suspected FASD, both in and out of the legal system. Additionally, as many new courses on FASD are being developed and offered by various groups and colleges, coordination of these training providers could reduce duplication and provide standardization.

- The provincial government should provide services to children, young people and adults affected by FASD who have a functional ability under 70 but have an IQ above 70.

A representative from the Port Alberni Mental Health indicated that the group, consisting of three workers that provide services to 14 First Nation tribes, focuses on the need to create "safety in communities" and build "healthy communities". The group is currently examining possible linkages between residential school attendance or mental health to FASD. It was noted that First Nation communities in the Port Alberni region also face issues of geographic isolation as some are only accessible by boat. The limited travel services make it difficult for the citizens of these communities to obtain the necessities (e.g. food, etc.) and access basic services (e.g. doctors and other services).

5. PRESENTATIONS

During the dialogue, representatives from three federal government departments provided an overview of their initiatives and resources.

5.1 Human Resources and Skills Development Canada (HRSDC)

[Wendy Cheny, Federal Facilitator, National Homelessness Initiative, HRSDC]

- In the summer of 2003, the Government of Canada consulted communities on proposed ways in which the National Homelessness Initiative could become more actively involved in supporting FASD initiatives. An identified gap and area of common recommendation was to develop opportunities for front-line service providers to develop skills and knowledge of FASD. Such opportunities would enhance awareness and understanding, thereby enabling service providers to be better equipped to meet the needs of adults affected by FASD.
- The National Homelessness Secretariat, in partnership with Health Canada and the Department of Justice, has developed a train-the-trainer model in communities across Canada. Approximately 18 communities across the country will receive FASD training. Prince George and Kamloops, in British Columbia, and Whitehorse, in the Yukon, are some of the communities that have been selected to participate. The College of New Caledonia will provide the master training to the selected communities which should commence within the next few months. An update will be provided to participants once more information has been received and details about this pilot project will be posted on the National Homelessness Web site: <http://www.homelessness.gc.ca>.
- The overall objective of this approach is to assist in the development of a coordinated, sustainable system of FASD skills development and tools to support service providers in homelessness in an effort to build on their ability to provide appropriate services to adults affected by FASD.

[Janice Nelson (Social Policy Consultant), Susan Hollick Kenyon (Social Policy Consultant) and Michelle Barkley (Program Officer), HRSDC]

- The next edition of HRSDC's Social Policy Digest will focus on FASD. This Digest will be translated into French and will receive wide distribution inside and outside of the government. Information on courses related to FASD offered through the Justice Institute of British Columbia (<http://www.jibc.bc.ca>) was provided.
- Local HRSDC offices offer funding to individuals with disabilities through the Opportunities Fund. Also youth can be supported through Skills Link, one of the programs being offered through the Youth Employment Strategy (YES) which helps youth make a successful transition to the workplace. More information on these programs is available on HRSDC's Web site: <http://www.hrsdc.gc.ca/en/home.shtml>

5.2 Public Safety and Emergency Preparedness Canada (PSEPC)

[Shannon Gander, Program Officer, National Crime Prevention Centre (NCPC), PSEPC]

- The NCPC in British Columbia will be having a program intake (Call for Proposals) May 2, 2005 for community mobilization. The Centre will be providing a proposal writing workshop and training on a "logic model" for project evaluation. For more information, contact Shannon Gander (Shannon.Gander@psepc-sppcc.gc.ca)

5.3 Public Health Agency of Canada (PHAC)

[Christine Liu, A/Program Consultant - Children and Youth, PHAC]

- PHAC was formerly Health Canada's Population and Public Health Branch. For more information, visit the PHAC Web site: http://www.phac-aspc.gc.ca/new_e.html
- PHAC is doing follow up work on the dissemination of the results of a health professional survey. A report entitled "Knowledge and Attitudes of Health Professional about Fetal Alcohol Syndrome: Results of a National Survey" has been completed.
- PHAC has published a report in the Canadian Medical Association Journal (March 1, 2005) entitled "Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis". In addition, PHAC has published a FASD Fast Facts booklet that is available in print and pdf. http://www.phac-aspc.gc.ca/dca-dea/publications/fasd-etcaf/framework_e.html
- Regionally, PHAC has supported a number of programs to strengthen their FASD component, namely: the Aboriginal Head Start Program, the Canada Prenatal Nutrition Program, and the Community Action for Children Program. In addition, PHAC will be launching the "SMART Guide: Motivational Approaches Within the Stages of Change for Pregnant Women Who Use Alcohol: A Training Manual for Service Providers" at the British Columbia Early Childhood Development Provincial Conference (March 15-17, 2005) facilitated by Nancy Poole.

6. CONCLUSION AND NEXT STEPS

Information from the evaluations indicated that the participants were quite satisfied with the results of the event and that it exceeded expectations. People commented that the event could have been longer to offer more time for discussion and networking, and that having provincial representatives would have been helpful. Some participants also expressed that they wanted to continue to network after the event to exchange information on FASD on an ongoing basis and potentially work together on some of the issues discussed - such as developing consistent and credited college courses on FASD.

Participants indicated that maintaining contact with groups working on FASD in different parts of the province was difficult and that this dialogue was a good step in creating networking opportunities for them. The community and federal participants expressed interest in continuing the connection through conference calls and e-mails. Some also mentioned interest in including representatives of the provincial government and from Aboriginal communities in the group.

The Rural Secretariat's Regional Advisor for British Columbia committed to sharing the final report with various units of Human Resources and Skills Development Canada, with provincial representatives that work with FASD, and members of Rural Team British Columbia – a cross departmental group of federal and provincial representatives and non-governmental organizations.

The following summarizes the key issues raised by participants and recommendations suggested to address these.

- Ongoing funding should be provided to deliver services to people affected by FASD.
- There is a cost benefit advantage to providing comprehensive and ongoing support to persons affected by FASD. Programs that support them could ensure that those with suspected FASD, both in and out of the legal system, be treated with due fairness. These programs could also help prevent other social problems.
- Work should also be undertaken with community colleges to develop FASD courses that would be credited. Communication among the colleges would ensure there is no duplication and that credited FASD courses are standardized.
- Adults affected by FASD whose IQ is below 70 should receive support as none is currently provided. For instance, if parents manage to keep their children affected by FASD safe until they become adults and leave home, many still end up in the justice system, on the streets, etc.

ANNEX: POTENTIAL PARTNERS OF FASD PROJECTS

Below are contact names and coordinates of organizations/groups that could be potential partners in supporting FASD projects in their respective areas where First Nations will be served. Aboriginal Human Resource Development Agreements (AHRDAs), under Human Resources and Skills Development Canada's (HRSDC) Aboriginal Human Resources Strategy (AHRDS), have been signed with each organization/group. More information about the AHRDS is available on: http://www17.hrdc-drhc.gc.ca/AHRDSInternet/general/public/HomePage1_e.asp.

Aboriginal Human Resource Development Agreements – BC / YUKON			
AHRDA AREA	AHRDA HOLDER	ADDRESS	CONTACT
CARIBOO / CHILCOTIN c.buchan@ccatec.com	Cariboo-Chilcotin Aboriginal Training Education Centre Society	205-197 North Second Ave. Williams Lake, BC V2G 1Z5	Craig Buchan Tel.: (250) 392-2510 Fax: (250) 392-2570
CENTRAL COAST / FRASER VALLEY snhrd@stolonation.bc.ca (office) roy.mussell@stolonation.bc.ca	Sto:lo Nation Human Resource Development	Bldg.#8A - 7201 Vedder Rd Chilliwack, BC V2R 4G5	Roy Mussell Tel.: (604) 858-3691 Cell: (604) 819-7060 Fax: (604) 858-3528
CENTRAL INTERIOR david.lindley@cipahrd.org	Shuswap Nations Tribal Council Society	#304 - 355 Yellowhead Hwy. Kamloops, BC V2H 1H1	David Lindley Tel.: (250) 314-1564 (STEP) or Tel.: (250) 828-9789 (STEP) Fax: (250) 374-6331
NORTH AND WEST COAST VANCOUVER ISLAND bander@oberon.ark.com netb@nuuchahnulth.org George Speck [Satch@namgis.bc.ca]	North Island/Nuu-chah-nulth Tribal Councils Aboriginal Management Society	1400 B Drake Road Campbell River, BC V9W 7K6	Bob Andersen Tel.: (250) 286-3455 Fax: (250)286-3487 Jack Cook Tel.: (250) 724-5757 Fax: (250) 723-0463
NORTH EAST asam@nenas.org	North East Native Advancing Society	Box 6847 Fort St. John, BC V1J 4J3	Audrey Sam Tel.: (250) 785-0887 Fax: (250) 785-0876

Aboriginal Human Resource Development Agreements – BC / YUKON

AHRDA AREA	AHRDA HOLDER	ADDRESS	CONTACT
OKANAGAN / KOOTENAY d_conlin@otdc.shaw.ca kareneh@silk.net rnicholas@kktc.bc.ca	Okanagan/Ktunaxa Aboriginal Management Society	101 - 1865 Dilworth Drive Suite 339 Kelowna, BC V1Y 9T1	Karen Abramsen - Administrator Tel.: (250) 769-1977 / Fax: (250) 769-1866 Debbie Conlin Tel.: (250) 542-0045 / Fax: (250) 549-7175 Rosemary Nicholas (Cranbrook) Tel.: (250) 489-5762 / Fax: (250) 489-5760
PRINCE GEORGE / NECHAKO karinh@bcgroup.net	Prince George Nechako Aboriginal Employment and Training Association/Society	1591 4th Avenue Prince George, BC V2L 3K1	Karin Hunt Tel.: (250) 561-1199 Fax: (250) 561-1149
SKEENA cmedeek@monarch.net	Skeena Native Development Society	P.O. Box 418 Terrace, BC V8G 4B2	Clarence Nyce Tel.: (250) 635-1500 Fax: (250) 635-1414
SOUTH VANCOUVER ISLAND danny.henry@csets.com	Coast Salish Employment and Training Society	201 - 5462 Trans Canada Highway Duncan, BC V9L 6W4	Danny Henry - Executive Director Marie Thomas - Executive Secretary Henriette Charlie - Finance Manager Tel.: (250) 746-0183 Tel. (toll free): 1-888-811-3919 Fax: (250) 746-0189
VANCOUVER / SUNSHINE COAST	First Nations Employment Society	Suite 101 - 440 Cambie St. Vancouver, BC V6B 2N5	Sharon Bowcott - Manager Tel.: (604) 605-8901 Fax: (604) 605-8902
VANCOUVER URBAN AGREEMENT – ACCESS john@buildingfuturestoday.com	ACCESS (Aboriginal Community Career & Employment Services Society)	600 - 1190 Melville St. Vancouver, BC V6E 3W1	John Webster Tel.: (604) 685-7933 Terry Reles - Admin. Tel.: (604) 685-7933 Fax: (604) 685-7938

Aboriginal Human Resource Development Agreements – BC / YUKON			
AHRDA AREA	AHRDA HOLDER	ADDRESS	CONTACT
YUKON alfa@yknet.ca	Aboriginal Labour Force Alliance (Includes provision of service delivery for Metis)	P.O. Box 31028 Whitehorse, Yukon Y1A 5P7 F – 207 Tlingit Street	Norma Claggett Tel.: (867) 456-4348 Fax: (867) 456-4956
YUKON hrd@cyfn.net	Council of Yukon First Nations	11 Nisutlin Drive Whitehorse, Yukon Y1A 3S4	Cassandra Puckett Tel.: (867) 393-9238 Fax: (867) 668-6577

Metis Aboriginal Human Resource Development Agreements – BC			
AHRDA AREA	AHRDA HOLDER	ADDRESS	CONTACT
BC PROVINCIAL OFFICE jenmcdonald@telus.net	Metis Provincial Council of BC (For service delivery organizations in BC, contact Jennifer Macdonald)	Suite 1000 - 789 West Pender Street Vancouver, BC V6C 1H2	Harley Desjarlais - President Keith Henry - Executive Director Tel.: (604) 801-5853 Fax: (604) 801-5097 Jennifer Macdonald - Coordinator Tel.: (250) 592-1662 Fax: (250) 592-1664