



NWAC – FASD Action Plan 2010-2015

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**Joan Riggs
Catalyst Research and Communications
Ottawa**

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NWAC – FASD Future Work

A. Introduction

The Native Women's Association of Canada (NWAC) is a nationally representative political organization comprised of thirteen Provincial/Territorial Members Associations. NWAC is founded on the collective goal to enhance, promote and foster the social, economic, cultural and political well-being of First Nations and Métis women within First Nation and Canadian societies.

NWAC is strategically positioned to contribute a gendered perspective to emerging issues such as fetal alcohol spectrum disorder (FASD). The prevalence of FASD in First Nation communities and in the Aboriginal population in general is not well-documented or researched. In fact, there are only a few areas in Canada where isolated studies have been conducted to identify the incidences.

The Union of Ontario Indians compiled a number of statistics on FASD amongst First Nations people. Other topics such as alcohol related illnesses and youth sexuality are included as these impose as major risk factors that may contribute to FASD.

- In Canada, First Nations peoples and FAS have been estimated to affect to up to 120 in 1000 live births. (The national average for FAS is 2-3 in every 1000 live births.)
- 69% of Aboriginal Youth in custody reported having been told by a health professional that they had one or more health conditions or disabilities such as chronic anxiety, depression, addictions, ADD/ADHD, and other learning disabilities including those associated with FASD.
- 43% of Health Service Workers have felt that the frequent use of alcohol is a problem within the First Nation communities.
- 43% of First Nation's people were able to identify FAS as a contributing factor to learning disabilities.

As a national Aboriginal organization, whose constituency is the Aboriginal women of Canada; NWAC is deeply concerned for the health of this generation and for future generations to come. NWAC asserts that the unique situation of Aboriginal women in Canada requires an ongoing and focused dialogue that ensures and assures the participation of Aboriginal women and girls as the key informants.

NWAC over the last year, as part of its FASD project commissioned a research paper, conducted a meeting of experts, collaborated with NWAC internal experts, expanded NWAC's network of local service providers and others dealing with Aboriginal youth involved in sexual exploitation and gangs and developed a five year research plan. This report is the research plan that was part of the 2009-2010 FASD-NWAC project.

B. Working Assumptions in the Development of the Research Plan

1. FASD is a life long condition.
2. FASD often goes undiagnosed. However specific behaviours that are identified as disruptive to the individual, family and community can be in evidence and create confusion and stress for the child, mother and family.
3. Fetal Alcohol Spectrum Disorder will not end if women are blamed or shamed in order to stop their alcohol consumption during pregnancy. It is important that prevention programs address why women are drinking during pregnancy and not stigmatize women who do drink.
4. While prevention programs are often focused on women not drinking during their pregnancy, the programs must be developed in a way that engages family and community. Women are interconnected to their social environment.
5. Although prevention programs are a key part of the overall strategy, there will continue to be children born with FASD. FASD is a life-long condition and has no cure. Children and people with FASD may have life-long needs that require specific supports and services.
6. There currently exist some programs in Aboriginal and urban communities that are working to support people with FASD and to ensure that children are diagnosed and supported as early as possible. There are many Aboriginal families who are raising their FAS children with little outside support but are effectively parenting without additional information or supports. There is not a comprehensive approach to supporting individuals with FASD and families throughout their life journey.
7. There are a number of connections between FASD and other social conditions that have not been fully explored but there is anecdotal information to indicate possible links between FASD and other social issues (sex trade, gangs, violence in their relationships) that Aboriginal women are facing. There needs to be further work done in addressing the social determinants that may cause or aggravate the experiences of FASD (e.g. housing, income, access to quality health care, knowledge of culture and education).

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe a range of disabilities that may affect individuals whose mothers drank alcohol while they were pregnant. The umbrella term covers several alcohol related medical diagnoses, which include Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS), alcohol related neuro-developmental disorder (ARND) and alcohol related birth defects (ARBD). (from Alberta FASD 10 year Strategic Plan)

C. How NWAC arrived at the NWAC-FASD Research Plan

The original goal of the 2009-2010 NWAC-FASD project was to develop a research plan that would detail how to best expose the linkages between FASD and disturbing phenomenon occurring in the Aboriginal community: sexual exploitation, gang activity and potentially missing and murdered Aboriginal women. The long-term goal was intended to encourage support for the early detection of FASD and ultimately break the cycle within the Aboriginal population.

As the project unfolded, the research plan expanded beyond both the original short and long-term goals.

The 2009-2010 Work

In the last year, NWAC undertook a number of specific initiatives to focus its work related to FASD. The work that has been done includes:

- A research project completed by Mark Totten and entitled, "Investigating the Linkages between FASD, Gangs, Sexual Exploitation and Women Abuse in the Canadian Aboriginal Population: A Preliminary Study."
- A meeting of experts in October of 2009 and a subsequent report, entitled "Fetal Alcohol Spectrum Disorder Meeting of Experts: Exploring the Linkages between FASD, sexual exploitation, gangs and Aboriginal women and girls."
- A meeting in February of 2010 of NWAC staff, board members and other Aboriginal organizations to discuss the work that needs to be done in the area of FASD.
- A meeting of NWAC staff to review the results of the above work to identify research directions that NWAC could focus on.

The meetings resulted in the identification of 25 distinct research questions. (see Section C below) The research questions can be organized under four key focus areas.

Four Focus Areas

Each of the four areas of focus have different outcomes:

Focus	Area to focus on	Outcomes
Prevention: Respectful, community and culturally based education and support services for individuals, families and communities. This includes public awareness-building, supportive education with women of child-bearing age, non-judgmental support services for women dealing with addictions during pregnancy, and supporting mothers to make healthy choices during	<u>Prevention programs</u> for youth, women and men before pregnancy. (e.g. family planning, pre-pregnancy programs and programs for addictions)	Decrease in the number of children experiencing/born with FASD. Increase in the awareness of the impact of alcohol consumption during pregnancy.

the early years of their child's life.		
Life Pathways: Providing an array of supports and services that recognize that FASD is a life-long challenge, and may be inter-generational. Each individual and family will have unique needs and these will change over the stages of their lifecycle, from infant to child to youth and then again when they become adults, as workers and parents themselves.	Supporting people who have FASD throughout their <u>life pathways</u> . (e.g. family supports, different education models)	Increase in the number of community and culturally based programs and services to support people with FASD and their families through their life journey. Decrease in the stigma associated with an FASD diagnosis.
Social determinants: Income, education, food security, unemployment, racism, social exclusion, and other factors are key determinants of health and well-being. Depending on whether these factors are present in positive or negative way in a person's life (e.g. whether one is rich or poor), they can either worsen the impact of FASD, or help a person more effectively manage with FASD.	Addressing <u>social determinant</u> issues that may cause and aggravate the experience of having FASD. (e.g. housing, income, access to quality health care, knowledge and access to culture; education)	Improvements in social determinant factors.
Systemic issues: Aboriginal women face systemic barriers and pressures that can push them into dangerous, violent and destructive life situations.	Addressing <u>systemic issues</u> that result in women with FASD ending up in dangerous and destructive life paths. (e.g. the connections between FASD, women abuse, sexual exploitation and gangs)	Decrease the number of women with FASD in these situations. (e.g. in gangs, being sexually exploited, experiencing abuse in their relationships)

D. Potential Research Questions to consider

The consultations produced an extensive list of research questions that could be pursued by NWAC. They are organized below based on the four focus areas:

1. Prevention

"An action oriented response is required, onset beginning in the family-planning stage of life (prior to FASD being an issue)." (Fetal Alcohol Spectrum Disorder Meeting of Experts Report, October, 2009)

1. What strategies are communities using to prevent FASD children when there are little resources, programs or supports in place?

2. Life Pathways

"Persons with an FASD diagnosis have specific characteristics that generate unique challenges and vulnerabilities, and require life-long intervention programs and services." (Fetal Alcohol Spectrum Disorder Meeting of Experts Report, October, 2009)

Models of Care and Programming

2. What are some alternative models of care and support to families (from birth onwards)?
3. What is the experience of women who give birth to FASD babies? What options are available to them immediately? (follow their life journeys)
4. How and when are children being diagnosed in communities? When they are diagnosed what are the immediate supports offered to mothers, children and families?
5. How can attachment be created when the mother is not ready? What are cultural-based alternatives and how can they be supported? (Grandparents, Aunties, kinship programs, etc.)
6. What needs to be in place so that mothers can be engaged in supporting their child and themselves when there is so much stigma and risk in them disclosing? How can they safely disclose when they have an active addiction?
7. What are the best practices in FASD interventions for Aboriginal people?
8. How is culture and Aboriginal identity being incorporated into service and program responses?
9. Do children with developmental delays and other disabilities follow a similar life-path as people with FASD?

3. Social determinants

Research is needed that focuses on "increasing awareness and prevention of vulnerabilities to sexual exploitation and gang involvement for children and youth with an FASD diagnosis....research specific to the Aboriginal population was lacking when the issue of FASD was combined with sexual exploitation and gangs, as well as with other variables, such as the social determinants of health." (Fetal Alcohol Spectrum Disorder Meeting of Experts Report, October, 2009)

Linking FASD, Gangs, Sexual Violence and other forms of violence

10. What is the link between FASD, gangs, sexual violence and extreme violence?
11. What are the connections between the missing and murdered women identified through Sisters in Spirit and FASD?

12. What is the connection between FASD and young men who are involved in sexual exploitation and trafficking?
13. What interventions are needed for boys who are pimping? Trafficking?
14. Is there a connection between bullying in the school and FASD? Is there a connection between bullying and joining gangs?
15. What is the link between FASD and suicide?

Aboriginal Youth in Gangs

16. How can children and youth be transitioned out of gangs?
17. What is the experience of Aboriginal girls in Gangs?
18. How can Aboriginal girls safely exit gangs?

Trafficking

19. What is the story of trafficking of Aboriginal girls and women in Canada?

4. Systemic Picture

"As one individual commented, FASD is no longer a singular issue, it is now cyclical – intergenerational fetal exposure to alcohol, where young women with FASD are now having children with FASD, and further contributes to the high number of Aboriginal children in the child welfare and justice system." (Fetal Alcohol Spectrum Disorder Meeting of Experts Report, October, 2009)

20. What is the economic cost of not dealing with FASD using:
 - a. the current approach;
 - b. a community-based/cultural-based approach;
 - c. a socio-determinants of health approach.
21. Provide an overview. Give a more complete picture of the FASD story in Aboriginal communities: the number of children diagnosed compared to the total population. The different experiences of these children; the services available to children and families. The different strategies that communities and families use.
22. What systems (health care, CAS, social services, housing, etc) currently are working with families that are dealing with FASD? What are the linkages between those systems? How do they support the family or aggravate the situation?
23. What are communities doing that have low incidences of FASD and low incidences of gang related activity? Are there specific social structures and community systems that need to be in place to achieve this?
24. How does popular culture impact on FASD children?
25. What do we learn when a gender lens is applied to FASD in Aboriginal communities?

E. The 2010-2015 NWAC – FASD Research Plan

The NWAC staff in reviewing the research questions and identified key focuses for the initial research plan. In developing the research plan, a number of criteria applied:

- The research will build on the existing work that NWAC is doing;

- The research can be integrated into other work being done within NWAC in other portfolios (to emphasize the interconnection between FASD and other issues); and
- The research responds to areas identified through the Experts meeting and internal consultation.

The five objectives all have either specific research activities or activities that will facilitate stakeholders being engaged and using the research in the future.

Objective 1: Develop knowledge on the experience of FASD and Aboriginal women and families.

Rationale: While there is a lack of comparable data on the use of alcohol and tobacco by mothers of young Aboriginal children compared to mothers of non-Aboriginal children, anecdotal evidence suggests that it is an issue. The use of alcohol by pregnant mothers is believed to pose a significant challenge in some Aboriginal communities. Based on scattered local and regional surveys, the incidence of fetal alcohol syndrome and effects (FAS/FAE) is believed to be much higher among Aboriginal children than among non-Aboriginal children, although no definitive statistics are available.

Thousands of children have been affected by pre-natal alcohol exposure. In Canada, First Nations peoples and FAS have been estimated to affect to up to 120 in 1000 live births. (The national average for FAS is 2-3 in every 1000 live births.)

The loss in human potential is immeasurable. The financial cost is formidable. Each child affected by FASD may require an estimated \$1 million to \$2 million over the course of their lifetime to support remedial medical, educational and social costs.

Actions:

- a) Research on "What is the economic cost of not dealing with FASD?", including:
- the current approaches (strengths and limitations);
 - existing and proposed community-based/cultural-based model and approaches; and
 - existing and proposed social-determinants of health models.

- b) Research on "What is the complete picture of FASD in Aboriginal communities?"

The story would include:

- What is the number of Aboriginal children diagnosed compared to the total population?
- What are the different experiences of Aboriginal children with FASD?
- What is the experience of women who give birth to FASD babies? What options are available to them immediately? (follow their life journeys)
- What services are currently available to children and families? How secure is that programming (are they pilot projects or long-term investments in the community)? What are the strengths and weaknesses of the current programs?
- What are the different strategies that communities and families are using to support FASD children and adults and families who have FASD members?

Objective 2: Increase the capacity of workers, policy makers and researchers working in the area of FASD to make connections between FASD and other life situations and conditions.

Rationale: A range of secondary disabilities associated with FASD have been identified including mental health problems, drug/alcohol addictions, disrupted school experience, joblessness and homelessness, and involvement with the law (Streissguth & Kanter, 1997). However, the full lifetime extent of the health and other problems experienced by those affected by FASD is difficult to estimate and requires a flexible and co-ordinated response by service providers.

Actions:

- a) Coordinate meetings that would bring together experts from disparate fields to promote collaboration on FASD issues.

- b) Expand NWAC's network of local service providers, and others, dealing with Aboriginal youth involved in sexual exploitation and gangs. (see Appendix A for a preliminary list of organizations)

Objective 3: Increase the knowledge of policy makers and program deliverers on the appropriate programs to support mothers who have children with FASD.

Rationale: Without clear prevalence and incidence data, determining current and future resourcing implications remains extremely difficult.

Actions:

- a) Conduct a research project that would explore specific ways to support mothers and families to be the most effective parent with an FASD child.

Objective 4: Increase FASD awareness and prevention among Aboriginal women, youth and young girls.

Rationale: Women who receive inadequate prenatal care and nutrition are three times more likely to have low-birth weight babies and to experience birth complications which may lead to chronic conditions or disability for the child.

The western approach to FASD is to isolate the mother from behaviour that might present risk to the unborn child. A traditional approach would see each member of the family undertaking roles to ensure healthy prenatal care is provided for the new addition to the family. This means that father's responsibilities in abstaining from alcohol and drugs are just as important as mothers.

Actions:

- a) Conduct a research project that would identify effective prevention programs for youth, women and men before pregnancy (e.g. family planning, pre-pregnancy programs and programs for addictions), and effective social policies that would contribute to reduced incidence of FASD.

Objective 5: Integrate the issue of FASD into the other work of NWAC.

Rationale: This will further strengthen the capacity of NWAC to integrate its key work on FASD into the different funding files.

Actions:

Research Questions that could be done by other parts of NWAC

Research Question	Proposed NWAC Program Integration	NWAC -FASD Position
a) How can attachment be created when the mother is not ready? What are cultural-based alternatives and how can they be supported? (Grandparents, Aunties, kinship programs, etc.)	Maternal Child Health	Coordinate with the Mothering-FASD Research Project (Objective 3)
b) What is the link between FASD and suicide?	NAYSPS	Coordinate knowledge transfer amongst FASD experts and the suicide prevent field (Objective 3)
c) There were a number of key areas that could be integrated into Sisters and Spirit including: <ul style="list-style-type: none">• Connection to FASD and men that are in jail for violent crimes against Aboriginal women.• Connection to FASD and the missing and murdered women.	Sisters in Spirit	Support the work that is being done through Sisters in Spirit as needed.

F. The Longer Term Outcome

The research plan has five objectives.

1. Develop knowledge on the experience of FASD and Aboriginal women and families.
2. Increase the capacity of workers, policy makers and researchers working in the area of FASD to make connections between FASD and other life situations and conditions.
3. Increase the knowledge of policy makers and program deliverers on the appropriate programs to support mothers who have children with FASD.
4. Increase FASD awareness and prevention among Aboriginal women, youth and young girls.
5. Integrate the issue of FASD into the other work of NWAC.

All of the five identified objectives will lead to a longer-term outcome that NWAC is interested in pursuing - the complete reframing of the concept of FASD so that it is no longer an isolated diagnosis but rather part of an integrated understanding of mental health.

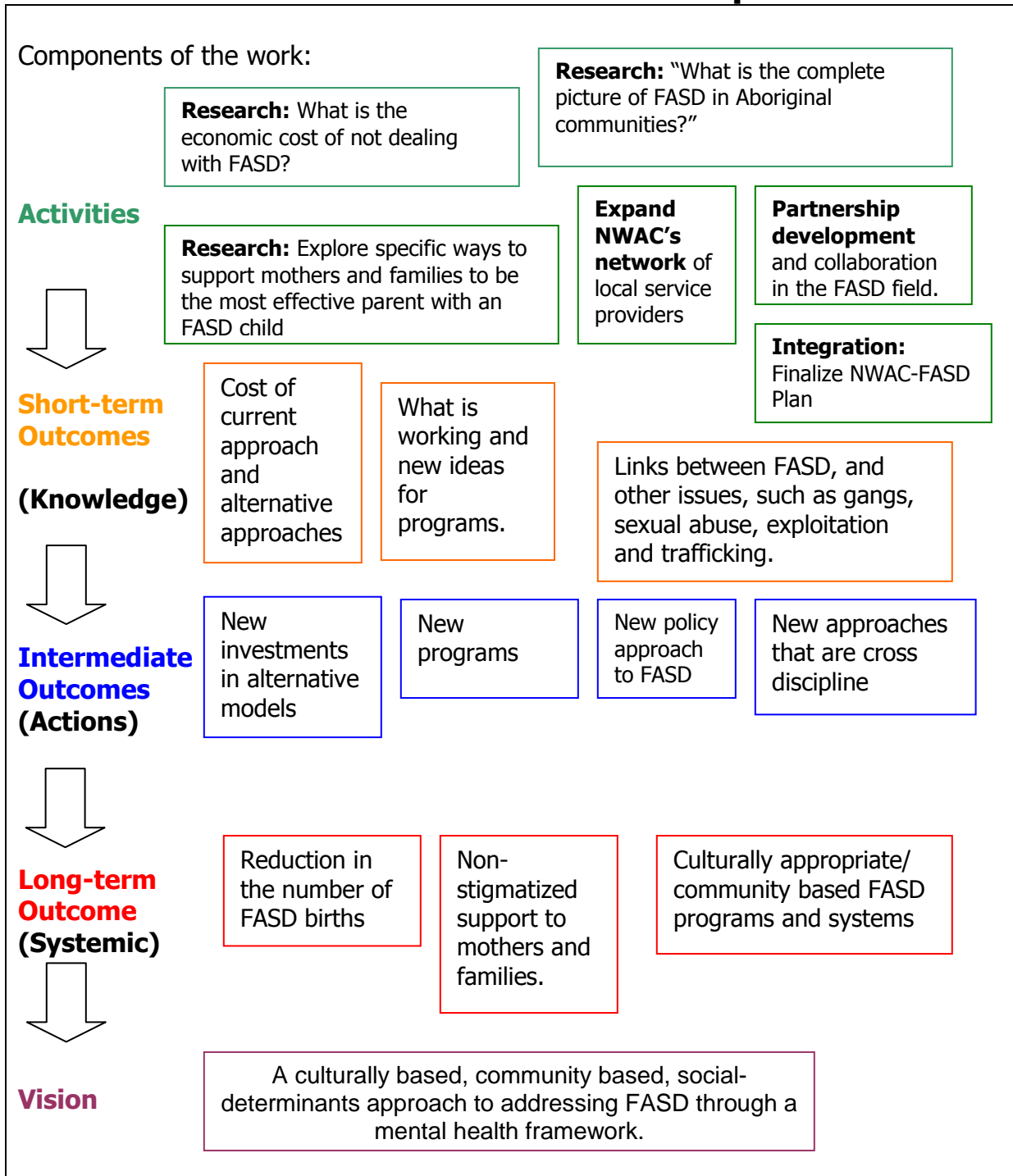
A wholistic understanding of mental health reflects cultural values, traditional teachings and facilitates the affirming of an Aboriginal identity that is not based on a diagnosis or ordained identity. By conceptualizing policy and programs through a lens of promoting and maintaining mental health than the diagnosis of FASD or trauma or another type of head injury becomes secondary to the issue of what will support this child and their family to experience mental health. This approach can allow families to talk about needs and supports without stigmatization. It also facilitates a rethinking of prevention to include investments in families and communities to address specific social determinants that lead to high alcohol consumption.

Some of the research being proposed in this five-year action plan is intended to support this longer-term outcome.

G. The Outcome Road Map

The outcome road map provides a summary of the outcome intended for each research initiative. See Appendix B for a description of the different types of outcomes.

The NWAC- FASD Road Map



H. NWAC-FASD Action Plan 2010 – 2015

Long-Term Outcome for All Activities		Complete reframing of the concept of FASD so that it is no longer an isolated diagnosis but rather part of an integrated understanding of mental health	
Objective	Activities	Short-Term Outcomes	Short-Term Indicators
1: Develop knowledge on the experience of FASD and Aboriginal women and families.	1. Refine the action plan and select key areas for implementation in the first year, for recommendation to NWAC Health Advisory Committee.		Revised, more detailed Action Plan adopted by NWAC
	<p>2. Conduct research on "What is the economic cost of not dealing with FASD?"</p> <p>a) Define specific scope of elements to be researched, including</p> <ul style="list-style-type: none"> • the current approaches (strengths and limitations); • existing and proposed community-based/cultural-based model and approaches; and • existing and proposed social-determinants of health models. <p>b) Select researcher(s) and undertake the work.</p> <p>c) Analyze results and develop action plan / recommendations. (e.g. through stakeholder gathering)</p> <p>d) Produce report, factsheets, or other products to disseminate the results of the research.</p> <p>e) Meet with NAOs, federal government, provinces, health organizations, and others to promote the implementation of recommendations arising from the research.</p> <p>f) Develop community-based materials, models and tools to encourage the implementation of recommendations arising from the research.</p> <p>g) Disseminate materials to practitioners and decision-makers at community, PTO, NAO, provincial and federal levels (presentations at conferences, joint meetings, electronic distribution, website, etc.)</p>	<p>Improved understanding of the economic cost of FASD being born by families, communities, governments and others.</p> <p>Communities, practitioners, First Nations governments, etc. are aware of new models and approaches</p> <p>Initial implementation of new approaches at community, provincial or national level</p>	<p>Materials produced and distributed</p> <p>Communities and practitioners starting to use materials</p> <p>Meetings with federal government, community decision-makers, etc.</p> <p>Positive feedback from practitioners and decision-makers</p> <p>Case studies of communities that implement new approaches</p>
	3. Conduct research on "What is the complete picture of FASD in Aboriginal communities?"	Improved understanding	Materials produced and

	<p>a) Define the scope of the research, including:</p> <ul style="list-style-type: none"> • What is the number of Aboriginal children diagnosed compared to the total population? • What are the different experiences of Aboriginal children with FASD? • What is the experience of women who give birth to FASD babies? What options are available to them immediately? (follow their life journeys) • What services are currently available to children and families? How secure is that programming (are they pilot projects or long-term investments in the community)? What are the strengths and weaknesses of the current programs? • What are the different strategies that communities and families are using to support FASD children and adults and families who have FASD members? <p>b) Select researcher(s) and undertake the work.</p> <p>c) Analyze results and develop action plan / recommendations. (e.g. through stakeholder gathering)</p> <p>d) Produce videos, stories, factsheets, report or other products to disseminate the results of the research.</p> <p>e) Meet with NAOs, federal government, provinces, health organizations, and others to promote the implementation of recommendations arising from the research.</p> <p>f) Develop community-based materials, models and tools to encourage community service providers to implement of recommendations arising from the research.</p>	<p>by service providers, governments and others of the reality of FASD for Aboriginal children and families.</p> <p>Communities, practitioners, First Nations governments, etc. are aware of new models and approaches</p> <p>Initial implementation of new approaches at community, provincial or national level</p>	<p>distributed</p> <p>Communities and practitioners starting to use materials</p> <p>Meetings with federal government, community decision-makers, etc.</p> <p>Positive feedback from practitioners and decision-makers</p> <p>Case studies of communities that implement new approaches</p>
<p>2: Increase the capacity of workers, policy makers and researchers working in the area of FASD to make connections between FASD and other life situations and conditions.</p>	<p>1. Refine the action plan and select key areas for implementation in the first year, for recommendation to NWAC Health Advisory Committee.</p>		<p>Revised, more detailed Action Plan adopted by NWAC</p>
	<p>2. Undertake efforts in partnership development and collaboration within the FASD field.</p> <p>a) Coordinate meetings that would bring together experts from disparate fields who would have an interest and see a relevance to exploring FASD. (e.g. continue the linkages between FASD,</p>	<p>New links, models or approaches emerge from</p>	<p>Report or other product from meetings</p>

	<p>sexual exploitation, gangs and Aboriginal women and girls).</p> <p>b) Produce report, presentations, article or other product to capture the results of the meeting and any new approaches or ideas emerging from it</p> <p>c) Coordinate meeting that would bring together experts on FASD and Suicide Prevention.</p> <p>d) Produce report, presentations, article or other product to capture the results of the meeting and any new approaches or ideas emerging from it</p>	<p>collaboration</p> <p>Connections are made between experts in different fields related to FASD</p>	<p>Feedback from participants about new connections and knowledge</p>
	<p>3. Expand NWAC's network of local service providers, and others, dealing with Aboriginal youth involved in sexual exploitation and gangs.</p> <p>a) Based on research that has been done, provide information to local service providers on how to make connections and build partnerships between their programs and other potentially related programs.</p> <ul style="list-style-type: none"> • Develop materials on the relationship between sexual exploitation and gangs in a format that is useful for service providers • Provide suggestions for possible program collaboration and linkages, and good practices for building partnerships • Disseminate and promote the materials through workshops, webinars, website, conferences of related service sectors, etc. <p>b) Maintain and expand NWAC's network of experts, local service providers and Aboriginal and other organizations working on issues of sexual exploitation and gangs.</p> <ul style="list-style-type: none"> • Produce newsletter or other regular updates on research, practices, partnerships, etc. • Convene working sessions, seminars and other gatherings to present research findings, exchange expertise, promote effective practices and develop alternative approaches • Seek out new contacts in various sectors to bring additional perspectives (e.g. attend conferences, stay up to date on new research, etc.) <p>c) Collaborate with the Canadian Association of</p>	<p>New connections made among programs</p> <p>New knowledge on sexual exploitation and gangs provided to workers in a range of sectors</p> <p>Larger network of NWAC contacts</p> <p>Contacts prove useful to NWAC in providing information, advice, ideas or new contacts</p> <p>New knowledge on sexual exploitation and gangs shared</p>	<p>Feedback from local service providers about new connections and new knowledge</p> <p>Number of contacts in NWAC data base</p> <p>Number of new connections among contacts</p> <p>New ideas from contacts</p> <p>Feedback from service providers and others</p>

	Occupational Therapists to work with Aboriginal women in prison to understand the dynamics of sexual exploitation and gangs from their perspective, and identify actions and supports which may be of use to women. Document their perspectives and the resulting recommended actions for service providers and others, and share these results.	with service providers and others	
3: Increase the knowledge of policy makers and program deliverers on the appropriate programs to support mothers who have children with FASD.	1. Refine the action plan and select key areas for implementation in the first year, for recommendation to NWAC Health Advisory Committee.		Revised, more detailed Action Plan adopted by NWAC
	<p>2. Conduct a research project that would explore specific ways to support mothers and families to be the most effective parent with an FASD child.</p> <p>a) Define the scope of the research. Some of the questions to explore would include:</p> <ul style="list-style-type: none"> • What are the existing and alternative models of care and support to families (from birth onwards)? • What needs to be in place so that mothers can be engaged in supporting their child and themselves when there is so much stigma and risk in them disclosing? • How can mothers safely disclose when they have an active addiction? <p>b) Select researcher(s) and undertake the work.</p> <p>c) Analyze results and develop action plan / recommendations. (e.g. through stakeholder gathering)</p> <p>d) Produce videos, stories, factsheets, report or other products to disseminate the results of the research.</p> <p>e) Meet with NAOs, PTOs, federal government, provinces, health organizations, and others to promote the implementation of recommendations arising from the research.</p> <p>f) Develop community-based materials, models and tools to encourage community service providers to implement approaches arising from the research.</p>	<p>Improved understanding by service providers, governments and others of the reality of FASD for Aboriginal children and families.</p> <p>Communities, practitioners, First Nations governments, etc. are aware of new models and approaches</p> <p>Initial implementation of new approaches at community, provincial or national level</p>	<p>Materials produced and distributed</p> <p>Communities and practitioners starting to use materials</p> <p>Meetings with federal government, community decision-makers, etc.</p> <p>Positive feedback from practitioners and decision-makers</p> <p>Case studies of communities that implement new approaches</p>
4. Increase FASD awareness and prevention among Aboriginal women,	1. Refine the action plan and select key areas for implementation in the first year, for recommendation to NWAC Health Advisory Committee.		Revised, more detailed Action Plan adopted by NWAC

youth and young girls.			
	<p>2. Conduct a research project that would identify effective prevention programs for youth, women and men before pregnancy (e.g. family planning, pre-pregnancy programs and programs for addictions), and effective social policies that would contribute to reduced incidence of FASD.</p> <p>a) Define the scope of the research.</p> <p>b) Select researcher(s) and undertake the work.</p> <p>c) Analyze results and develop action plan / recommendations. (e.g. through stakeholder gathering)</p> <p>d) Produce videos, stories, factsheets, report or other products to disseminate the results of the research.</p> <p>e) Meet with NAOs, PTOs, federal government, provinces, health organizations, and others to promote the implementation of recommendations arising from the research.</p> <p>f) Develop community-based materials, models and tools to encourage community service providers to implement approaches arising from the research.</p>	<p>Improved understanding by service providers, governments and others of effective prevention programs and measures.</p> <p>Communities, practitioners, First Nations governments, etc. are aware of effective prevention approaches</p> <p>Implementation at community, provincial or national level of some of the prevention approaches promoted by NWAC</p>	<p>Materials produced and distributed</p> <p>Communities and practitioners starting to use materials</p> <p>Meetings with federal government, community decision-makers, etc.</p> <p>Positive feedback from practitioners and decision-makers</p> <p>Case studies of communities that implement recommend-ed approaches</p>
5: Integrate the issue of FASD into the other work of NWAC.	<p>1. Finalize and refine the NWAC FASD Research Plan developed during the 2009-10 fiscal period.</p> <p>2. Move forward on the NWAC FASD Research Plan through incorporating select research initiatives into NWAC work.</p>	<p>Research by other sections in NWAC leads to action on FASD in other fields</p>	<p>Policy recommendations, reports, tools, workshops or other products indicating action on FASD</p>

I. An Aboriginal process of doing research in NWAC

NWAC, through the work of Sister in Spirit (SIS), has developed a respectful and effective approach to doing research in Aboriginal communities. The research that would be undertaken in this Research Plan would be consistent with the approach outlined in the Sister in Spirit Research Framework: "Reflecting on Methodology & Process"

Some of the key elements of the research approach would include:

1. Participatory research.
2. Use of in-depth interviews and storytelling.
3. Action oriented focus for the use of the research.
4. Aboriginal people are involved in the design, delivery and outcome processes of the research programs and initiatives.

A key teaching that informs the approach to addressing FASD is that everything is interconnected. "The NWAC Health Department operates a cohesive unit, recognizing the inter-connections of health issues to the social determinants of health and utilizing a culturally relevant gendered approach in its work." (from the October, 2009 report) This applies in four specific ways to the work that NWAC is proposing:

1. Research must include the historical context of colonization and intergenerational trauma, and identification of strengths and resiliency of Aboriginal community.
2. Work on FASD need not be done in isolation. The nature of FASD is that it is connected to the social determinants of health. As such the connections to FASD and other issues, and the connections between FASD workers and other workers need to be better understood. Workers in the helping professions who do not have a sound understanding of FASD cannot properly assess what family members may need as supplementary supports.
3. Work can begin at any point within the family with a clear intent to strengthen the family to support all family members. Regardless of where the intervention starts (with the child being diagnosed, the infant being nurtured in appropriate ways, the parent being supported to parent in a new way or the community being supported to engage with and support a family with an FASD child) it will have an impact on the other parts of the circle.
4. Work within NWAC is interconnected. There is value in having other files working collaboratively with the designated resources to FASD. This is especially relevant given that the FASD portfolio at NWAC is currently under-funded.

J. Next Steps

In this first year, and as part of the actions committed to for 2010-2011, NWAC would refine this Research Action Plan. The steps will include:

- costing out all of the proposed action steps;
- presenting to the NWAC Health Advisory Committee, who would determine the overall research direction and final research projects;
- engage the NWAC decision making process to identify which work plan (or combination thereof) will be implemented over the next five years;
- develop an organizational process to annually review the direction of the research. While the research questions have been proposed for the five-year plan, it may change through the internal approval process or more compelling and urgent research questions will arise throughout the five years.

Appendix A

Initial List of Service Providers

NNADAP Treatment Centres and provincial groupings, e.g. Association of BC First Nations Treatment Programs

Friendship Centres

Urban Aboriginal Health Centres (e.g. Aboriginal Health Access Centres in Ontario, Vancouver Native Health Society, Aboriginal Health and Wellness Center in Winnipeg, etc.)

Community Health Centres and Health Clinics, especially in communities with a significant Aboriginal population

FASD Diagnostic Centres

Disability organizations (e.g. BC Aboriginal Network on Disability)

Key Worker Parent Support Agencies (FASD support program in BC)

Research bodies (e.g. Institute for Aboriginal Health at UBC, Centre for Aboriginal Health Research at U of Manitoba)

Health programs in First Nations communities (e.g. Maternal and Child Health, Substance Abuse, Counselling / Mental Health services, etc.)

Appendix B

OUTCOMES

The Road map applied an outcome-based approach to identify the key outcomes that the NWAC research and actions are intended to accomplish. The table below provides examples of types of outcomes that can be accomplished.

Short-term outcomes are focused on people learning something new. The change is the acquisition of new knowledge or awareness of an issue. The focus on research in the Action plan is focused primarily on short-term outcomes.

Mid term or intermediate outcomes are intended to change institutions or people's actions through a change in behaviour or institutional practice.

A long-term outcome involves a change in systemic conditions and often has a much longer time frame.

SHORT <i>Learning</i>	INTERMEDIATE <i>Action</i>	LONG-TERM <i>Conditions</i>
Awareness Knowledge Attitudes Skills Opinion Aspirations Motivation	Behaviour Practice Decisions Policies Social action	Social-Cultural Economic Political Environment