Taking Action: Thinking out of the Box -An Action Plan on Maternal-Infant Care for Aboriginal families

Submitted by:

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INTRODUCTION

CULTURAL PERSPECTIVES:

Since time immemorial, women in Aboriginal communities have brought forth new life in the environment of most comfort to them, with the attendance of female family members, midwives and members of their communities. The act of childbirth was very much a community event which inspired individuals to Give Thanks to the Creator of all living things: Sonkwyadih:sonh – The Great Mystery, for the miracle of life itself.

The peaceful entrance of a new being into the physical realm of existence substantiates the delicate balance that exists between the Spiritual and Physical planes of existence. Birth begins the circle of life that is completed with the exit from this realm that is known as death, at which time our Spirits return to the Spirit world from whence we came.

In many Aboriginal communities, children were observed at play, and chosen for their roles in adulthood, and groomed for those roles from an early age. As a girl child matured, she was told of the significance of taking care of the waters, lakes and streams, which are the 'blood' of Mother Earth, and of Mother Earth, from which all plant life emerges. She was taught how to respect the plant life, which includes grasses, trees, flowers, food and medicines. She learned which plants were beneficial, and how to care for herself with the gifts that the Creator provided. When she became a woman and she was visited by her Grandmother Moon for the first time, this was a special occasion to be celebrated. Ceremonial rites were often conducted and the young woman was instructed on her changing role, and how to care for herself, her husband-to-be and the children she would bring forth, who would be loaned to her from the Creator. These teachings were often repeated when a couple were joined together in marriage, and when a woman became heavy with child. She was reminded of what she should and should not do during her pregnancy to ensure a safe and healthy pregnancy, an uneventful delivery and a healthy baby. Hence, the teaching of health promotion and pre-natal care, beginning long before a child was even conceived.

From this perspective, Aboriginal women have always held a keen sense of well-being, and healing, and have been at the forefront of health for their families, while maintaining cultural awareness, and ensuring that traditional teachings are passed on to the next generation. This cultural awareness connects the healthy parts of the past, despite historical challenges, and connects them to the present, and gives direction for continuation into the future. Traditional healers, midwives and traditional forms of healing are vital to the health of Aboriginal families, for this and future generations whose faces cannot yet be seen. Our stories, ceremonies and traditions help us to keep our connections to the past. As old practices are revitalized and integrated with modern knowledge, and communities become aware, Aboriginal families become stronger and promote health, healing and well-being through ownership of health status, from the very beginning.

Traditional ceremonies, such as the Sweat Lodge Ceremony, Talking Circles, Smudging, Medicine Ceremonies, Coming of Age Ceremonies, Women's Full Moon Ceremonies, Birthing Ceremonies, Memorial Feasts and Spirit Camps reinforce and strengthen the family and community. These healing practices and sacred activities have occurred since time immemorial. These teachings have been passed on from generation to generation of medicine keepers in an organized way so that these practices might continue to treat, and prevent physical and psychological imbalances. Traditional ceremonies contribute to the healing of individuals and families and reaffirm the norms of the entire participating community, and carry on the training and practice of the traditional healing perspective.

Aboriginal strength, wisdom and adaptability involve knowing how to survive the many struggles we have encountered, including the colonial systems thrown to us over the years. New solutions, ideas and creativity have evolved within the ceremonial life of Aboriginal families and communities. Aboriginal health care providers build on this strength by providing culturally competent community-based care starting in the communities, with families before each child is born.

Now, for more than 500 years, Aboriginal women in Canada have faced social, political and cultural changes that have negatively impacted on health, cultural identity, social structures and traditional values. These negative influences have led to the decline of traditional midwifery practice in many parts of Canada. The medicalization of childbirth has necessitated that women give birth in hospitals, rather than in their communities, on lands with which they had a spiritual connection. Western medical practices, however beneficial, have taken away traditional birth customs as an optional ceremony for Aboriginal women, creating a dependence on a health care system complete with medical practitioners unfamiliar and often intolerant of ceremonial practices and traditional belief systems.

Today, in remote communities and in the North, women must leave their communities for several weeks before their child is born, and are separated from their husbands, children, families and community supports for weeks, or months. These changes in the delivery of obstetrical care for Aboriginal women were not based on the needs of the patients, who indicated a decrease in maternal risk factors, but rather, on policy based on convenience. Despite arguments made by Otto Schaeffer of the Northern Medical Research Unit, to keep northern birth practices intact, Health Canada embarked on a project that removed expectant mothers from their communities in the act of childbearing, beginning in the 1960's. During the period between 1960 and 1993, fewer nurse-midwives were available, as training was not obtainable in Canada, and overseas recruitment had ceased. Traditional midwifery was undermined in favour of the growing trend for hospital births, and the medical management of pregnancy and childbirth. The control of community birthing was removed from the hands of traditional birth attendants and family support systems, and hence, the health of communities has deteriorated, and has been complicated with preventable issues associated with pregnancy, such as Fetal Alcohol Syndrome/Efffects, and high rates of infant mortality.

SUMMARY

A PLAN FOR ACTION:

In 2006, NWAC embarked on an inquiry conducted nationally through cooperation of Aboriginal front-line health workers and nurses in northern and remote regions of Canada. Many of these workers took the responsibility to outreach to expectant mothers and new young Aboriginal mothers to hear their voices and engage their input. The purpose of this inquiry was to hear the voices of Aboriginal women impacted by community health programmes and to present recommendations for strategies on how to improve supports to First Nations and Inuit women who travel far from their homes to give birth.

The Native Women's Association of Canada is relatively new to this area of health promotion. However, acting on recommendations made in the 2006 inquiry, NWAC has worked with community partners in the development of the booklet, "Journey for Two" a resource booklet for women who must give birth away from home. Distribution and dissemination of this valuable resource guide was begun in the 2008-09 fiscal year, and has been well received. In 2009, some 7870 copies of this booklet were distributed across Canada, and requests are ongoing.

This Plan of Action has been developed in response to the voices of Aboriginal women across the country, in consultation and cooperation with front line Aboriginal health care workers, professionals and nurses across Canada, who participated in an inquiry conducted by NWAC in March of 2006. This inquiry examined possible strategies to support First Nations, Inuit and Metis women who travel away from home to give birth. The 2006 inquiry provided recommendations to the Native Women's Association of Canada and to Health Canada's Maternal Child Health Care in the Community Programs Directorate on national strategies to support Aboriginal women during the perinatal period.

This document builds on four years of addressing concerns relating to Maternal Child Health issues since the 2006 Inquiry. It re-affirms the mission, vision and values of Aboriginal women's leadership in the context of perinatal health, positive pregnancy outcomes and healthy beginnings for Aboriginal infants and children and presents strategic objectives for short and long-term planning. This direction is derived from recommendations for addressing these urgent matters in Aboriginal families and communities. Ultimately, this Plan of Action will provide a framework for the management and implementation of programs and services for Aboriginal women, infants and children and will set a course for raising awareness, community support, future planning and prevention of pregnancy complications, and issues such as fetal alcohol syndrome/effects, malnutrition, impaired parental-child bonding and perinatal and infant mortality.

The process involved in the development of this Plan of Action has been exclusive and dynamic. It began with NWAC's preliminary inquiry in 2006, where priorities and key issues were first identified. Through a series of consultations, the process has evolved into the development of an operational plan whereby Aboriginal women in leadership and communities could anticipate the expectations for the coming year and for the next five years. This Plan of Action also reiterates the set of values and principles developed by community members, key stakeholders and Aboriginal health care workers, all of whom underline and guide the process through the delivery and accomplishment of goals that have been set.

To be reviewed on a bi-annual basis by the Native Women's Association of Canada, Health Advisory Committee, the Plan of Action will continue to articulate the performance measures for assessing the work of the NWAC Health Department, in its five-year strategy on Maternal-Child Health.

GOALS AND OBJECTIVES

GOALS:

The long term goal is to have a consistent and structured Maternal-Infant Health program in both urban and rural Aboriginal communities across Canada to reduce the likelihood of pregnancy complications amongst Aboriginal women, and to ultimately reduce the infant mortality rate amongst the Aboriginal population by having a foundation for a healthy start beginning before birth. It is anticipated that this healthy start will include birth options for all Aboriginal women, and the access to birthing support within their home communities for those who choose to give birth closer to home. This type of programming will promote healthy beginnings, stronger families, resiliency and community participation in maternity care and early infant-child development. The result will be young Aboriginal women possessing and maintaining a positive identity and choosing their place of birth, with full access to the supports needed.

The goal of this proposal is to establish a foundation and framework for community partners, health care workers and Aboriginal women as a whole to facilitate full access to appropriate care that will contribute to positive birth experiences. It is anticipated that this foundation will empower Aboriginal women in their childbearing years to take control of their birth experience and access care choices and provide a solid, healthy foundation for their unborn and newborn children that is grounded in cultural roots and tradition.

OBJECTIVES:

NWAC realizes that we cannot be the sole messenger for Maternal-Infant Health, therefore it is proposed that NWAC establish the groundwork to help educate community partners and create dialogue and eventually work with them to consider Maternal-Infant Health promotion activity models and community birthing/midwifery. With knowledge from our Action Plan, community partners who work with the Aboriginal women and the expanding childbearing family will be aware of:

- Cultural and Traditional teachings regarding pregnancy, birth, the mother and child and the expanding family;
- Access to Prenatal and Postpartum care;
- Preventing and Managing Complications of Pregnancy;
- Healthy weight maintenance and nutrition "Right from the Start";
- Infectious disease and the Perinatal period;

- Safe motherhood;
- Supports for Aboriginal mothers who require transfer during pregnancy/birth;
- Supports for Aboriginal fathers including resources for fathers who may be left behind as their partners travel away from their communities to give birth;
- Resources for Aboriginal fathers, including single fathers;
- Breastfeeding and breastfeeding support;
- The importance of family and community bonding with the newborn including traditional teachings about child bearing, child care and birthing ceremonies;
- Family Planning;
- Where to go for additional supports;

FINDINGS OF THE LITERATURE:

THE CHALLENGE:

Our Elders believe that many of the social and societal ills faced by Aboriginal people, are not only the result of external factors and social determinants, but stem from how our children are born, and the disconnection that results from being born in unfamiliar territories, far from the bonds of our loving families and community supports. A Mohawk midwife once said:

"The problems that we see today with our young people, and the problems we have in our communities all stem from the way that we get born." – Katsi Cook, 1993.

The alienation of childbirth from the community has had devastating impacts in some communities (Athias, et al 2007; Moffit, 2004; Becker, 2003; Jasen, 1997; Fournier, 1997; Neil, et al, 1990). This situation has been a major grievance of Aboriginal people throughout Canada, particularly in northern and remote communities. An essential component of traditional Aboriginal health is the connection to the land, which functions as an integral part of Aboriginal identity. Evacuation to centres, hundreds of kilometres away breaks the first connection between an Aboriginal child and the land (Douglas, 2006; Becker, 2003; Houd, 1998, 2004; Ross - Leitenberger, 1995; Mason, 1987). In a study conducted by Kaufert and O'Neil, (1990), it was reported that Inuit women in the Kivalliq Region who had given birth to their first children in their communities and later ones in Churchill or Winnipeg, made this explicit when they said that only their first children were real Inuit, not the later ones born in the south. Flying mothers out to southern hospitals deprives them of much-needed social supports during a period of stress, and can impact the health of the unborn child, and induce complications of pregnancy and delivery. (Chatwood, 1996; Luo, et al 2004; Wenman, 2004; It also deprives families and the community of their part in managing and sharing in the birth experience. Husbands are often ill-prepared to care for children left behind, for long periods of time, and family integrity may suffer due to marital strain resulting from lengthy separation (Paulette, 1997). This is illustrated in a report prepared for the Society of Obstetricians and Gynecologists of Canada by Couchie and Sanderson, (2007) "... You arrive alone in this place where you have never been. You can't adjust to their strange food, so you eat very little in the last few weeks of pregnancy. Everything is in a different language. Sometimes an interpreter is available. Your family calls after two weeks to say that your children have been taken to another relative's. The house you know is already over-crowded. Your children cry on the phone to you, and you know that you can't pay for this phone bill when you return home."

The infant mortality rate is the number of infants who die during their first year of life. The infant mortality rate in Canada in 2004 was 5.1 per 1,000 live births, and is largely preventable. Among the First Nations population, the infant mortality rate was nearly double, at 9.8 per 1,000 live births for infants under one month of age, and more than three times the national rate (6.1 per 1,000 vs. 1.7 per 1,000) for infants between one month and one year of age. (PHAC, 2008; Green, 2007; Smylie, 2006; Luo et al, 2004)

Reductions in maternal and infant mortality require adequately functioning health systems as well as complementary policy developments in a number of intersecting areas including, education, infrastructure, transportation and gender equity. Political leadership and political will are essential to ensure that these sectors interact with the health sector in a coherent way to reduce maternal and infant mortality. (WHO, 2009) The poor progress to date, and the alarming numbers of Aboriginal infants who die each year is reflective of a lack of resources in maternity care during pregnancy and insufficient supports to the expanding family. An increasing number of social problems and marginalization experienced by Aboriginal families, beginning from birth and early infancy can be attributed to the failure to recognize the need to return birth to communities from which we essentially emerge.

As pointed out by Jasen (1997), at the turn of the 19th century, many Canadians, including those in government were convinced that the "Indian race" was too degenerate to survive, and a concerted policy of cultural assimilation was the only practical and humane response. The retention of cultural traditions, especially those associated with religion and medicine, was the primary obstacle to the success of such a policy (Titley, 1986). The Department of Indian Affairs appointed its first Chief Medical Officer in 1904, and his reports reflected similar attitudes coupled with a determination to persuade a parsimonious government to provide health care. Dr. Peter Bryce collected data on the disasterous impact of tuberculosis and the high incidence of other diseases on Indian reserves and in his statistics (reliability of this data has been questioned), reported that these problems were related to childbirth. He attributed the incidence of complications in childbirth to the "native customs prevailing at childbirth" (Government of Canada, Sessional Papers, 1910).

The medicalization of childbirth in more northern communities was not begun until midcentury. This was a complex process that involved a variety of government agencies, religious institutions and the RCMP. The nature ant rate of change varied greatly from place to place, however some unity is demonstrated by epidemiological patterns which emerged. Patterns of ill health were reproduced in one region after another, as outside intrusion disrupted traditional economies, created new settlement patterns, introduced new diseases for which there was no natural immunity. Assimilationist policies and services were offered to Status Indians and Inuit within the colonial context, meaning that they were wards of the state and lived directly subject to federal control. The government's answer to the tuberculosis epidemic provided a model and prototype for a policy regarding childbirth (Jasen, 1997).

During the 1950's, the federal government began to give serious attention to the problem of infant mortality in Aboriginal communities, and began to use this information as a prime indicator of its own success or failure as a civilizing agency. Statistics compiled from the 1930's onwards indicated that both maternal and infant death rates were higher than the national average among status Indians and considerably higher amongst the Inuit (National Archives of Canada, 1966). Regarded as a sickly, misguided race, Aboriginal women became the subject of statistical surveys and the development of a far-reaching assimilationalist policy aimed at transforming the culture of childbirth (Jasen, 1997).

Nursing stations were established across Canada in all communities of one hundred people or more, and were originally staffed by British nurses, chosen because of their midwifery skills. (Biggs, 1994). It was their job to implement policies determined in Ottawa, and some intervened with their own "off to the colonies" attitudes and treated their patients as misguided children. Some of their autobiographies reveal a tendency to devalue the knowledge and coping skills of Aboriginal women, and assumed that Aboriginal women knew little or nothing about their own bodies. Part of their mandate was to supplant traditional midwives with their own nursing practices at nursing stations as defined by government policy (O'Neil, 1990).

During the 1980's government policy shifted, and despite recommendations made by physicians such as J.A. Hilde, and O. Schaeffer (Mason, 1987) to the contrary, the evacuation of all women in remote and northern communities to distant centers was implemented through government policy. The negative effects of the evacuation policy on women and their families has been well-documented during the past two decades (Douglas, 2006; Luo, 2004; Mussell, 2004; Tremblay, 2002; Briggs, 2001; Jasen, 1997; Paulette, 1997; Daviss, 1990, 1993, 1996, 1997; Fletcher, 1993; Schaefer and Hildes, 1993O'Neil, 1990; Kaufert, 1990; Voisey, et al 1990; Kaufert & O'Neil, 1997; Shepard, 1996; Calm Wind and Terry, 1993; Sennett & Dougherty, 1991; Pauktuutit, 1989; Schaefer, 1976, 1981;).

Until as recent as 1995, little attention has been paid to the problems of Aboriginal women who must await the birth of their children in an alien environment, far from their family members, nor of the plight of families who must manage without them. Flying mothers out to southern hospitals deprives them of much-needed social supports during a period of stress, and can impact the health of the unborn child, and induce complications of pregnancy and delivery. It also deprives families and the community of their part in managing and sharing in the birth experience. Jasen (1997), indicates that connections between the ideology underlying this policy and the consequences to which it has given rise have been highlighted by medical anthropologists. They have provided evidence that although evacuation has been justified through the language of risk, the very notion of "risk" was itself constructed, for it was based upon information recorded on obstetrical forms created by individuals with their own, ethocentric, culturally-biased understanding of childbirth (in Lindenbaum and Lock, 1993). As a result, a considerable gulf separates Aboriginal women's notions of risk and the biomedical models used to determine where they should give birth. For many women, the concept of risk is not focused solely on the unborn child, but encompasses the risks posed to the family when the mother is absent for several weeks. They worry about who will care for their children, and fear their husbands' resentment of their absence. They also believe that family violence is related to the exclusion of spouses and siblings from the entire process of birth. Declining infant death rates have become a metaphor for the success and moral virtue of colonialist policies, however, by isolating infant mortality in this manner, and seeking a clinical solution in the separation of women from their communities, authorities have transferred the impact of re-settlement, poverty and disease to the body of Aboriginal women.

In any region where evacuation is an issue, women have described what this loss of control has meant to them as individuals. In the past, women learned about birth by assisting relatives and friends. Many Aboriginal women of the current generation have never seen a baby born, and will travel out of their communities alone when it comes time to give birth. In this sense, Aboriginal women have become alienated from their own bodies. This general lack of awareness and education, coupled with difficult social and economic conditions in Aboriginal communities sets up Aboriginal women and their babies to be high risk (Paulette, 1997).

In the view of many Aboriginal women, self-sufficiency has been eroded by a process of colonialization which introduced new health risks and by a civilizing mission which undermined old traditional knowledge. Many of the ceremonies and traditions associated with the celebration of birth and motherhood are endangered and are at risk of being lost forever. There is a window of opportunity at this time, as there are still some women who can remember the times when birth occurred within the communities on the lands they have a spiritual connection to, and there are those that remember the ceremonies associated with birthing, motherhood and rites of passage from infancy to adulthood.

Based on key findings of the 2006 inquiry, evidence indicates that the access, standard, type and consistency of care vary considerably for northern First Nations and Inuit women, both in their homes and in the visiting communities. Geography, distance to larger health centers, availability of nurses, doctors, midwives, essential medical equipment and relationships to other professionals in larger care centers all impact on maternal care delivery. There is no evidence of continuity of care, nor of community-driven, community-paced, culturally appropriate, integrated health service delivery to women who are evacuated for birth.

The literature is unclear regarding the variances and standards of housing women are subject to in the visiting community while the expectant mother waits to deliver her infant. Anecdotal evidence indicates varying standards from community-based, culturally relevant and safe women's transition housing to cheap hotels in unfavourable urban neighbourhoods.

It is also documented that a spouse, family member or other support to accompany an expectant mother during the birth process is not considered a necessary medical escort by Non-Insured Health Benefits Program, and is not funded, nor does the program share in the cost of this expense. Although the presence of family, and support persons in labour is universal, considered a fundamental human right by much of mainstream society and is a cultural norm in most First Nations, Inuit and Metis communities, this is denied or inaccessible to women who are required to deliver outside of their communities. Additional financial burdens, such as travel costs for spouses, family members or small children, and child care expenses for children left in the home are borne by the mother/family. Should complications arise, and the mother and newborn are required to stay beyond the expected time frame, additional housing and maintenance costs are not covered.

In 1988, it was noted that pressure for a more community responsive system of obstetrical care is part of a wider demand for more community control and of a drive to preserve traditional values in relation to pregnancy and childbirth. Many Aboriginal women believe that Aboriginal midwifery should be revived and modernized. One attempt to "bring birthing back to the North" can be illustrated by the success of the Innulitsivik Maternity located at the health centre at Pirvuungnituk, along the Hudson Bay coast. The objectives of this centre include providing high quality services to childbearing families in the Hudson Bay communities through the peri-natal period. Education and care extend to areas of family planning, healthy sexuality, gynaecological health, family violence intervention and prevention, newborn, infant and childhood development, care and nutrition. The goal of this project is to place the responsibility for organization and provision of women's health care services in the hands of the Inuit women. The staff consists of three midwives, three local Inuit midwives in training and four maternity workers who are responsible for most of the daily post-partum care. The services are provided in the local language and basic care is provided by local Inuit women under supervision of professional midwives. This is the first program to re-establish maternity care in the North, and despite reports of high maternal death rates and infant mortality amongst Aboriginal infants and children under 5, has resulted in no maternal or neonatal deaths since it opened.

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Reductions in maternal and infant mortality require adequately functioning health systems as well as complementary policy developments in a number of intersecting areas including, education, infrastructure, transportation and gender equity. Political leadership and political will are essential to ensure that these sectors interact with the health sector in a coherent way to reduce maternal and infant mortality. The poor progress to date, and the alarming numbers of Aboriginal infants who die each year is reflective of a lack of resources and a failure to recognize the need to return birth to communities from which we essentially emerge.

The World Health Organization, through the Partnership on Maternal Newborn Child Health has indicated in its four year strategy on MNCH that: "...often, the policies developed for maternal, newborn and child health programmes, interventions and implementation approaches are developed independently of each other and in isolation ... (and the voices of Aboriginal women) ... are not adequately reflected in the overall health development plan. Maternal-infant and child health programmes are planned and delivered in vertically integrated systems to separate groups, such as nutrition supplement programmes, reproductive health advice to women..." early childhood programmes, and there is not sufficient communication resulting in a lack of continuum of care. Inter-sectoral planning and linkages between programmes is virtually non-existent, indicating that "... the continuum of care concept through the life cycle is not well-understood, nor does it figure prominently in planning maternal-infant-child health activities..."

Concerns have also emerged regarding the shortage of maternity care providers in Aboriginal communities that grows more acute with each passing year. The Aboriginal Nurses Association of Canada has indicated that the current national data indicates that there will be a 78,000 mainstream nursing shortfall by 2011 and will increase to 113,000 by 2016. This projected shortfall among mainstream nurses will be increasingly felt by Aboriginal and remote communities where the nursing workforce is insufficient to meet the rising health care demands. According to a study published by NAHO in 2008, this shortage in nurses and physicians is felt most acutely in rural and remote communities and has fostered an increased acceptance of midwives as appropriate care providers for low risk pregnancies. For Aboriginal communities, this development provides opportunities for the restoration of midwifery and community births. As well, the Canadian Nurses Association in it's 2009 Pan-Canadian Symposium highlighted that the continued availability and appropriate utilization of skilled health workers, across disciplines and settings has never been more important than now. Shortages of professional health care providers have led health care teams to rely increasingly on the support of unregulated health care workers.

In 2006, NWAC embarked on a project to address the concerns about the fragmented medical care provided to expectant mothers living in semi-isolated, isolated and remote-isolated communities, and examined the significant rise in youth pregnancies. Examination of the widely known, multiple poor socio-economic conditions faced by these women at this crucial point, essentially has provided a backdrop for the improvement of health for pregnant Aboriginal women and their children and thereby provided possible solutions to decrease the infant mortality rate in this vulnerable population, and to prevent issues that may result from a disconnection to family, community and culture, beginning from birth.

Health Canada has recognized the importance of returning birth closer to home, and has recognized the importance of cultural teachings and practices, particularly its impact on future health issues. Health Canada reported:

"In First Nations families or communities where original cultural teachings and practices have been maintained or restored, there is usually a positive sense of the many roles, social duties and obligations to be fulfilled However the experience of many First Nations is steeped in social disintegration and conditions associated with marginalization-physical, emotional, and sexual abuse, neglect, poverty, substance abuse and deplorable socio-economic standards. Many First Nations are feeling the impact of what has been termed "transgenerational grief", carried from the trauma previous generations experienced in residential schools and other forms of cultural oppression."

Although we recognize that the ideal situation for birth in Aboriginal communities, is to have the mother bring forth life within the community or within a reasonable distance of her support and loved ones, this may not be possible in the next five years. In the meantime, small efforts can be made to support the expanding family, as we move closer to our ideal situation.

A BLUEPRINT FOR ACTION – IMPROVING MATERNAL CHILD HEALTH

The challenge:

As has been outlined, the health and well-being of Aboriginal mothers, infants, and young children are of critical importance, both as reflections of the current health status of Aboriginal peoples as a whole and as predictors of the health of the next generation. Aboriginal people have long recognized the importance of the family as society's primary institution for supporting healthy child development and seek effective solutions for community-based early childhood interventions and support services primarily focused on families. In remote areas of Canada, and in many First Nations communities, efforts are on-going to address these concerns, however, despite these efforts, there is ample evidence to suggest that widespread improvement of the local maternal and child health care system continues to be of real and immediate importance. In several key areas of health care, mothers and young children in this community are not receiving the health care services they need, and the result is premature illness and preventable death.

Priority Areas and Best-Practice Domains

- Broad Integrated Strategies on Maternal-Newborn-Child Health (including Chronic Illness & Special Needs)
- Prenatal Support and Care
- Nutrition & Breastfeeding Support
- Strengthening Families and Family engagement (including Family Behavioral Health)
- Care coordination/service integration
- Education and Training

Community Action

Clearly, any effort to confront the multiple issues impacting the overall maternal and child health care system will require a vision of tremendous breadth and power that originates from the community's own needs, values, and goals. It is therefore, essential to listen to the consumers who are attempting to access needed services for their children and families while at the same time dealing with other fundamental life challenges, such as obtaining stable housing, food, and transportation. It is also equally important to address the limitations of the current system. These include:

- Transportation challenges and difficulty accessing available services
- Cultural and Socio-economic discrimination in the health care system
- The challenge of dealing with health care problems in the context of other basic needs

Competition among agencies providing services for children

Key informants interviewed during focus group sessions and information collected in the period preceding the development of NWAC's publication "Journey for Two" have provided valuable insight and have demonstrated courage in sharing their stories. They told of painful experiences and described efforts to be resourceful and independent in spite of tremendous needs. Despair and hopelessness are common responses when faced with the "Everest-like mountain" that the health care delivery system has become, and the insurmountable barriers that often exist in accessing care in remote communities. We must ask ourselves: "What can be done to help families scale this mountain?" Key informants have recommended the following directions for change:

- Improve access
- Enhance coordination
- Adopt a family-centered approach to service delivery
- Instill cultural safety, cultural competency and assurance of respect for families

The vision, must inform an ongoing change strategy that reflects the broad array of critical factors and influences that determine the health of individuals, families, and communities. To be achievable and sustainable over the long term, the strategy must drive an action plan that encompasses significant and widespread changes in consciousness and practice; unprecedented tripartite cooperation among federal, provincial, and First Nations governments and between and among the different departments and agencies within these organizations; new types of public-private partnerships to leverage existing infrastructure supports; resources to reduce disparities in access and quality of care; and public education and engagement campaigns that attempt to change public attitudes and standards, educate community residents, and support community-based interventions.

Vision

Based on previous assessments and through various key informant interviews, key components of a shared vision for achieving an outstanding local maternal and child health care system have been identified with common underlying themes:

- Promotion of healthy lifestyles and positive health outcomes
- Reduction of preventable disease and environmental health risks
- Elimination of health disparities and inequities
- Access to quality care for young children, mothers, and families

Ideally, a functioning health care system will have the following characteristics:

- A family-centered, culturally competent approach to care, in which providers address the needs of and draw on the strengths of the entire family being served;
- Integrated/holistic services, with service providers working closely together, addressing all aspects of a family's health and social needs that affect the at-risk child;

- A high-quality maternal and child health care workforce, well trained in the principles of family-centeredness, cultural competence, and integrated/holistic care;
- Families well educated about available programs and resources and about healthy behaviours (e.g., proper nutrition, the importance of prenatal care, smoking cessation, substance abuse issues, reducing environmental health risks) and empowered to demand high-quality maternal and child health care.

Action Plan

Toward a Model Maternal and Child Health Care System

It is recommended that a policy- and practice-improvement pilot project be conducted in four communities across the country that will be identified as part of a collaborative partnership to operate under the direction of an expanded stakeholders' leadership collaborative, including Aboriginal stakeholders and Aboriginal leaders in health care delivery. The goal of the demonstration will be to begin building a model maternal and child health care system that will lead to improved health care for mothers and young children in each region.

At the *policy level*, the coordination conducted through a project team will:

- Organize two policy working groups to develop plans for
 - 1. integrated national data collection, analysis, and dissemination of information on maternal and child health care service utilization and outcomes; and
 - 2. flexible, performance-based funding initiatives in maternal child care that rewards quality improvement and provides incentive for improvement.
- Support the leadership collaborative in its efforts to tailor and implement proposed policy changes in the pilot regions.

At the *practice level*, the project team will:

Create and support at least two community-based practice-improvement teams that Will:

- 1. involve strategic partnerships among local community health planners, programs, and families;
- gather baseline information on specific indicators related to the key priority areas of prenatal care, nutrition, behavioural health, chronic illness, and specialcare needs, with linkages to environmental health;
- 3. adopt and test proven processes and practices for increasing family engagement and care coordination in accordance with the plan-act-study-do rapid cycle quality-improvement model; and
- 4. develop data systems and make recommendations for adequate funding programs to support these practice improvements
- Monitor and evaluate the progress of the community-based practice-improvement teams, basing the evaluation on process and outcomes data provided by the individual

teams, as well as changes on key indicators of family engagement and care coordination measured first at baseline and then at the completion of the program;

- Synthesize the information from the evaluation into a community report card documenting the progress of the community-based practice-improvement teams;
- Develop a national plan for the sustainability and diffusion of quality improvement strategies that are shown to enhance maternal and child health care

The primary outcomes of this policy and practice improvement demonstration will be:

- A local leadership collaborative structure and process for improving policy and practice components of the maternal and child health care system that have been identified as priorities by community stakeholders
- National plans for:
 - 1. child health care service utilization and outcomes; and
 - 2. flexible, performance-based payment mechanisms; both of these plans will incorporate strategies for overcoming anticipated barriers
- Community-based practice-improvement teams that have demonstrated and documented their success
- Mechanisms that will enable the sustainability and diffusion of the improvement process

Generalizability to Other Communities

Recognizing that communities differ markedly with respect to their history, demographics, economy, and governance, it is uncertain whether the "one size fits all, cookie cutter approach" community-based collaborative process would be effective across the country, and must account for regional variation and levels of community infrastructure and support. Certainly, to a large degree, the success of this process in each community will be attributable to the historical importance of the family, as well as the energy and cohesiveness of community leadership, and the ability to mobilize significant resources to support visionary change.

At the same time, the idea of creating healthy communities is gaining momentum across Aboriginal communities, in urban and semi-urban centers, rural, isolated and remote areas and regions across the Canada, and in mainstream society both nationwide and around the world. Although, in most cases, these communities have identified goals and pursued action plans related to issues other than maternal and child health care, they share many of the same characteristics with the underserved, high risk communities in many urban centers including a common vision, a willingness to work collaboratively, a free flow of information among all major stakeholders in the community, and clear opportunities for improvement. For those seeking improvement in maternal and child health care in particular, or in service delivery to families in poverty more generally, many of the best practices, barriers, and potential

solutions presented in this plan of action could serve as a basis for developing a community-based collaborative approach designed specifically to address their communities' needs.

Designing an Innovative Approach to Improving Maternal and Child Health Care Barriers and Issues Faced by Families in the Community

To gain a better understanding of the strengths and weaknesses of the local maternal and child health care system, the project team and the learning collaborative considered it essential to listen to the consumers who are attempting to access needed services for their children and families while at the same time dealing with other fundamental life challenges, such as obtaining stable housing, food, and transportation. Consumer members of the learning collaborative identified a subset of families representing different racial and ethnic groups and communities who describe both positive and negative experiences with aspects of the local health care system related to the four priority areas. Since the focus of this initiative is on improving the local system of maternal and child health care, only primary caregivers who are mothers were interviewed. As the initiative moves forward, it will be important to identify the issues and concerns of fathers who serve as primary caregivers and to integrate appropriate strategies for addressing their issues and concerns in the community's overall action plan.

A selection of vignettes is presented to illustrate various situations faced by Aboriginal families. In a few cases, parents found local agency and program staff to be supportive and helpful, and families were able to develop positive relationships with providers. At the same time, several common themes are illustrated across families that elucidate important limitations of the current system. While the examples provided do not encompass the full range of experiences encountered by the many different local consumers seeking maternal and child health care, they serve as a useful starting point for identifying some of the major problems that need to be addressed if improvements are to be made. The chapter concludes with a summary of the directions for change recommended by the voices of Aboriginal women, mothers and key informants. The project coordinator has considered these recommendations when formulating the action plan.

Accessing the System

"I guess it's a matter of knowing where to go and who to contact . . . it's just really frustrating . . . I see a lot of parents with small children who do not have access to information or are presented with numerous barriers, having to jump through hoops imposed by the system to get the services that they need for their children." -- A mother and provider-agency board member

A Mother's Story:

An Aboriginal grandmother in her sixties who is overweight, diabetic, and has cardiovascular disease lives with her husband and three grandchildren in an urban center in a lower-middle-class neighbourhood. Her poor health makes it difficult to take care of both herself and her grandchildren. "I tell [the doctors], by the time I'm finished taking care of three kids, I don't have

the energy. All I want to do is go to sleep. So they're aware of it. They just ignore it. They conveniently forget." The grandparents do not receive any financial compensation to assist with the expenses of raising her grandson and granddaughters, nor does the family receive any financial support from the children's father. The children's mother is incarcerated in a federal penal institution, and is unable to contribute to the children's support or health care needs. To complicate matters, the family doctor recently retired, and now the family must seek health care through a walk-in clinic or through the hospital emergency room, because of a shortage of family physicians. The grandmother is challenged by her inability to seek the appropriate help for her grandchildren, because she does not know what is available or who to contact for services that would benefit the most.

Aboriginal mothers have identified significant problems finding and obtaining much needed services for themselves and their children. Several mothers have mentioned that they would have accessed services at their local nursing station if they knew what was offered, and others have identified that transportation and access are often problematic. One mother indicated that medical transportation in her community had to be approved at several levels before it was approved, and often had to be approved by their Chief and Council, indicating clearly why it was required. This presents barriers to access, and potentially violates confidentiality with respect to health care issues, particularly in small communities where everyone knows everyone else. One mother spoke of issues regarding confidentiality when she tried to approach the health clinic in finding resources to help her with her drug problem. She indicated that she went to the health clinic, but a neighbour's daughter works in the clinic as a receptionist, and she was afraid that if she were to tell her why she was seeking help, the word would get out about her drug problem, and she would have the child welfare agencies knocking at her door to apprehend her child. She looked for help by seeking outside agencies, who told her that her problem was not serious enough, and turned her away. As a result, her drug problem worsened, and her child was later apprehended. She is now in treatment and trying desperately to put her life in order so that she can get her son back. This situation could have been prevented if the needed resources were available to her, and her confidentiality maintained and respected.

Prejudice, Stereotyping, and Disrespect

"I was six months pregnant and living in a women's shelter, following increasing family violence. I had no family doctor in the city, and had to go to the walk-in clinic down the street for my prenatal visits. I felt that they judged me for being in the shelter, being and Aboriginal woman and for how many kids I had. Ireally felt that they (in the clinic) treated me poorly and their judgements affected the care I received." — an Aboriginal mother

A Mother's Story

A single Aboriginal mother in her late twenties lives with her three –year-old daughter in an urban center in a lower-middle-income neighborhood in close proximity to an industrial coke factory, which exacerbates the child's asthma. This mother believes that many health care professionals that she has encountered have treated her poorly because she is a single

Aboriginal mother on social assistance. "The doctor that I was dealing with, he just had the worst bedside manner . . . no one should talk down to me, you know . . . because I'm Native, unemployed and living on the welfare. I felt like we were second rate citizens"

Aboriginal mothers recounted several stark examples of racial and economic discrimination in the health care system. One Aboriginal mother attributed the callous and neglectful treatment she received during pregnancy to negative stereotypes and judgments made by providers because the father of her baby was a native of Senegal. This same mother believed that health care professionals did not provide thorough care for her when a possible miscarriage was identified, and she was left unattended in the hospital emergency room for several hours. A number of mothers also felt they received poor treatment because they relied on social assistance programs. Several young mothers described feeling that health care professionals did not show respect for them as parents and were highly critical in their knowledge of their children's needs. One mother felt that service providers undermined her role as a parent, and felt that she was constantly on her guard, one step away from being reported to child welfare authorities simply by the fact that she was a young Aboriginal mother, living alone, poor and on welfare.

Families Face Competing Demands

"Sometimes professionals don't understand that even though you wanted to make a doctor's appointment, you needed to go get food."—An Aboriginal mother, northern Canada.

A Mother's Story

A single Aboriginal mother in her late teens with a learning disability and chronic asthma has an 18 month old son who was born premature and has several serious health complications, including asthma. She and her young son live with her mother and stepfather, in a remote community where there is no nursing station, and where they must travel to a neighbouring community for health care. The child's grandmother spoke of times when the medical community undermined their daughter's knowledge of the child and his care. She recounted a situation when she had taken her son to the nursing station because he was having an asthma attack, "the nurse asked me how I knew my baby was having an asthma attack? I shoved him under her nose and said, 'Blue is not a good color for a Native baby.'" The family has also failed to get help because the community agencies they utilized often competed against one another. The child's grandmother also remarked how difficult it was to see the doctor, and how the doctors are always changing. It's hard to establish trust and relationships with doctors when you don't know if it will be the same doctor next time, and you will have to tell your story all over again. Support has come from doctors who truly cared and went the extra mile to help them. "After we met this one doctor, she immediately turned everything around for [the baby] and got his medications okayed with 'medical services'." Both the mother and the grandparents find it difficult to tend to the child and take him to the nursing station for clinic appointments because it is quite a distance from their home community and because of their rigid work schedules. They are fortunate that the grandfather "works second shift so [they] can juggle getting [the baby] to the doctor's. . . . it's something as simple as your employer doesn't care that you are a parent or a caregiver."

Several mothers described the challenges of dealing with health care problems in the context of other basic needs, such as obtaining stable housing, food, and transportation. They reported that health care staff often showed little understanding of how "the little things" made seemingly simple steps in getting and following through with care quite difficult. Providers often fail to recognize the competing demands that families face. Family members—including mothers with addictions, serious illness, or learning disabilities, as well as grandparents—have difficulties attending to the physical and psychosocial needs of children when their own health or other needs are great.

Directions for Change: What Families Want

"We've been asked about problems in the system before, but nothing ever changes. How do we know that things will change now?" – an Aboriginal mother raising her grandchild

The women who contributed to the evolution of this document have demonstrated courage in sharing their stories. Many told of painful experiences and described efforts to be resourceful and independent in spite of tremendous needs. Despair and hopelessness are common responses when faced with the "Everest-like mountain" that health care delivery systems have become. What can be done to help families and young mothers scale this mountain? The voices of Aboriginal women have recommended the following directions for change:

- Improve access. Families identified several things that would help others identify and use services effectively, such as better information and more transportation. The information should include not only what services are available, but also what rights the families have in obtaining those services, whether they can refuse services, and what responsibility they have in participating. One mother suggested that central locations such as children's schools, band offices and the Welfare Department would be good places to disseminate information, since families often have frequent contact there.
- Enhance coordination. Families need a liaison to help when multiple agencies are involved. Agencies can take a positive approach to helping families keep track of their needed services and appointments. One mother was pleased to receive reminders about medical checkups for her daughter. Several families also stressed the need for better coordination and collaboration among agencies and less competition.
- Adopt a family-centered approach to service delivery. Families recommended that health care agencies pay more attention to the entire family situation, including basic needs and the health of the caregivers as well as those of the children. Mothers noted the need for substance-abuse treatment facilities that can accommodate women with children. A grandmother talked about the difficulty of caring for her grandchildren when she herself suffers from depression, diabetes, and other health problems. She has trouble giving her grandchildren the full attention doctors suggest that she give. Her recounting of a lack of energy suggests how depression may be a "silent traveler."
- Instill and assure respect for families. Perhaps the dominant concern raised by families was how to "get respect" from health care staff and how to eliminate racial, cultural and class discrimination. One mother suggested setting up a hotline for reporting discrimination

in health care (like the hotline for reporting discrimination in housing). Several mentioned how important it was for the health care provider to listen and to hear the family's story and for the provider interaction to demonstrate respect. Another mother echoed this concern and explained that if staff did not garner trust from the family, including the child, they were unlikely to get families to provide the information they need. The physicians who go the extra mile are the ones who make a difference. While not all health care provision is bad, best practice is far too rare.

Barriers to Engaging Families at the Local Program Level

"Recruiting nursing staff and enhancing skills of care providers is a major challenge." -- A First Nations community health planner.

Lack of Staff Skills, Numbers, and Types

- Staff must have the skills to establish trusting relationships with families, to apply culturally sensitive approaches that successfully recognize the range of needs that families have, and to address those needs.
- Nurses are generally recognized as an important asset for maternal and child health care programs. Given the current nursing shortage, it is often difficult to hire nurses, more difficult to hire nurses interested in working in community settings, especially in remote areas in the north where services are most needed and even more difficult to find nurses who live in the community where the initiative is located.
- Given the high intensity of relationships established in community settings, successful programs need to proactively establish a supportive staff environment that addresses the potential isolation of staff and staff burnout.

Funding Limitations and Licensing Geared to Individual Patient Service

- There is a lack of funding for "child-friendly facilities" and child care to support parents enrolled in treatment plans.
- The building of trusting relationships with families is not as difficult when program funding is available.
- Funding to support outreach workers who can identify women in need of prenatal care and encourage them to access available services is a particular concern. The current reimbursement structure, which is geared to treatment services within a facility, discourages engagement of families who are more likely to utilize maternal and child health services through home visits or in a community setting. Home-visiting services authorized by First Nations and Inuit Health Branch which include prenatal and postpartum services are extremely limited.
- Prenatal care services are seldom integrated with behavioural health services, and providers must rely on a different network of health care workers to extend these services through outreach or home-visiting programs.
- Additional licensing regulations that limit the location of service provision discourage family engagement in less-formal community settings and/or in the home.

Factors Impacting Provider/Family Relationships

"The system 'sets families up to fail' when it provides specific services, such as prenatal care, medical aspects of care, addictions services, or child-development services without addressing the more basic needs of the family." — An Aboriginal care provider

- Providers and families often do not share the same perception of a child's problem or of his or her need for services. And in cases where providers and families do agree on the need for services, they may each prioritize those needs differently. While the family tends to place highest priority on basic needs (e.g., shelter and food), providers tend to focus on specialized medical care or child-development services.
- Many families are seriously impoverished and therefore lack the resources to either arrange or get to health care appointments. Providers often do not recognize these challenges and mistakenly conclude that the parents are "noncompliant with treatment recommendations."
- Aboriginal mothers tend to have a general distrust of public service providers and thus may not attempt to obtain services for their child from a new provider with whom they have no history.
- Within some families and communities, parents are concerned that any health problem of a child will be viewed as evidence of parental neglect and the child will be removed from the family by child protective services. These concerns exist even in cases where the health concern is clearly not related to neglect.
- Depression may significantly limit parents' ability to engage with the health care system and to acquire services on behalf of their children, especially in communities where outreach is not available.
- Too many providers unrealistically expect that patients will come to them and therefore fail to reach out to those in need of care who may be uncomfortable in professional settings. Far too many pregnant women have no family or support network to engage them in an effective care program. It is also difficult to establish continuity of care for mothers and children that do not have a stable residence, such as those in transition homes or shelters for abused women.

Lack of Transportation to Services and Programs

- Travel distances to specialized services or preferred services are a barrier to service provision. Many families cannot afford the cost of transportation, particulary when the family lives in a remote community and mothers must be flown in to urban centers hundreds of miles from home to give birth.
- Many providers mentioned issues related to the Medical Transportation Program . These include regulations regarding healthy dependents accompanying the family member who is taking a sick child to receive care, and supports for mothers who must be flown out of their community for delivery.
- Issues also include reliability, and limitations on what the medial transportation driver/pilot can do to assist passengers en route.

Issues have also been raised with respect to the multi levels of approval that is often
required for medical transportation, which is often not seamless. Young women have
recounted how approval for transportation has been denied because full disclosure was not
provided to band council when attempting to arrange transportation to the city for an
elective termination of pregnancy.

Barriers to Coordinating Care and Integrating Services at the Local Program Level Lack of Staff Skills, Numbers, and Types

- Unhelpful and disrespectful staff at key family-serving agencies can hamper effective integration of care.
- Not enough family advocates or care coordinators are available to assist eligible families in obtaining needed and available services.
- Not enough behavioral health specialists are skilled in serving young children (under five years of age) and in addressing problematic relationships and bonding issues between primary caregivers and newborns, infants, toddlers, and preschoolers.
- Confidentiality issues, are also barriers to coordination of care.

Linkages Across Programs and Services

- There is an urgent need to improve integration within behavioral health and between behavioral health and physical health. Barriers include initial identification of a particular condition (e.g., substance abuse or depression), the individual's ability to recognize the need for treatment, access to treatment, and integrating care across family service providers.
- Lack of coordination of medical care among large hospitals and community services is also an issue.

Directions for Change: What Providers and Program Staff Want

- Strengthen provider and staff skills. Providers and program staff need cross-training in cultural competence—how to establish rapport with families; how to recognize and respect families' needs; how to successfully involve families as bona fide collaborators; and how to build upon families' strengths. Child-development professionals need to better understand the parent/child relationship, and behavioral health specialists need to learn how to address the impact of a parent's substance abuse or mental illness on the child's development and how to engage families in appropriate treatment programs, with a particular focus on maternal depression, both during and after pregnancy. Child-care staff need to be able to support children with special-care needs and/or communicable diseases. All staff involved in prenatal services or programs need to be more knowledgeable about nutrition. They should be able to introduce new shopping patterns to families, as well as ways to manage the family food budget. They must also know how to engage social support services in efforts to improve a family's nutrition.
- Enhance linkages and support relationships among agencies and providers. A shared vision of integrated care must be created among leaders and across the various levels

of all agencies involved in meeting families' needs. This could be achieved by requiring agencies to jointly define their roles relative both to the family and to each of the agencies that are involved. Establishing a forum in which providers within communities could learn about each other would be useful for supporting the development of more-collaborative relationships and processes. Explicit communication strategies need to be developed among providers for supporting coordinated care for individual families. Stronger linkages between the Canada Prenatal Nutrition Program (CPNP) and other family-service programs should be developed and supported.

• Improve access to information. There is a needs for a central clearinghouse of information about available services that is "user-friendly" for both providers and families and that includes information on real-time waiting lists. A national hot line, operated by the Health Canada's Maternal Child Health Program could be made available for First Nations, Inuit and Metis expectant mothers seeking counseling, assistance, and information on resources and services.

Lessons Learned from Promising National and Local Programs

From a review of the published literature and information on the Internet, the project coordinator has identified a number of promising maternal and child health care programs that provide family-centered care and pursue program coordination or integration in a variety of ways.

Strengths-Based Treatment Models

Most of the programs interviewed operationalize family-centeredness by employing particular treatment models that focus on families' strengths. These models define the family as the unit of service, placing great emphasis on building strong personal relationships with families and establishing structural activities designed to engage families and ensure that they feel comfortable and respected.

A variety of models exist for engaging and providing services to families. There is no single best model, but most successful service providers select one, provide their staff with intensive training in it, and fully implement it when working with families. The models often include a curriculum for training staff and protocols for dealing with families. In addition, most of them attend to the needs of both children and parents, usually defining the unit of service as the entire family.

One model, the Developmental Training and Support Program developed by Victor Bernstein at the University of Chicago, focuses on strengthening the relationship between the parent and the infant or child. Program staff first work on building a strong and trusting relationship with the parent. Central to this process is mutual identification of the family's strengths. Program staff attempt to build on those strengths in developing a mutually agreed-upon service plan with the family, and they support continued family involvement in the implementation and evaluation of the plan. Many of the programs that utilize this model also first address the immediate needs of the family, such as housing, employment, and lack of food. In most cases,

addressing these needs involves collaborating with social service providers. Families are usually more willing to address behavioral health, chronic disease, and other problems after they have received help with their more immediate needs.

Strong Relationships with Families and Across Programs

Closely related to the use of specific strengths-based models for engaging families is the development of a strong relationship between program staff and the family. Staff of successful programs spend a great deal of time getting to know families. It has been reported that a close bond between service provider and family (especially the mother) is forged over the course of several face-to-face meetings. The establishment of close working relationships with the staff of collaborating programs is equally important, and it also facilitates the engagement of mothers and families.

Home-Visiting Programs

Several of the programs interviewed have a home-visiting component. Home visiting can be especially effective in engaging families who are reluctant to seek services at a hospital, clinic, nursing station or other facility. It also enables program staff to assess family members' health needs within the context of their living environment (both the home and the community). In some cases, home visitors are nurses or social workers who provide some services directly and refer families to other providers for other services. In other cases, home visitors are specially trained paraprofessionals such as CHR's or NAADAP workers (often from within the community being served) who serve as care coordinators, connecting families to service providers and educating them about the range of resources available in the community. The community paraprofessionals are most successful when they reflect the demographics of the population served. One of the programs has home-visiting teams that comprise both a public health nurse and a trained paraprofessional. While the paraprofessional focuses on outreach, educating the family about available services and linking the family to other providers, the nurse provides case management, direct services such as prenatal care and developmental screenings and assessments, and more-detailed medical information.

Location of Programs and Staff

Some programs engage families by locating staff in places that low-income families are already frequenting, such as family health clinics, child-care settings, or local health departments. It has been documented that most low-income families prefer to receive services in familiar, family-friendly locations and that this approach eliminates the need for families to travel what are often long distances for services. In some instances, staff from different agencies collocate in a single site, offering a sort of "one-stop-shopping" approach to service provision. Even these programs, however, must refer families to outside providers for certain services.

Use of Paraprofessional – non medical Staff

Whether they deliver services through home visits or in a family health clinic or other community-based location, some programs find the use of lay staff to be an important means of engaging families. In most cases, lay staff are trained paraprofessionals who serve as outreach workers or care coordinators. Some programs hire former program recipients or others from within the community being served. But other programs have been effective at engaging families and achieving positive health outcomes without the use of lay staff. Programs reviewed indicated that professionals—nurses in particular—often command a higher level of respect from families than lay staff do.

Involvement of Parents

A few programs maintain a family-centered approach in part by involving parents in governance, often as members of advisory boards, such as Head Start policy councils. Most of the programs included in this review, however, do not give families a role in governance but instead allow them to play a major role in developing their own service plans. This typically means that parents decide who will be included on their treatment team and help to determine what the goals of treatment or service use will be. They often invite other family members or friends to be a part of the team. Some of the programs also regularly convene parent discussion or support groups, where parents can learn from and get to know each other and also get better acquainted with program staff. Research suggests that these kinds of activities can be crucial to effective family engagement but that including parents in governance is not essential.

Strategies and Practices Used to Coordinate Care or Integrate Services Use of Multidisciplinary Treatment Teams

In many programs, treatment teams include members representing several different service providers who collaborate on a given family's service plan. Members of treatment teams may be substance-abuse counselors, mental health counselors, early-intervention specialists, pediatricians or physicians, and, in some cases, emergency housing staff, food bank representatives, or court workers. This multidisciplinary approach increases the likelihood that all of a family's needs will be addressed and is an important means of improving a fragmented service delivery system. In some cases, all multidisciplinary staff are employed by the same agency; in others, contractual agreements or memoranda of understanding between agencies ensure that staff from different agencies work together on families' service plans.

Cross-Training of Staff

Some programs encourage greater service coordination by providing cross-training for their staff. One program that has integrated peri-natal, child-development, and child health services provides training in behavioral health for its care coordinators. The training enables the care coordinators, who visit families in their homes, to recognize possible mental health or substance-abuse problems and make proper referrals. In another program, behavioral health

specialists provide similar training for child-care and child-development workers, thus strengthening the links between those two systems. Cross-training can also reduce philosophical differences between service providers in different systems, thereby facilitating collaboration between systems (e.g., family health and behavioral health care) and better equipping staff to screen and make proper referrals for problems that fall outside their areas of expertise.

Integrated Information Resources

A few programs have integrated data systems that enable case managers or care coordinators to track individual families and share data across programs. Case managers and care coordinators can determine whether families are eligible for certain services, have a medical home, have received certain services or kept appointments, and so on. Such data systems have been used to develop systematic, streamlined referral and feedback systems across agencies. In addition, many of these systems include data on health outcomes.

Another innovation that has facilitated service coordination in one urban area is a detailed Web-based inventory of all service providers available in the region. Health clinic staff in the area routinely access this database on their computers to identify resources for families. In addition, they can enter data on a family's income and other characteristics to make a preliminary determination of eligibility for specific programs.

Personal Relationships

In many of the programs, effective coordination of services across providers rests as much on personal relationships as it does on specific structural characteristics. Typically, close ongoing relationships among program directors provided the impetus for coordination, often accompanied or followed by the development of solid relationships between program staff. Unfortunately, such collaborative arrangements tend to be fragile; some program directors described collaborative efforts that suffered or collapsed as a result of leadership changes and staff turnover in partner agencies.

Strong Leadership

Strong leadership is necessary for establishing and maintaining effective partnerships across agencies. Most of the programs included in this review have benefited immensely from having at least one strong leader (e.g., an agency director) who took the initiative in contacting other program leaders, developing a plan for service coordination, and securing funding to pay for services provided, coordination of activities and other system improvements.

Potential Policy Levers for Enhancing Local Improvement Efforts

Any effort to improve the maternal and child health care system must take into account the full network of government programs and regulations that impact this system. Through various

programs such as Aboriginal Head Start, Canada Prenatal Nutrition Program, and the Aboriginal Diabetes Initiative, government serves as the purchaser of health care services in the public-sector market and can determine the nature of the services it buys through contractual arrangements with managed care entities. In its capacity as a regulator, government can impose significant legal requirements on health care providers, organizations, and managed-care entities and may set standards regarding the nature and quality of public-sector maternal and child health services.

While there are numerous opportunities for maternal and child health care policy reform at the federal level, this project focused its attention on projects that would be most likely to enhance community improvement efforts vis a vis, a review of relevant, publicly available documents.

This section concludes with some thoughts on broader reforms that could foster additional improvements in maternal and child health care.

Toward Broader Policy Reform

- Maternal and child health care providers are substantially overburdened by legal and administrative requirements related to licensing laws, public-health regulations, managed-care contractual provisions, etc. Administrative paperwork and reporting should be converted into time spent in direct patient contact.
- Many of the government programs, provider organizations, and health plans that comprise the maternal and child health care system engage in some kind of data collection, with regard to either service utilization or health outcomes. Clinical and health-status data are vital to any community-based effort to improve maternal and child health care, since such information is needed to show that particular interventions or reforms result in measurable improvement in outcomes. But data collection presents two core challenges:
- (1) determining what kinds of information are needed to support maternal and child health care quality-improvement efforts and who should collect it, and
- (2) eliminating redundancy and minimizing the burdens of collection, while ensuring data access for appropriate users.

Government policymakers have an important role to play in facilitating community-based maternal and child health care data collection, through streamlining reporting processes, eliminating duplicative and conflicting regulatory requirements, and partnering with regional maternal and child health care quality-assessment efforts.

A Blueprint for Community Action

Community stakeholders seeking to improve maternal and child health care face a number of daunting challenges that defy any single program or policy prescription.

Maternal and child health care involves a vast array of programs and services; numerous and multifaceted relationships among government agencies, and health care providers; and a complex patchwork of federal and provincial policies, municipal government policies, regional health board directives and tribal and band council resolutions that, to varying degrees help shape the nature and quality of maternal and child health care services delivered to Aboriginal women and children. Caught in this system are the consumers of health care services, who must bear the impact of its inefficiencies and inadequacies while simultaneously meeting their other basic life needs.

Clearly, any effort to confront the multiple issues that impact the overall maternal and child health care system will require a vision of tremendous breadth and power that originates from the community's own needs, values, and goals. This vision, in turn, must inform an ongoing change strategy that reflects the broad array of critical factors and influences that determine the health of individuals, families, and communities. These factors range from individual behaviours and the overall community environment to specific practices, programs, and policies that affect the way health care is delivered. To be achievable and

sustainable over the long term, the strategy must drive an action plan that encompasses significant and widespread changes in consciousness and practice; unprecedented cooperation among federal, provincial, and local governments, including First Nations Band councils, and Tribal health care authorities and between and among the different departments and agencies within these organizations; new types of public-private partnerships need to be established to leverage existing infrastructure supports; resources to reduce disparities in access and quality of care; and public education and engagement campaigns that attempt to change public attitudes and standards, educate community residents, and support community-based interventions.

Vision

The following key components have been identified, that is indicative of the shared vision of Aboriginal mothers, across Canada and their desire for achieving an effective and accessible maternal and child health care system:

- Promote healthy lifestyles and positive health outcomes
- Reduce preventable disease and environmental health risks
- Eliminate health disparities
- Ensure access to quality care for young children, mothers, and families

Ideally, such a system will have the following characteristics:

- An established medical or social service home or homes for each family in the community and/or each mother and her child(ren)
- A family-centered, culturally competent approach to care, in which providers address the needs of and draw on the strengths of the entire family being served
- Integrated/holistic services, with service providers working closely together, addressing all aspects of a family's health and social needs that impact the at-risk child
- A high-quality maternal and child health care workforce, well trained in the principles of family-centeredness, cultural competence, and integrated/holistic care
- Families well educated about available programs and resources and about healthy behaviors (e.g., proper nutrition, the importance of prenatal care, smoking cessation, reducing environmental health risks) and empowered to demand high-quality maternal and child health care
- Effective leadership at the national, regional and local levels, with clear lines of authority and accountability for performance

Action Plan

Outlined below is a complete set of action steps that should be implemented for an effective maternal and child health strategy.

• At the policy level, the action plan will expand the engagement of community stakeholders; improve the dissemination of information on maternal and child health care programs, services, and resources; build the community's capacity to monitor health outcomes for provider accountability and quality improvement; target specific areas for regulatory, licensing, and other policy reform; and enhance advocacy

for improving maternal and child health care.

- At the provider level, the action plan will establish new types of training, strategies, and practice that will result in increased family engagement and care coordination.
- Expand the capacity of local health plans to drive quality improvement by shifting reimbursement incentives to encourage:
 - Efforts by providers to build trusting relationships with families and to extend the social network for making valid and reliable referrals
 - Implementation of family-bundled services
 - Coordinated, longitudinal primary care services
 - More outreach, engagement activities, and prenatal/infant home-based services with documented positive outcomes
 - Care coordinators focused on maternal and child health care across agencies and services
 - More culturally relevant caregiver and family behavioral health services, infant and toddler mental health services, and caregiver/infant relationship support services
 - Benefits and services for grandparents and/or other family members
 who are non-parental primary caregivers, including supports for fathers and/or
 grandmothers to accompany pregnant women who must be transferred out of their
 community for birth.
- Work with the leadership collaborative and community-based systems-improvement demonstration teams on the development of flexible, performance-based payment
 - structures that reward teams for:
 - Conducting cross-training of staff in the family-strengths-based approach that results in demonstrable improvement
 - Preparing families and staff for the empowered-family role
 - Developing strategic partnerships designed to implement evidence-based interventions that address the needs of multiple family members in an integrated fashion
 - Adopting best clinical practices at the community level
 - Extending services beyond small numbers of participants enrolled in special programs to the patient population at large

Actions for Care Providers/Agencies

- Work with the leadership collaborative and community-based quality-improvement demonstration teams to:
 - Refocus cross-organizational culture on the family (e.g., the mother, her children, and other significant caregivers), rather than the individual patient, as the unit of care
 - Increase family engagement through involvement in program governance (e.g., as members of advisory boards) and sharing the responsibility for developing their individual service plans
 - Endorse flexibility and risk-taking in meeting families' needs, rather than simply "following the rules"
 - Develop concrete plans for standardized training and service coordination across

- organizations, with explicit linkages to the family's home community
- Design data systems and financing mechanisms that will support such plans
- Identify a project team in each agency to represent and champion the leadership collaborative in-house
- Build a family-strengths-based approach to care:
 - Respecting, listening, and responding to families
 - Understanding the family's perspective
 - Seeking family input and mutually identifying its basic needs (e.g., housing, food, transportation, etc.)
- Helping families to meet those needs by building on their strengths
 - Develop strong, trusting relationships between staff and families
 - Strengthen relationships between the parent/caregiver and the infant or child
 - Improve cultural competency, professional objectivity, and the ability to work outside traditional boundaries and across diverse community settings
 - Enhance specific provider skills in targeted areas, such as infants' social and emotional development, proper nutrition, and working with children with special needs
- Educate providers and practitioners across disciplines and throughout their careers (with a particular emphasis on student programs for physicians and nurses); offer continual reinforcement and support, possibly through state accreditation programs; and track the results of cross-training to document its effectiveness
- Engage family members in identifying and implementing specific strategies that will be effective in working with other families across different cultures and subcultures

RECOMMENDATIONS FROM ABORIGINAL WOMEN:

The recommendations made by those who were interviewed and canvassed in the 2006 inquiry into support for Aboriginal women who travel long distances to give birth have been categorized into four program objectives to be addressed as part of a five-year operational plan. These objectives have been grouped into five main components, and in many cases mirrors findings from the review of literature, existing model programs and resources:

- A. Broad Integrated Strategies on Maternal Newborn Child Health;
- B. Strengthening Families: Supports for Mothers, Fathers and Families;
- C. Breastfeeding Support;
- D. Prenatal Support and Care;
- E. Education and Training

The following illustrates the 5-point plan which was developed in consultation with those health care workers, professionals and Aboriginal women from across Canada who participated in the 2006 review, and is inclusive of recommendations from these discussions, as well as emerging issues in maternal-child health.

Broad Integrated Strategies:

- Partner with Health Canada on the development of a Maternal-Child Health Model that
 is culturally-appropriate, culturally-adaptable, and integrates Best Practices and
 Innovative Electronic Technologies to meet basic standards and improve access to
 information and care.
- Partner with Health Canada and professional organizations such as the Society of Obstetricians and Gynecologists of Canada (SOGC), the Canadian Association of Midwives (CAM) and the Canadian Nurses Association (C.N.A.) on the development of Base Standards of Maternity Care for women in remote and northern communities.
- Work with health professionals, nurses, physicians, midwives and allied health workers, including community health representatives, emergency medical workers, etc. for information-sharing, networking, mutual support and knowledge-transfer, specific to maternity transfer in the northern and remote regions. (Start with Best Practices and Current Information Sharing Exercise and repeat on a regular basis such as annually);
- Engage in regular updates on culturally appropriate maternity care to be delivered to all
 visiting hospitals and health centres to facilitate continuity of care and increase comfort
 level, including ensuring a cultural liaison person is available to provide support to the
 expectant mother during the entire visiting period, and including the labour and birth.
- Develop culturally appropriate materials on pregnancy, birth, maternity care and infant care to be distributed to local health centres, including continued distribution of the "Journey for Two" Resource manual for expectant mothers.
- Engage with Licensed and Regulated Midwives to mentor and educate Aboriginal women at the community level to assist with pre and post natal care,
- Establish alliances with Associations of Midwives, local governments, provincialterritorial governments, Health Canada and Aboriginal communities to motivate the education of Aboriginal midwives and enable the return of birthing closer to Aboriginal communities. (similar to Pirvuunituq Model).
- Explore, identify, analyse and document linkages between issues such as Pre-natal care, Maternity experiences, Breastfeeding, nutrition and infant bonding, father's involvement in infant and early childhood care, fetal alcohol syndrome/effects, early childhood and the potential for future involvement with child poverty, apprehension and other societal affects;

Strengthening Families:

Support for Mothers, Fathers and Families:

- Increase effectiveness of infant bonding through encouragement of participation of family members and spouses at birth;
- Establish supports for Aboriginal fathers, including development of "Dad-friendly", culturally-appropriate resource materials, posters and pamphlets that can be adapted to fit;
- Develop a resource manual specific for Aboriginal fathers as an adjunct to the "Journey for Two" manual for expectant mothers who travel away from home. "Finding Our Way: A resource manual for Aboriginal fathers";
- Work with Health Canada and/or local governments to provide a means of support for expectant fathers and/or grandmothers to accompany birth mothers in the labour and birth process;
- Develop culturally appropriate materials for distribution to local health centers regarding healthy pregnancy, the developing fetus, well-baby care and potential complications (what to do in an emergency) to be disseminated among expectant families;
- Develop a DVD with Traditional Healers, Midwives and Elders speaking about traditional birth ceremonies, naming ceremonies and the traditions of early child care, "Teachings of the Cradleboard".
- Develop a Culturally-appropriate, adaptable Toolkit that will address specialized support
 for mothers at risk and hard-to-reach Aboriginal mothers such as women who are
 struggling with addictions, housing and poverty to ensure that mothers and families
 receive appropriate support before, during and after the birth of their babies to
 enhance bonding and prevent apprehension by child welfare authorities.

Breastfeeding Support

- Establish a network and develop a Resource Guide for community health workers, nurses and Aboriginal women regarding available lactation consultants and breastfeeding counselors and options for those that wish to pursue this as a health career, consistent with the criteria established by the International Lactation Consultant Association;
- Develop culturally appropriate materials and information, such as a poster and booklet or pamphlet on breastfeeding basics and benefits in easy to read language for new mothers, that can be distributed nationally to hosting hospitals, clinics and health centers, as an early intervention for minimizing breastfeeding problems and to empower breastfeeding women and increase success rates for breastfeeding amongst Aboriginal women;

Perinatal Support and Care:

- Establish a network and Develop a Resource Manual for community health workers, nurses and perinatal/maternity support workers to improve pregnancy outcomes, promote better maternal and infant/child care, increase linkages between existing programs and ensure that families have access to the full range of preventive and primary health care, support and educational resources that benefit the expanding family, including specialized services for mothers at risk;
- Develop a "Train the Trainers" manual for Community Health Workers in Maternity/Perinatal Health to educate health care workers and/or community women to support expectant mothers and new families. The goal will be to establish a community-based, family-centered program to move towards achieving optimal health status amongst expectant and parenting Aboriginal mothers. These workers will provide home-based case management services, assess women and children that are engaged in the program and provide assistance in overcoming barriers to care:
- Develop educational materials for Aboriginal women that address potential complications in pregnancy such as gestational diabetes, pregnancy induced hypertension, fetal alcohol syndrome/effects and premature labour and provide information to help prevent complications such as these, provided in easy to read language.
- Engage in a series of workshops for expectant parents including newborn care, how to swaddle, making a moss bag, etc. There has been evidence to support the theory that swaddling infants up to six months of age can reduce the incidence of sudden infant death syndrome (SIDS). Reviving traditional practices such as swaddling and carrying babies in the traditional "tikanogan" can contribute to the reduction of SIDS and infant mortality amongst Aboriginal infants.

Education and Training

Education and Training for internal capacity will include participation at conferences and workshops where the focus is on birth, maternal health, infant and child health and issues that influence birth outcomes.

Education and Training for Aboriginal fathers and fathers to be regarding the
importance of maternal support, infant bonding and basics of infant care such as diaper
change, feeding, swaddling and essentials for a dad's outing. May be conducted
through a series of workshops and drop-in centers at the community level, or may be
initiated through the introduction of Aboriginal specific, dad-friendly materials and fact
sheets distributed nationally;

The World Health Organization has recommended and helped to facilitate the training of traditional birth attendants in developing countries around the world through the 1970's and late 1990's in an effort to reduce maternal mortality rates and improve pregnancy outcomes. In many developing countries most births are assisted by traditional birth attendants, who acquire their skills through experience and apprenticeship rather than the formal education that characterizes skilled birth attendants, such as doctors, midwives and nurses. Programs have been developed through a variety of education resources, including Johns Hopkins University, and include segments on promoting healthy pregnancy, recognizing complications and how to respond to minor complication, and refer for assistance in major complications, as well as emergency intervention. These programs have been very successful, and could serve as a model adapted for Traditional Aboriginal Birth Attendants, which could include a cultural component. Given that health human resources such as nurses and midwives are limited and there is strong evidence to support that a shortage of health professionals is in existence, particularly in underserved areas of the north and remote areas of Canada, it is imperative that training of traditional birth attendants be facilitated, as part of a solution. It is not anticipated that this activity will occur within the next five years, however, this is an area that warrants further exploration. Further assessment and analysis of this issue will be undertaken over the next five years, leading to a comprehensive plan to return birth closer to home for Aboriginal women. This will include

Networking with existing resources which includes the Canadian Association of Midwives and their regional counterparts, practicing midwives to act as mentors, the Society of Obstetrician-Gynecologists of Canada, the Canadian Pediatric Society, The Canadian Public Health Association, the Canadian Nurses Association, FNIHB Nurses working in the northern and remote areas of Canada, the Aboriginal Midwifery Program in Manitoba, the Six Nations Birthing Centre and the Pirvuungnituq Maternity, as well as international resources that have had successful outcomes, such as Johns Hopkins University, among others to establish a training program for Traditional Aboriginal Birth Attendants, in an effort to safely bring birthing back to Aboriginal communities.

Future plans may include activities such as:

- Development of a "Train the Trainers" manual that can be used by Traditional Birth Attendants and Midwives, as part a valuable resource for women at the community level and contribution to curriculum development for Aboriginal midwives.
- Working with existing education programs and models that can be adapted to facilitate training and skills-building for traditional birth attendants and Aboriginal midwives.

EXPECTED RESULTS AND OUTCOMES

Objective	Anticipated Outcome
Help to reduce and eliminate barriers to	Improved access to quality prenatal, postpartum
prenatal, postpartum and infant care	and primary infant care through dissemination of
	culturally-appropriate materials and publications
	such as "Journey for Two"
Support for Aboriginal fathers	Improved family relationships and infant
	bonding between infants and Aboriginal fathers
Healthy weight management and healthy	Prevention of gestational diabetes, Type 2
nutrition "Right from the Start" working with	Diabetes and its complications for both mother
CPNP	and child
Traditional culture as a means to promote	Knowledge of where resources are and the
perinatal health and healthy birth outcomes	possibility to implement cultural activities for
(such as traditional birth ceremonies, swaddling	expectant mothers and young families;
and how to make a moss bag)	Development of a DVD on traditional practices,
	ceremonies and customs on child birth and child
	care.
Improve pregnancy outcomes and decrease the	Improved pregnancy outcomes, healthy babies,
infant mortality amongst Aboriginal peoples	healthy mothers and a decrease in infant
	mortality in the Aboriginal population in 5 years.
Support for women who are transferred out for	Improved satisfaction with birth experience and
birth and support for Aboriginal fathers	stronger infant bonds with family and community
Support for breastfeeding, and community	Increased number of mothers breastfeeding
supports	their infants by 50% in 3 years

In response to the crisis of maternal mortality, increased levels of infant mortality and poor pregnancy outcomes in developing countries around the world, the World Health Organization has recommended and helped to facilitate the training of traditional birth attendants through the 1970's and late 1990's. It has been reported that the Aboriginal population in Canada mirrors the health status of the developing world, particularly with infant mortality rates and pregnancy outcomes. In many developing countries most births are assisted by traditional birth attendants, who acquire their skills through experience and apprenticeship rather than the formal education that characterizes skilled birth attendants, such as doctors, midwives and nurses. Programs have been developed through a variety of education resources, including Johns Hopkins University, and include segments on promoting healthy pregnancy, recognizing complications and how to respond to minor complication, and refer for assistance in major complications, as well as emergency intervention. These programs have been very successful, and could serve as a model adapted for Traditional Aboriginal Birth Attendants, which could include a cultural component. Given that health human resources such as nurses and midwives

are limited and there is strong evidence to support that a shortage of health professionals is in existence, particularly in underserved areas of the north and remote areas of Canada, it is imperative that training of traditional birth attendants be facilitated, as part of a cost-effective solution.

Such a solution would not only facilitate community ownership and empower Aboriginal women in taking control of birth, but also provide much needed support to overcome barriers that prevent Aboriginal infants and children from receiving a healthy start in life. Understanding that the goal of bringing birth closer to home is still some way off into the future, NWAC has identified a number of activities that will help move towards the ultimate goal of healthy mothers, healthy infants and improved birth outcomes for the Aboriginal population.

EVALUATION PLAN

EVALUATION COMPONENT

As a part of the five-year Plan of Action on Aboriginal Maternal-Child Health, it is anticipated that an evaluation component/framework will be developed at the outset of the project. This evaluation component will form a close connection between planning and implementation. As the evaluation framework has yet to be developed or completed, it will be necessary to take into account two methods of evaluation which will be incorporated:

Process Evaluation:

which will involve monitoring of the activities of the project, measuring level of achievement of indicators, feed-back forms, evaluation forms from group discussions, workshops and the proposed international summit on Indigenous women and maternal – newborn health, etc., to provide material for adjustments in planning and program implementation.

Impact Evaluation:

which will consider the results at the end of the project. This will be accomplished through a variety of methods such as: feed-back forms, surveys, review of evaluation forms from process evaluation, and/or full scale evaluation research to compare current community Pregnancy and Infant Health knowledge and Pregnancy outcomes, parenting, support for fathers, and breastfeeding to these situations in five years' time.

DISSEMINATION

Results of workshop participants, as well as reports from conferences attended and hosted by the Native Women's Association of Canada will be posted on the NWAC website as well as communicated through the NWAC Health Newsletter.

Materials developed, such as the resource manual for Aboriginal fathers, promotional materials and educational resources such as posters, pamphlets, booklets and any DVD's produced on traditional birth ceremonies, naming ceremonies and traditional teachings on child care will be distributed nationally to PTMA's and NWAC events, gatherings and meetings as appropriate, as well as publicized and made available through the establishment of an information clearinghouse, as has been recommended.

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