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FACULTY OF GRADUATE AND
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Learning From Success: An Exploration of Community-based Stakeholders' Views on Improving
Care for Pregnant and Parenting Aboriginal People

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Learning From Success:

An Exploration of Community-based Stakeholders' Views

on Improving Care for Pregnant and Parenting Aboriginal People

Dawn Smith

Thesis submitted in partial
fulfillment of the requirements for
the PhD degree in Population Health

Faculty of Graduate and Postdoctoral Studies
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ABSTRACT

The human rights abuses and resource exploitation of Aboriginal people in Canada's colonial past and neocolonial present has left a legacy of inequitable health and social conditions that contribute to increased perinatal risk factors. The complex "system" of administration, governance and health services delivery impedes program innovation and responsiveness alienating relationships between Aboriginal people, health care providers and organizations. These dynamics underlie the problems of poor access to, participation in, and outcomes of care during pregnancy among Aboriginal women and families.

The study used a critical postcolonial stance and an emancipatory methodological approach to describe community-based stakeholders' perspectives on their experiences improving care for pregnant and parenting Aboriginal women and families. Phase I exploratory interviews with 16 First Nations community, policy, and health service leaders and providers identified Aboriginal 'innovator' organizations for participation in phase II. Two Aboriginal health care organizations in one region of British Columbia participated in the comparative case study. Data were collected through exploratory interviews and small group discussions with 57 people, document review and researcher field notes and were analyzed using the interpretive descriptive method.

Seventy three people participated, with 60 percent self-identified as Aboriginal and 90.4 percent women. Results show that Aboriginal parents' experience, and therefore the intention of care must be situated within an understanding of colonial and neocolonial relations, especially the intergenerational impact of residential schools; safety in health care relationships and settings; and responsiveness to peoples' experiences, priorities and capacities. Care for pregnant and parenting Aboriginal people involves multiple stakeholders who may hold different views of health care roles, relationships and decision-making. While the two cases shared a similar vision of roles and relationships, differences in processes of health system change, and in the governance models impacted the Aboriginal organizations' experiences of improving care for pregnant and parenting Aboriginal people.

Greater stakeholder involvement in governance of care may enhance Aboriginal organizations' capacity to achieve safe and responsive care. This can contribute to moving forward from the intergenerational impact of residential schools, toward Aboriginal peoples' vision for strong and healthy children, families and communities.

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I am indebted to the Aboriginal organizations and individuals who participated in this study. For reasons of confidentiality they can't be named, but I would like to express my humble respect and deep appreciation for those people in each organization and community who welcomed me, and gently guided me through the subtleties of their organization, community and world.

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LIST OF ABBREVIATIONS

ACADRE – Aboriginal Capacity and Development Research Environments

AFN – Assembly of First Nations

AHF – Aboriginal Healing Foundation

FNIHB – First Nations and Inuit Health Branch

F/P/T ACPH – Federal/Provincial/Territorial Advisory Committee on Population Health

IGIRS – Intergenerational Impact of Residential Schools

INAC – Indian and Northern Affairs Canada

NAHO – National Aboriginal Health Organization

NTC – Nuuchah Nulth Tribal Council

RCAP – Royal Commission on Aboriginal People

RHA – Regional Health Authority

SIDS – Sudden Infant Death Syndrome

OVERVIEW OF THE DISSERTATION

This dissertation emerged from the population health issue of inequities in access to prenatal care for Aboriginal people in Canada. While there has been considerable research describing intervention approaches with the general population, evidence to understand how to improve the problem of late access and low use of prenatal care, and poor pregnancy outcomes among Aboriginal people is scarce. The study adopted a postcolonial standpoint and used qualitative data collection methods in a comparative case study design within an emancipatory research methodology to explore the perspectives of stakeholders to this issue. In particular, the study sought to describe perspectives from Aboriginal parents and community-based providers and organizations reputed to have developed an innovative approach to care for pregnant and parenting Aboriginal people. The purpose of the study was to describe, from a postcolonial standpoint, community-based stakeholders' perspectives on their experiences designing, implementing, and evaluating care for pregnant and parenting Aboriginal women and families.

The contents of the dissertation are divided into four parts. The dissertation begins with a statement of the research problem, the research purpose and questions, and background information on Aboriginal health status, determinants and health care delivery systems in Part I. The rationale for using a critical postcolonial standpoint to study this population health problem is outlined. Used in combination, population health and postcolonial perspectives enable an 'upstream'¹ analysis of how approaches to prenatal care in Aboriginal communities have contributed to health and social conditions

¹ 'Upstream' is a metaphor for taking a preventive approach in health care intervention. A 'downstream' approach intervenes *after* health problems have emerged and have progressed to the stage that activities of daily living are affected and more expensive, complex intervention is required. An 'upstream approach' aims at prevention and development of skills and capacity for successful living. It requires explanations for the source of health inequities.

experienced by Aboriginal populations in Canada. A literature review explores and evaluates the strengths and weaknesses of the evidence describing maternal child health care in Aboriginal communities. The a priori conceptual framework, and operational definitions that were used at the outset of the study are described. Principles of emancipatory methodology, and qualitative methods used in the two phase comparative case study design are briefly summarized. Salient characteristics of the study setting and population of interest are outlined. This is followed by a brief section on study implementation which describes: events and decisions made during study implementation, strategies used to build rigor, how the study was influenced by participants, and a critically reflexive account of my influence as research instrument.

In Part II the study results are presented in a series of three papers for peer reviewed publication. The papers are formatted according to the guidelines for authors for the target journals indicated. Paper # 1 was published in *The Canadian Journal of Nursing Research*, and reports on results pertaining to the research question ‘what are Aboriginal parents’ views of the importance of pregnancy and parenting?’ This analytical and descriptive work was put at the forefront of the analysis to reflect participants’ views that care during pregnancy and parenting must flow from the perspectives and values of the people they serve. Thus, before describing the features of support for pregnant and parenting Aboriginal people, Aboriginal parents’ views of what is important about their pregnancy and parenting experiences had to be captured. The implications from paper #1 were then used to set the context for analysis and description in paper #2.

Paper #2 was prepared for submission to *Advances in Nursing Science* and reports on results pertaining to the research questions ‘what are community-based stakeholders views on care during pregnancy and parenting?’, and ‘how does (this) care during pregnancy and parenting make a difference to Aboriginal women and families?’. Paper #3 was prepared for *The International Journal of Health Services* and describes results related to the research questions, ‘what were Aboriginal organizations’ experiences improving care for pregnant and parenting Aboriginal people?’ and ‘what was the influence of context on Aboriginal communities experiences improving care for pregnant and parenting Aboriginal people?’

Part III integrates the results and describes implications of the study for the field of population health. Contributions of the study to improving access to and responsiveness of interventions for Aboriginal people during pregnancy and parenting are described. Insights into the design and evaluation of population health interventions, and the development of population health science are outlined and limitations of the study are presented. Part IV describes the contributions of collaborators. This is followed by the references for Part I and Part III, and the appendices.

The organization of the dissertation reflects the guidelines of the population health PhD program, as well as an effort to illustrate how many ways of knowing informed the results. For example, Charlie George's hummingbird carving is a *symbolic* representation of many of the themes identified in the results. The carving was offered for sale during fieldwork. Charlie described the meaning behind each of the symbols in the carving, and why he had placed them together. I purchased the carving and asked for permission to use the image². Later, I contacted Charlie again, and sought his permission to use the image along with the written results during dissemination. The image and explanation are used to open Parts I and III. *Critical reflexivity* is another way of knowing that has been integrated into this document. Excerpts of critical reflective writing are integrated into presentation of the dissertation because critical reflexivity was so central in both the process and results of the research. The excerpts of critical reflective writing were chosen to show growth and evolution of my thinking and understanding as I moved through the dissertation experience, and to make explicit the links between participant voice and expression, and use of myself as research instrument. Critically reflective

² I used the informed consent developed for the study when seeking permission to use the carving. Once I had the results written, a summary was sent to Charlie with a specific description of how the carving image would be used for dissemination.

writing is used at the end of Part I, to open Part II., and to link the hummingbird carving image and integration of results at the opening of Part III.

Part I:

INTRODUCTION



Used with permission

These birds were carved by Charlie George of Heiltsuk Nation in Bella Bella, British Columbia. Charlie's explanation of the carving resonated strongly with the participants' perspectives.

The hummingbirds symbolize the flow between the past and the future. The mother hummingbird with a baby riding on her back echoes participants' long-term view of the significance of pregnancy and parenting.

Charlie's description of the direction, courage and strength symbolized by the eagle fit with the strength and energy embodied by participants in the study, striving toward their vision of a better future for their children.

Charlie's description of the raven as the traditional trickster, reminded me of participants' accepting attitude toward the changeability, ebbs and flows of life. Charlie carves in cedar because it is a source of strength for First Nations people, and symbolizes the connection with the environment from which it draws its strength.

Statement of the Problem

The problem of poor access to supportive care during pregnancy in Aboriginal¹ populations is well documented (Bridge, 1999; DeCosta & Child, 1996; Goldman & Gleib, 2003; Hoyert, Freedman, Strobino & Guyer, 2001; Humphrey & Holtheimer, 2000; Luo, Wilkins, Platt & Kramer, 2004; Luo, Kierans, Wilkins, Loston, Uh & Kramer, 2004; Public Health Agency of Canada, 2005). This widespread pattern of tardy or no care during pregnancy, implies a lack of culturally appropriate support during pregnancy that is relevant to the needs and strengths of Aboriginal women and families (Browne & Smye, 2002; Long & Curry, 1998; Powell & Dugdale, 1999; Sokolowski, 1995; Westenberg, van der Klis, Chan, Dekker & Keane, 2002). The underlying problem is that prenatal care for many Aboriginal women continues to be dominated by an expert-directed, biomedical model of care that usurps rather than complements traditional knowledge related to pregnancy and childbirth (Adelson, 2004; Dion-Stout & Kipling, 1999a; Dion-Stout & Kipling, 1999b). This approach to care disempowers clients *vis-à-vis* health care providers (Browne, 2003; Browne, Fiske & Thomas, 2000; Browne & Smye, 2002) and decreases real access to the supportive relationships women and families need during pregnancy. As a result, many Aboriginal people miss out on the individual and population health benefits of preventive and health promoting interventions before, during and after pregnancy.

¹ The term Aboriginal Peoples "refers to organic political and cultural entities that stem historically from the original Peoples in North America, rather than collections of individuals united by so-called 'racial' characteristics" (*Royal Commission on Aboriginal Peoples*, 1996). In Canada, these include the First Nations, Inuit, and Métis peoples. Use of the term Aboriginal is not meant to negate the uniqueness of the three groups, but to be inclusive and reflective of the diversity of the populations being served by the organizations involved in this study.

Aboriginal people have emphasized that new health and healing systems must embody equity in access to services as well as health status outcomes, holistic approaches to interventions, Aboriginal authority over health systems, responsiveness to differences in cultures and community realities and, where possible, community control over services (Royal Commission on Aboriginal People [RCAP], 1996). While governments have acknowledged the need for change (Canadian Population Health Initiative, 2004; Romanow, 2002), innovative approaches to care for pregnant and parenting Aboriginal people have yet to be described in the literature. Focusing particularly on care during pregnancy and parenting, this dissertation contributes to understanding how to shift from the colonialist health care programs of the past to approaches that are effective in reducing inequities in health while also promoting self-determination of Aboriginal peoples.

Research Purpose and Questions

The purpose of this dissertation is to describe, from a postcolonial point of view, community stakeholders' perspectives on their experiences designing, implementing, and evaluating care for pregnant and parenting Aboriginal women and families. At the start of this emancipatory study, the research questions were:

1. What was the influence of contextual factors on Aboriginal communities' experiences in designing, implementing and evaluating prenatal care?
2. What was the process of transforming the prenatal care approach in this community?
3. What are the attributes (knowledge, values and procedures) of approaches to prenatal care in Aboriginal communities?

4. What are the perspectives of Aboriginal communities on how their approach to prenatal care makes a difference?

Background

This background section outlines the distribution of Aboriginal people in Canada; cites examples of inequities in health and social conditions related to prenatal care; and explains historical, jurisdictional, and administrative complexities of delivering and improving health services for Aboriginal people.

Population Description.

Aboriginal people are a young and rapidly growing population relative to the rest of Canada. Their growth rate (3%) is double that of the general population. The term 'Aboriginal population' in Canada counts persons who self-identify as First Nations, Métis or Inuit, as well as people who report themselves as Registered or Treaty Indians, or Band or First Nation members. Since the *Indian Act* of 1876 (Government of Canada, 1985), the federal government has had jurisdiction over health services delivered in Aboriginal communities². About 410,645³ (41.1%) of the nearly one million people identifying as Aboriginal live in 602 First Nations or Métis communities under federal jurisdiction for provision of health services (Indian and Northern Affairs Canada [INAC], 2004). Many of these communities are geographically isolated, having either no road access or access for only part of the year. The majority (67%) of Aboriginal Peoples in Canada live in ar-

² First Nations, Métis and Inuit communities under federal health care jurisdiction are often referred to as Indian Reserves or communities 'on-reserve'. In this dissertation, I will simply refer to communities under federal jurisdiction as 'Aboriginal communities'.

³ Differences in population estimates may be explained in part by inaccurate enumeration resulting from Aboriginal communities choosing not to participate in the census, and to population growth between 2001 and 2003.

areas where provision of health care is a provincial responsibility (Statistics Canada, 2003). Delivery of health care to Aboriginal people in Canada crosses provincial and federal jurisdictional responsibilities for health care.

Health and Social Conditions.

Inequities in health and social conditions between Aboriginal and mainstream Canadian populations have been well documented (Canadian Population Health Initiative, 2004; Federal/Provincial/Territorial Advisory Committee on Population Health [F/P/T ACPH], 1999; First Nations and Inuit Regional Longitudinal Survey Steering Committee, 1999; Romanow, 2002). For example, in the year 2000 the gap between life expectancy of registered Aboriginal people and other Canadians was estimated to be 7.4 years for men and 5.2 years for women (INAC, 2002). Aboriginal people have twice the premature mortality rate of the mainstream population (6.6 versus 3.3/1000), with some areas as high as 9.3/1000 (Martens et al., 2002).

Access to the determinants of health, including adequate income, food supply, housing, and safe water and sanitation continue to be a challenge in many Aboriginal communities. Forty-six per cent of people in Aboriginal communities live in inadequate housing (INAC, 2002), compared to 20% of non-Aboriginal people in rental accommodation. Poverty is widespread with 60% of all Aboriginal children from birth to six years of age living in low-income families (compared to 25% in the Canadian population) (F/P/T ACPH, 1999). Forty-four per cent of people residing in Aboriginal communities live below the low income cut-off point (versus 20% in the Canadian population) (F/P/T ACPH, 1999).

Risk factors during pregnancy include high rates of teen pregnancy (9% of Aboriginal children live with teenage mothers as compared to 1% in the non-Aboriginal population). Though the exact prevalence is not known, estimates of defects from alcohol-use during pregnancy among Aboriginal people range from 2.8 to 9.1/1000 live births (Canadian Pediatric Society, 2002). Substance use during pregnancy is associated with poverty, substance use of significant others, and family violence (Howell, Heiser, Harrington, 1999). Maternal smoking has been associated with low birthweight babies (Kramer, 1987; Lumley, Oliver, Chamberlain & Oakley, 2004; Stevens-Simons & Orleans, 1999) and sudden infant death syndrome [SIDS]. In British Columbia between 1987 and 1992, the status Indian SIDS death rate (5.97 per 1,000 live births) was over three times the SIDS death rate for British Columbia as a whole (1.57 per 1,000 live births), though the rate has improved sharply since 1995 (British Columbia Vital Statistics Agency, 2002). Infant mortality from injuries is nearly four times the rate in non-Aboriginal populations (Assembly of First Nations [AFN], 1999), indicating possible risks related to physical environment, equipment, family coping skills and lifestyle. These statistics demonstrate how disadvantage may begin from before conception, and continue during fetal development and over the lifetime of Aboriginal people. Appendix A summarizes perinatal health risk factors and indicators for the Aboriginal and general Canadian populations between the years 1991 and 2000.

Delivery of Health Care Services

Health care services for Aboriginal people are delivered through a complex collection of independent administrative, governance and implementation systems, rather than an integrated system of support. In federal jurisdiction, health care services have been deliv-

ered directly through the First Nations and Inuit Health Branch (FNIHB) of Health Canada (formerly known as the Medical Services Branch). However, delivery of health care services has undergone considerable change over the last two decades through health transfer processes.

Transfer of health services to First Nations' control. As outlined in FNIHB (2000), health transfer has evolved since the 1960's when the federal government position was to discontinue special services, remove treaty status and move to increased if not full assimilation of Native people into Canadian society (1969 White Paper). In their response (the 1970 Red Paper), First Nations emphasized federal responsibility for health care to First Nations people, as well as a desire for "greater control over their lives and government delivered community programs" (FNIHB, 2000). This set the agenda for a process which enabled First Nations to exert more control over health priorities and approaches to address them, and the federal government to meet its fiduciary responsibilities. Over the next two decades of federal government-First Nations relations the health transfer process was developed, culminating in a health transfer policy framework in 1989 (FNIHB, 2000). The health transfer framework laid out a process for transferring resources for Indian health programs south of the 60th parallel to Indian control. The framework emphasized the following goals and conditions as outlined in FNIHB (2000):

- transfer of health program control was optional and would occur at a pace determined by the community;
- communities could design health programs to meet their needs;
- certain public health and treatment programs were mandatory;
- accountability of Chiefs and Councils to community members;

- flexibility for communities to allocate funds according to community health priorities and to retain unspent balances;
- responsibility for communities to eliminate deficits, for annual financial audits and evaluations at specific intervals;
- “permits multi-year (three to five year) agreements”;
- “does not prejudice treaty or Aboriginal rights”; and,
- “operates within current legislation”.

Upon the decision to enter the process of developing a transfer agreement, funding was provided to the First Nations community for planning and development activities such as setting up a health management structure, assessing health needs, and developing a community health plan, prior to taking control over the delivery of health programs (FNIHB, 2004).

However, not all communities were prepared to take this level of control. So in 1994, Integrated Community-Based Health Services Agreements (now called Consolidated Contribution Agreements – General) (FNIHB, 2004) were developed to enable communities a limited level of control over health services. Under these agreements, communities are not able to re-prioritize or redirect health resources. As of September 2005, 80% of eligible First Nations Communities are involved in the First Nations Control Process as follows: 47% through Transfer Agreements (143 Signed Community-Based Transfer Agreements representing 286 First Nations Communities); 19 through Agreements for Treatment Programs, Hospitals and 2nd/3rd Level Services; and 32%

through Integrated Community-Based Health Services Contribution Agreements (165 Agreements representing 196 First Nations Communities)⁴ (FNIHB, 2005).

Over the last decade some improvements have been noted, such as greater congruence between health care services and local values and beliefs, increased emphasis on the role of family, culture and prevention, and more effective integration between traditional and western approaches (RCAP, 1996; Smylie, 2000). However, there are still significant obstacles and concerns to be addressed, including community capacity for effective management and governance of services (Auditor General, 2000), fears that the federal government will withdraw from fiduciary responsibility for health (Boyer, 2003; Waldram, Herring & Young, 1995) and failure of transfer agreements to address emerging needs (O'Neil, 1995). "Action must be taken to create new models to co-ordinate and deliver health services, ... give Aboriginal people a direct voice in how health care services are designed and delivered"(Romanow, 2002, p. 212), address health needs further upstream, and adapt health services and programs to each community's unique cultural, social, economic and political circumstances.

Maternal child health care services. Maternal child health care is part of the primary health care services delivered in community health centres and northern nursing stations, mostly by registered nurses who work in collaboration with community health representatives. Approximately 1,200 fulltime equivalents of registered nurses are employed by FNIHB or directly by the First Nations communities or organizations and manage their

⁴ Seven Inuit Communities are included in transfer agreements, and there are 5 Integrated agreements involving 5 communities in the Yukon.

own health services with funds provided by FNIHB through contribution agreements (Smith, 2003).

The FNIHB's maternal child health care program is comprised of: 1) prenatal care; 2) evacuation for birth to provincial tertiary care facilities; and 3) postnatal care. According to recent maternal child health program manuals (Smith, 2002), program design for pre- and post-natal care varies considerably among regions (FNIHB-Pacific Region, 1998; FNIHB- Saskatchewan Region, 1996; FNIHB-Manitoba Region, 1995; FNIHB-Quebec Region, 1987). Some regions adopted an evidence-based prevention and population health approach to service delivery and evaluation, though most regions continued to employ policy developed in the 1980s that took an individual, biomedical and task-oriented approach. Some strengths were noted. For example, one region employed a community development approach, one region included some description of cross-cultural considerations, one region had a prenatal screening protocol, and one region added a section to the program manual on family-centered care. However, in general, FNIHB programs have been criticized for overemphasis on crisis intervention rather than prevention, and downstream, biomedical, individually-focused programs in perinatal health (Chamberlain, Barclay, Kariminia & Moyer, 2001; O'Neil and Gilbert, 1990).

In addition to the pre- and post-natal programs delivered primarily by nurses in partnership with community health representatives, there are a number of related programs. These programs include the Canada Prenatal Nutrition Program, Fetal Alcohol Syndrome/Fetal Alcohol Effects Prevention Program, the Aboriginal Head Start on Reserve, Better Beginnings/Brighter Futures, and Canada's Action Plan for Children. Responsibility for these programs is split between Human Resources Development Canada, Indian

and Northern Affairs Canada, local Aboriginal governments, and the FNIHB of Health Canada. Many of the approximately 602 Aboriginal communities in Canada are geographically isolated, and do not have the population, resources or capacity to support these programs. More recently these longstanding challenges to the delivery of a continuous system of support during and after pregnancy have been complicated by nursing shortages. For example, in 2002, nursing staff vacancies were as high as 50% and nursing staff turnover rates reached 40% in 18 months in some communities. Small isolated communities have reported having as many as 42 different nurses in one year (Minore, Boone, Katt, Kinch & Birch, 2001).

These challenging health and social conditions, geographical, and jurisdictional, and health service administration and delivery issues are layered on top of a socio-political legacy of colonial-style policies that exploited Aboriginal resources (e.g., lands, culture, Indigenous knowledge), violated human rights (e.g., residential schools, the right to own property, the right to vote, the right to raise their own children) (Aboriginal Healing Foundation, 2002; Battiste, 2000), and created a dependent yet alienated relationship between Aboriginal people and health care providers (RCAP, 1996; Romanow, 2002).

Looking Upstream: A 'Postcolonial Population Health' Problem

Population health extends beyond an individual notion of health, and "focuses on the interrelated conditions and factors that influence the health of populations over the life course" (F/P/T ACPH, 1999, p. 7). The concept of population health has evolved over the last 20 years, and builds on a much longer evolution of understanding of health developed in public health, community health and health promotion (Hayes & Dunn, 1998; Health Canada, 2001). Population health takes a socio-environmental or ecological view

of health and addresses underlying causes of inequities in health between population groups (F/P/T ACPH, 1999; Stokols, 1996). What constitutes a 'health inequity' depends on one's views of justice and society, and the reasoning behind how the differences were created (Kawachi et al., 2002; Macinko and Starfield, 2002).

In this study, critical postcolonial perspectives were used to explain inequities in health experiences by Aboriginal people within a population health framework (Health Canada, 2001). Population health's emphasis on indicators of health status and the determinants of health, was strengthened by a socio-historical analysis of how social conditions have been created, largely through the colonial legacy. Previously, inequities in health and access to effective health services by Aboriginal people have often been attributed to characteristics of "Aboriginal" lifestyles, behaviours or culture (Browne, 2002; RCAP, 1996; Smylie, 2000). Framing health inequities of Aboriginal people from an individualist, paternal or victim-blaming (neoliberal) perspective was more typical of the biomedical-dominated approach to public and population health in the 1970's and 1980's (Rachlis & Kushner, 1994; Romanow, 2002). The 1990's witnessed a shift to a socio-environmental approach that emphasized an analysis of how environments, in combination with genetics, lifestyle and personal coping skills, determine health and wellbeing across the lifespan (Evans, Barer & Marmor, 1994; Frank, 1995; Smedley and Syme, 2000). Thus, a *postcolonial* population health perspective enables a more upstream analysis of inequities in health and social conditions experienced by Aboriginal people.

Postcolonial Theory and Criticism

Postcolonialism evolved as a complex interdisciplinary dialogue seeking to critically review and transform the relationships set up by colonialism. It is "concerned with the

historically determined relationships of dominance and subordination... inaugurated by the onset, rather than the end of colonial occupation” (Gandhi, 1998, p. 3). Among the ‘postcolonials’ are postcolonial theory (Spivak, 1994; Said, 1978), postcolonial criticism (Young, 2001) and postcolonial Indigenous thought (Battiste, 2000; Smith, 1999). These perspectives have in common an agenda to comprehend, deconstruct, resist and transform the impact and institutions of colonialism (Battiste, 2000; Reimer-Kirkham & Anderson, 2002), which I see as a critical postcolonial viewpoint. A critical postcolonial standpoint fits under the umbrella of critical theory (Mill, Allen & Morrow, 2001) and examines “the unequal relations of power that are the legacy of the colonial past and neocolonial present, and the ways in which the cultures of dominant groups have redefined local meanings, and dictated social structures, including health care delivery systems” (Anderson et al., 2003, p. 197).

In a seminal text on postcolonial Indigenous thought, Battiste (2000) outlines four doors into postcolonial resistance and transformation: 1) mapping colonization (west); 2) diagnosing colonialism (north); 3) healing colonized Indigenous people (east); and 4) visioning the Indigenous renaissance (south).

The first door, *mapping colonization*, seeks to understand and critique the trauma of colonization as a system of oppression. Colonization came in two main forms: settling and domination (Young, 2001). The settlers became an in-between agent for the colonizing nation and the Indigenous people, “whom the (settlers) would for the most part slaughter, expel from their own lands, or exploit as a labour force” (Young, 2001, p. 19).

Battiste’s (2000) second door, *diagnosing colonization*, explores the “unquestioned and conflicting assumptions” that underpin the oppressive relations in a colonial world

(p. xxiii). As Said (1978) argued, all western systems of cultural description are deeply contaminated with “the politics, the considerations, the positions and the strategies of power” (cited in Moore-Gilbert, 2003). Said further emphasized the inseparable nature of Western systems of representation and knowledge with Western material and power structures. Diagnosing colonization involves exploring assumptions and processes of racialization and critiquing essentialism (Anderson et al., 2003).

This “perverse longevity” of colonialism is sustained in large part, by persisting colonial hierarchies of knowledge and value that reinforce what Edward Said calls the ‘dreadful secondariness of some people and cultures’ (cited in Gandhi, 1998, p. 7). “Eurocentric science ignores/has excluded the majority of the knowledge and linguistic categories of more than half the world” (Battiste and Henderson, 2000, p. 121). In contrast, post-colonial scholarship rejects hierarchies that subordinate some forms of knowledge and processes of knowledge formation to others (Young, 2001). Instead, multiple ways of knowing and using knowledge would be valued for their utility in improving society. Indeed, dismantling the hegemony of Eurocentric standards of evidence has begun. “The Supreme Court of Canada has ordered the legal profession to include and respect Indigenous oral traditions in standards for evidence... — other decision-makers should likewise consider the validity of Indigenous” (Battiste, 2000, p. xx) and other forms of knowing as evidence to inform improvement of social and public processes such as law, health care and education.

“Indigenous knowledge emerged from the processes of Indigenous peoples’ collective experience with ecologies, including the products of their human minds and hearts. All Indigenous knowledge flows from the same source: relationships within the global

flux, kinship with other living creatures and the life energies embodied in their environment, and kinship with the spirit forces of the earth” (Battiste and Henderson, 2000, p. 125). Postcolonial scholarship must be designed and conducted in a way that attends to and includes all forms of knowledge, and is sensitive to how it will be used to heal and renew Indigenous people and communities.

The third door is *healing colonized Indigenous peoples* by engaging in intellectual and practical efforts to “heal ourselves, our collective identities, our communities, and the spirit that sustains us” (Battiste, 2000, p. xiv). Bhabha (1994) refers to this stage as a “painful putting together of the dismembered past to make sense of the trauma of the present” (cited in Young, 2001, p. 63). Healing involves restoring Indigenous ecologies, consciousness and language, and respecting that Indigenous people must develop their own process of healing and recovery (Battiste, 2000). Healing of colonized Indigenous peoples means that both Indigenous and non- Indigenous people must respect individual identities and experiences (Anderson et al., 2003).

The fourth door envisions an “*Indigenous renaissance*”— or “a postcolonial society that embraces and honors diversity” (Battiste, 2000, p. xviii). This will involve creating bridges between Indigenous and other forms of knowledge, including Western or Eurocentric science. Working toward a society that embraces and honors diversity requires that scholars and practitioners maintain a critical reflexivity on themes and processes of power and domination (Anderson et al., 2003).

Battiste’s four doors suggest an inclusive approach to changing ideological and social structures that maintain inequities between Aboriginal and non-Aboriginal populations. It positions Aboriginal people as central agents of this societal change. It moves beyond

dichotomies of knowledge and divisive ‘us-them’ ways of thinking, towards recognition and valuing of the strengths made available through integrating diversity. That is the central work and contribution of this dissertation: to explore how combining postcolonial and population health approaches may contribute to new knowledge that will reduce inequities in access to care during pregnancy and parenting experienced by Aboriginal people.

A Postcolonial Population Health View on Prenatal Care in Aboriginal Communities

A postcolonial population health approach moves analysis of the problems of prenatal care in Aboriginal communities ‘upstream’ to the source of the problem of inequities in health, suggesting that understanding the fundamental problem lies in analyzing how colonial values and ideologies have influenced social relations, that in turn have influenced health care policy. The influence of colonialism on the social environment and access to appropriate prenatal care for Aboriginal people are briefly described here.

From a postcolonial perspective “inequities in health and social indicators [of Aboriginal people] cannot be glossed over as lifestyle, behavioural or cultural issues, [but] are manifestations of the complex interplay of historical, socioeconomic and political conditions” (Browne & Smye, 2002, p. 28). Health policy dominated by western and biomedical worldviews, values and practices, maintains the colonialist relationship between Aboriginal people and health care providers. Policy that subordinates Aboriginal values and beliefs has inherently limited utility in promoting health. Viewing the conditions of Aboriginal people through a ‘culturalist’ lens implies that “issues of access, compliance and poor health status stem from cultural characteristics that conflict with mainstream, routine health care practices” (Browne & Smye, 2002, p. 43). This ahistorical and apolitical perspective is “problematic since [it] diverts attention away from the underlying structural

inequities influencing the macro-level dynamics of health inequalities and the micropolitics of health care encounters” (Reimer-Kirkham & Anderson, 2002, p. 10).

During the nineteenth century, “European impressions of Aboriginal women were dominated by associations with animal nature and the myth of painless childbirth” (Jasen, 1997, p. 383). Then, in the early twentieth century, “high infant and maternal death rates began to arouse official concern”, and were “blamed on Aboriginal women’s ignorance of healthy child-bearing practices”. As part of its “civilizing mission”, the Canadian government adopted an interventionist policy of... evacuating pregnant women to distant hospitals (Jasen, 1997, p. 383). This colonial history has devastated traditional knowledge related to pregnancy and childbirth (Calm-Wind and Terry, 1992; Grieg, 1990; Voisey, Okalik, Brown and Napayok, 1990), and has had a serious impact on the social, cultural and psychological wellbeing of Aboriginal women, children, families and communities (Dion-Stout, M. & Kipling, G., 1999b; O’Neil, 1995; Paulette, 1990; Stonier, 1990).

In 2002, as part of a strategy to transform nursing in the FNIHB, a review of maternal child health care was conducted in response to the longstanding concerns related to evacuation for childbirth (Smith, 2002). Maternal child health program manuals from national and all FNIHB regions were reviewed, key informants were interviewed and the international literature on maternal child health care with Aboriginal and mainstream communities was synthesized to identify the strengths and gaps in the current approach. The review found maternal child health care in many Aboriginal communities centered on bio-medically oriented policy such as evacuation of women in late pregnancy for “medically safe births”. FNIHB maternal child health care programs were found to be inconsistent in content, implementation and support across the country (Smith, 2002). For

example, interventions to strengthen personal and family coping skills, and provide greater support for pregnant and postpartum women and families in the community environment are not systematically included in regional prenatal care program designs (FNIHB-Manitoba Region, 1995; FNIHB-Pacific Region, 1998; FNIHB-Quebec Region, 1987; FNIHB-Saskatchewan Region, 1996). Little if any reference to traditional knowledge was made by FNIHB program manuals. There were exceptions however, and some work had been done to encourage nurses to consider cultural values and beliefs, and collaborate with community stakeholders (FNIHB-Pacific Region, 1998).

Literature Review

The purpose of this literature review was to identify prenatal care approaches that improved early access to appropriate prenatal care for Aboriginal women and families. Assumptions from population health and a postcolonial standpoint influenced the method of searching, screening, and synthesizing the literature. Assumptions included: a) research evidence could inform improvements to prenatal care for Aboriginal women and families; b) literature applying varied approaches and analyses should be included; and c) Canada's colonial past and neocolonial present should be taken into account in approaches to prenatal care for Aboriginal people.

Method

The published and grey literature was searched and screened, and the evidence of prenatal care was synthesized. A systematic search strategy was developed, modified and run separately on each of the four databases, MEDLINE, CINAHL, EMBASE and SOCIOFILE (*See Appendix B: Maternal Child Health care Search Strategy*). Systematic

review databases were searched by hand and the results are listed in *Appendix B*. The published literature search included evidence from the period from 1995 to June 2005⁵. Grey literature such as government synthesis reports, proceedings of conferences and roundtables, and descriptive and qualitative research reports was identified over a period of two years (January 2002–January 2004). The sources identified in the grey literature from earlier dates (e.g., 1990) were included so that seminal documents from a variety of Aboriginal and non-Aboriginal sources were incorporated⁶.

The articles were initially screened for relevance to Aboriginal communities. Those retained were studies meeting one or more of the following criteria: a) having a focus on prenatal care; b) undertaken with Aboriginal or Indigenous populations; c) describing models for geographically isolated populations. All studies examined client/community perspectives. Studies were reviewed for quality using appropriate methodological guidelines⁷. Studies that focused on the effectiveness of individual-oriented biomedical interventions were excluded.

Cultural safety emerged as an issue in the delivery of maternal child health care with on-reserve Aboriginal populations (Smith, 2002). However, there were no studies of cultural safety in the context of prenatal care in the published and grey literature on maternal child health care. Thus an additional search of the literature was conducted to identify theories and evidence of cultural safety in health care more generally. The search strat-

⁵ The Automatic update service of the University of Ottawa library was used to update the search results. Last update was in June 2005.

⁶ For example, the work of O'Neil & Gilbert (1990) has played a pivotal role in bringing health and human rights issues related to maternity care for Aboriginal women in Northern Canada to the attention of policy-makers. The study by Calm-Wind and Terry (1991) was identified by several key Aboriginal informants as a seminal study of the work of traditional midwives from the Anishnawbe-Aski Nation in Ontario.

⁷ Studies were reviewed according to criteria for quality in qualitative (Hills, 2000), quantitative (Law, Stewart, Pollock, Letts, Bosch & Westmoreland, 1998), and systematic review (Moher, Cook, Eastwood, Olkin, Rennie & Stroup, 1999) methodologies.

egy for cultural safety is described in *Appendix C: Cultural Safety Search Strategy*. This search yielded a total of 87 hits, but after screening for articles describing results of empirical investigations, reviews of evidence, conceptual analyses, and cultural safety policies from governments and professional associations, the total number of included articles on cultural safety was 14⁸.

Results

Included studies are summarized in *Appendix D: Summary Table of Included Studies*.

Table 1.1 shows the methodology, population and setting (geographically isolated or not) of the studies included in this review.

Table 1.1: *Methodology, Population and Setting of Included Studies*⁹

Methodology of the Study	Total #	# Aboriginal Population	# Isolated Settings
Studies from Programs* of Research	25 studies (4) programs	19 studies (3) programs	0
Systematic or Comprehensive Reviews	15	1	0
Narrative Reviews	8	3	3
Quantitative Studies	13	6	3
Program Evaluations/Audits	6	5	3
Qualitative Studies	15	10	4
Total	82	44	13

*Programs involve a series of interdependent research projects related to a single theme, and usually involve stronger partnerships between researchers and decision-makers (Canadian Health Services Research Foundation, 2004).

⁸ The majority of published references to cultural safety were commentaries for and against the introduction of cultural safety as a standard for nursing practice in New Zealand.

⁹ Columns in Table 1.1 do not represent mutually exclusive categories.

The frequency analysis shows strengths and weaknesses in the included studies from a variety of perspectives. For example, more than half of the included articles (44) described empirical investigations, program evaluations, policy syntheses of prenatal care and related intervention approaches with Aboriginal populations. Nearly half of these (19/44) were reports from programs of research done over time in a single community¹⁰, demonstrating the benefits of collaborative efforts between researchers and Aboriginal communities over a sustained period. The majority (18) of articles included were reports of small qualitative studies with single communities, narrative reviews, or program evaluations. Furthermore, though there were 15 systematic or comprehensive reviews of prenatal care interventions, only one of these was done with studies involving Aboriginal populations. There were very few studies and no systematic reviews of prenatal care intervention in isolated settings. Principles of prenatal care were extracted from the included studies. They are described below.

Principles to Inform the Approach to Prenatal Care

Principles of prenatal care gleaned from included studies concerned: multi-dimensional, culturally safe, client/woman-centered, trusting relationship, continuity, and community involved/driven. Each of these principles and salient aspects of the evidence to support them are described below.

¹⁰ Table 1.1 also includes the studies from the Diabetes Prevention Project at Kahnawake, which described the process and outcomes of community participation in intervention design, implementation and evaluation.

Multi-dimensional

A multi-dimensional program is: a) holistic, using a whole person model of health; b) ecological or multi-level; and c) comprehensive, using a range and combination of strategies.

Holism or a whole person model of health is congruent with Aboriginal worldviews (Bartlett, 1995; Calm-Wind and Terry, 1991; Malloch, 1989) and includes spiritual and emotional as well as mental, physical and intellectual dimensions of persons. *Ecological* infers the assumptions from ecological theories of human development. Ecological theory assumes that people's development and wellbeing are embedded in our relationships with the environment (Baranowski, Perry & Parcel, 1997; Bronfennbrenner, 1979; Bronfennbrenner and Evans, 2000; Fong & Furoto, 2001; Greene, 1994). The environment can be viewed as multiple levels of the physical, social, political, economic and cultural world (Bronfennbrenner and Evans, 2000). *Levels* of the environment that are the focus of perinatal health interventions include individual, family, community, as well as the broader regional, provincial and national environments.

Comprehensive or multiple intervention programs combine different strategies at various levels to achieve better outcomes, for greater numbers of people, than a single strategy can achieve (Edwards, Mill & Kothari, 2004). Multiple prenatal care intervention programs incorporate a variety of aims beyond reducing biomedical morbidity and mortality, such as increasing capacity and skills for health, or stimulating support for health in the environment. Multiple prenatal care intervention programs are ideally designed with the involvement of target groups and stakeholder agencies from a variety of sectors. The evidence on prenatal care interventions reviewed here suggests that multiple inter-

vention programs be centered on a trusting relationship between a woman and her primary provider (e.g., nurse, midwife, general practitioner). Examples of strategies used in combination with home visiting include: screening protocols (Mueller and Thomas, 2001), outreach to high risk groups (Poole, 2001), peer support (Martens, 2002; Martens & Rompf, 2002), public education strategies (Martens, 2001), and staff education and training (Affonso, Mayberry, Inaba, Robinson & Matsuno, 1995). Use of screening protocols was found to increase assessment, detection, and referrals for abuse during pregnancy, but was most effective if accompanied by empowerment and advocacy, outreach to increase access to services for victims, and staff training and ongoing education (Mueller & Thomas, 2001; Wiist & McFarlane, 1999). Comprehensive and multiple intervention programs, and participant involvement in tailoring interventions were found to be more effective with adolescent clients than single interventions (Brunton & Thomas, 2001).

Multi-dimensional prenatal intervention programs have been evaluated across a variety of populations. For example, in their systematic review Dicenso, Guyatt & Wilan (1999) looked at programs that were behaviour-focused, of long duration, actively involved participants, shared facts, focused on social pressures, incorporated modeling and included adult or peer leaders. They found, based on extensive input from adolescents, community partners and key informants, that they were more positively viewed by pregnant adolescents. Other systematic reviews (Ciliska, Mastrilli, Ploeg, Hayward, Brunton & Underwood, 1999; Brunton & Thomas, 1999; Howell et al., 1999) and programs of longitudinal research (Kitzman, Olds, Sidora, Henderson, Hanks, Cole, Luckey, Bondy, Cole & Glazner, 2000; Olds, 2002) have found that comprehensive, multiple intervention

programs improved access to pre- and post-natal services for clients who were at greater risk. Multi-dimensional intervention programs have also been found to improve prenatal health behaviours such as better nutrition, decreased tobacco use (Edwards, Sims-Jones & Hotz, 1996), enhanced social support and increased use of community services (Kitzman et al., 2000; Olds, 2002). Improved postpartum outcomes such as breastfeeding initiation and duration rates (Martens & Rompf, 2002; Sikorski, Renfrew, Pindoria & Wade, 2002) and better longer-term infant, child, and maternal life course outcomes with at-risk populations have also been reported (Kitzman et al., 2000; Olds, 2002). However, a review of comprehensive, multi-component prenatal care programs for preventing low birthweight concluded that measurement of the impact of intervention programs is plagued by blurring of causal pathways between risks and program outcomes, and failure to examine process variables (Stevens-Simons & Orleans, 1999). Research is needed to examine outcomes of multi-dimensional prenatal intervention programs across Aboriginal populations and health care contexts in Canada, such as with Inuit and Métis populations or with Aboriginal communities at various stages of transfer to self-governance of health services, and across diverse geographical settings.

Cultural Safety

Many studies of prenatal care interventions with Indigenous peoples aimed to be responsive to culture, and used concepts such as cultural appropriateness, cultural sensitivity, cultural competence, culturally-based (Affonso et al., 1999a & 1999b), transcultural care (Leininger, 2003), cultural security (Houston, 2002), and cultural safety (Browne, 2001; Smye & Browne, 2002). Some of these culture-related concepts and their underlying views of culture are described in *Appendix E: Culturally Related Concepts*. It is be-

yond the scope of this review to fully explore the ideological underpinnings and assumptions behind these terms and their use. I refer readers to the more comprehensive discussions of Anderson, Perry, Blue, Browne, Henderson, Khan et al. (2003), Cooney (1994), Coup (1996), Reimer-Kirkham, Smye, Tang, Anderson, Blue, Browne et al. (2002); and Reimer-Kirkham & Anderson (2002), and will highlight three key themes extracted from this literature. These are: a) understanding race, racialization and culture; b) consideration of subject-object relations, or the problem of *Othering*; and c) positioning health encounters in the context of colonial and neocolonial power relations. In this study, views and the underlying assumptions of cultural safety were adopted.

A postcolonial analysis departs from the culturalist notion of culture as a static set of beliefs, values, norms and practices attached to a discrete group sharing a common ethnic background. Such notions are based on racialization, whereby “social significance or identity is attached to certain biological features for the purpose of categorization into social collectives” (Reimer-Kirkham & Anderson, 2002, p. 4). From a critical postcolonial perspective, *race* is “a social construction manipulated to define, structure, and organize relations between [socio-historically created] dominant and subordinate groups... Races do not exist outside of representation but are formed in and by it in a process of social and political struggle (Reimer-Kirkham & Anderson, 2002, p. 3). Unfortunately, culturalist perspectives and the underlying liberal ideologies of individualism and egalitarianism continue to predominate in health care, and to a large part determine how “culture” is dealt with by health care policy.

Racialization adds an extra layer to the problems engendered by liberal ideologies and the associated subject-object relationships set up between providers and ‘patients’ in

health care. To the assumptions of superiority and the ‘naturalness’ of dominance by health providers, are added others underlying *Othering* according to racialized categorization of persons. *Othering* is “the setting apart as exotic, interesting or different — an act of representation by which identity is assigned, human existence is categorized, and people are characterized according to assigned criteria, and experiences are homogenized” (Reimer-Kirkham & Anderson, 2002, p. 5). These authors explain:

The roots of Othering lie in imperial exploitation and the colonial project. During this era, identities such as “the West”, “European”, and “White” conflated with conceptions of rationality, civilization, and Christianity, produced images of paganism and savagery through binaries such as naked/clothed, oral/literate, and technologically backward/advanced. These images continue today with constructions of Other as childlike, passive and exotic... In most health care theorizing, White-dominant culture remains transparent and unspoken for the most part, positioned as “normal” (Reimer-Kirkham & Anderson, 2002, p. 5).

A central premise of cultural safety, which sets it apart from other culturally related concepts, is that to step beyond the problems of racialization and *Othering* of Aboriginal people, the quality or ‘appropriateness’ of health care is to be evaluated by Aboriginal people themselves. This position removes the assumptions and treatment of Aboriginal peoples as objects in health care encounters, and the accompanying processes of racialization, *Othering*, and domination. It has been argued that becoming ‘expert’ on another’s culture and transmitting one’s view (e.g., through teaching) as facts, is an extension of the colonial process (Coup, 1996). This is one of the limitations of cultural competence and transcultural science (Leininger, 2003) from a postcolonial perspective (Coup, 1996; Cooney, 1994).

A third key difference between cultural safety and related concepts, is the position they take on the role and impact of health care encounters in the context of colonial and

neocolonial power relations. Cultural safety assumes that a central problem of health care encounters from the perspective of Aboriginal people is that health care by and large is structured as a reflection of colonial and neocolonial power relations in society. Culturally safe care would then involve action on a variety of levels, from the micro (e.g., examination of health care providers' own values, attitudes and beliefs) to more meso levels (e.g., exchanges between providers and clients; design of programs; organizational or regional allocation of resources; design of macro level policy) to explicate and take action on oppression. Cultural safety explicitly recognizes and seeks to transform the influence of socio-political and historical power relations on prenatal care policy, its implementation, and Indigenous peoples' experience of it. It is a way of "making sense of difference that does not succumb to racialization, *Othering*, and reinforcement of existing power inequities" (Reimer-Kirkham & Anderson, 2002, p. 8).

Cultural safety and prenatal care. Cultural safety is a concept developed by Maori nurses to analyze nursing practice from their perspective as the Indigenous minority in New Zealand (Polashek, 1998). Culturally safe care or practice involves "actions which recognize, respect and nurture the unique cultural identity of [aboriginal people], and safely meet their needs, expectations and rights" (Wood & Schwass, 1993, pp. 5, 6). Viewing access to health care through the lens of cultural safety suggests that until unequal power relations in health care are acknowledged and addressed, the barriers to health care for minority people will remain (Ramsden, 1993). Culturally safe care would be what is perceived by Aboriginal people as familiar (i.e., not alien) and meeting their needs in service, treatment and attitude... It is about "setting up systems which enable the less powerful to genuinely monitor the attitudes and service of the powerful, to comment

with safety, and ultimately create useful and positive change” (Ramsden, cited in Polashek, 1998, p. 453).

As yet, there have been no published reports of research on cultural safety in the context of prenatal care with Indigenous populations. Research on cultural safety in health more generally is relatively recent. It has focused on describing the impact of culturally unsafe care on Aboriginal women’s experiences with mainstream health care services in northern British Columbia, Canada (Browne & Fiske, 2001; Browne, Fiske & Thomas, 2000; Browne, 2003), Vietnamese immigrants’ experiences in Vancouver (Anderson et al., 2002), nurses’ experiences caring for people from cultures other than their own (Spence, 2001), the experiences of graduates of nursing programs including preparation in cultural safety as a requirement of entry to practice in New Zealand (Walker, 1998), and examination of the effect of cultural safety nursing education on nursing and midwifery practice (Jeffs, 2001). As is fitting with the novelty of the concept, these studies have been small, exploratory, qualitative investigations of the determinants, characteristics and impacts of various dimensions and applications of cultural safety from differing perspectives and at different levels. At this early stage, it is already clear that there is an empirical basis as well as an ethical one for suggesting that cultural safety influences access to care, and women’s experience in health care encounters. From an ethical perspective, cultural safety is about promoting appropriate use of power by health providers (Ramsden, 1993) through their attitudes and the application of personal, community empowerment, community development and social action skills to reduce inequities in health.

Research on the concept of cultural safety has enhanced understanding of barriers to health care that are unique to Aboriginal people in colonized countries (Browne, 2003; Browne, Fiske & Thomas, 2000; Browne & Fiske, 2001; Smye and Browne, 2002). Research on barriers to prenatal care for Aboriginal women, such as differences between Aboriginal cultures and western-style health and prenatal care models, poor communication and paternalistic practitioner behaviours (Long & Curry, 1998) suggest that cultural safety may be an issue. Evidence from cultural safety research suggests a need to develop methodologies and information systems that will support design and evaluation of health care services from the perspective of Aboriginal clients and communities. Future research on cultural safety could also explore Aboriginal people's efforts to heal and transform from, as well as recognize and diagnose (Battiste, 2000), the impact of colonization on prenatal care.

Trusting Relationships

Research evidence suggests that trusting relationships are central to effectiveness in most perinatal health interventions. A trusting relationship can be described as a consistent, sustained, emotionally safe one-to-one relationship between a pregnant woman and a care provider. It is most often developed through interactions in the person's home as well as in community spaces. Trusting relationships are characterized by mutual positive regard, respect and consistent presence over time, events, experiences, and stages of pregnancy. Trusting relationships flourish best in culturally safe, holistic and woman-centered programs (Calm-Wind and Terry, 1991). Falk-Raphael's (2001) qualitative study of the views of public health nurses and their clients on empowerment found that strategies for facilitating empowerment included developing a trusting relationship, advo-

cacy, providing information and developing skills and capacity. "Development of a trusting relationship required respect, empathy and creation of a safe environment", and was characterized by mutuality and by the authenticity of the nurse (Falk-Raphael, 2001, p. 1).

A trusting relationship with a member of one's own culture, especially someone respected and sanctioned by the community to provide healing services, appears to enhance the use of both traditional and western perinatal health services (Affonso et al., 1999a, 1999b; Calm-Wind and Terry, 1991; Goldman & Glei, 2000; Glei & Goldman, 2002). Non-use of prenatal care by Aboriginal women has been linked to western-style prenatal programs, rushed appointments, cold impersonal or authoritarian interaction styles, substance use, domestic violence, and the breakdown of cultural wisdom due to federal assimilation policies (DeCosta and Child, 1996; Long & Curry, 1998; Sokoloski, 1995). Positive influences on prenatal care access and use by Aboriginal women include community values and beliefs about the importance of children; primary provision of care by nurses; integration, training and support of a local person as a lay health provider; a well developed system of monitoring and tracking care pathways within and between levels of care; and collaboration among community, nurses and lay providers (Baldwin and Stevenson, 2001; Hiebert, 2001).

An example of a multi-dimensional prenatal care program centered on building trusting relationships is the *Malama na Wahine* or Caring for Pregnant Women Program (Affonso et al., 1999a, 1999b, 1996, 1995, 1992; Mayberry et al., 1998). This was a culturally based, interactive prenatal care program for Indigenous women implemented by public health nurses in the State of Hawaii, USA. The program aimed to involve local

women as partners with public health nurses, and promote respect for and integration of cultural and ethnic ways of knowing and healing into maternal child health care. Critical success factors were: willingness of staff to enter the life world of the pregnant women, teambuilding strategies such as joint training sessions, recognizing and building on community strengths, eliciting and incorporating community and client opinion into program goals and protocols, regular team meetings, and ongoing recruitment of local volunteers to avoid burnout. The program demonstrated increased satisfaction with care, earlier initiation of care and higher participation in prenatal care. Intervention research is needed to investigate similar approaches to prenatal care with Aboriginal populations. Furthermore investigation of the influence of these approaches on client satisfaction, participation in care, as well as perinatal health outcomes across the diverse Aboriginal populations and contexts in Canada is needed.

Continuity

A number of systematic reviews, experimental and epidemiological studies have investigated approaches to increase continuity of care between organizations and across the pre-conception to postpartum periods for a variety of populations in British, Australian and Canadian settings (Greene, Renfrew & Curtis, 2000; Glei & Goldman, 2000; Goldman & Glei, 2002; Homer, Davis, Brodie, Sheehan, Barclay, Wills & Chapman, 2001; Waldenstrom & Turnbull, 1998; Waldenstrom & Nilson, 1997; Blais, Joubert, & l'Équipe d'évaluation, 2000; Collin, Blais, White, Demers, Desbiens & l'Équipe d'évaluation, 2000; Reinharz, Blais, Fraser, Contandriopoulos, & l'Équipe d'évaluation, 2000). These studies reported that midwife-led care demonstrated comparable levels of medical safety, some improvements in birth outcomes, such as the rate of caesarean sec-

tion; and higher patient satisfaction compared to standard physician- and hospital-based care. The evidence reviewed here suggests that what mattered most to women were aspects of woman-centered care such as consistency of care within a trusting relationship (Greene, Renfrew & Curtis, 2000). Attributes of a woman-centered or humanized approach meant adapting care to the woman's needs, trusting in the woman's capacity, giving the woman control over decisions and offering choices (De Koninck, Blais, Joubert & Gagnon, 2001). Definitions, principles and guidelines for woman-centered care have been developed for the general population (Hills & Mullet, 2002). A strength of the woman-centered approach when applied to Aboriginal populations is the shift of the evaluative viewpoint from the provider to the client. Evaluating care from the client's perspective is consistent with the approach recommended for enhancing cultural safety of health care for Aboriginal people (Polashek, 1998). However, further efforts to develop evidence for prenatal care with Aboriginal populations could build on the strengths of both woman-centered care and cultural safety research. Policies and practice guidelines could be developed, and outcomes and measures specific to Aboriginal populations and contexts could be identified.

Findings of studies related to continuity from pre- to post-natal care in a variety of non-Aboriginal populations appear to be congruent with results of studies in Aboriginal populations. A key determinant of both Indigenous women's satisfaction with care and important clinical outcomes such as early initiation of care, increased rates of breastfeeding initiation and duration was the extent to which perinatal services were culturally appropriate (Buchareski, Brockman & Lambert, 1999; Mayberry, Affonso, Shibuya & Clemmens, 1999; Affonso, Liu-Chang & Mayberry, 1999a; Affonso, De, Korenbrot &

(Cargo, Levesque, Macaulay & McComber, 2003; Macaulay et al., 1998; Montour et al., 1998; McComber et al., 1998; Potvin, Cargo, McComber, Delormier & Macaulay, 2003). The Kahnawake Diabetes Prevention Project is an oft-cited example of an approach that has facilitated community governance, integrated western and traditional approaches to health, and established an empirical basis for a continuous cycle of community capacity building and improved health outcomes.

Three programs of research with Indigenous communities, then, have shown that community involvement, and integration of western and traditional approaches to health have improved access to, participation in, and outcomes of intervention programs (Affonso et al., 1999a; Cargo et al., 2003; MacAulay et al., 1998; Martens et al., 2002). All three programs were based on community-academic partnerships with strong leadership from Aboriginal partners, and long-term vision and commitment by academic partners (Affonso et al., 1999a; Cargo et al., 2003; MacAulay et al., 1998; Martens, 2002).

Examples of community-controlled approaches developed by Aboriginal communities were also found in the grey literature. These communities have established models of prenatal and maternal child health-care that fit into their unique culture and context (Lavoie, 2001). Examples include the Innulitsivuk Maternity in Povungnituk, an Inuit community in a very remote area of northern Quebec, and the work of the Mohawk First Nation in Akwesasne, Ontario. The maternity program at the Inuulitsivik Health Centre was started in 1986 by a local Inuit women's group in response to dissatisfaction with federal policy changes that required all Inuit women to travel away from their communi-

ties to southern hospitals for childbirth¹¹. Reductions in deaths from prematurity and rates of low birth weight have been achieved by the program (Houd, Qinuajuak & Epoo, 2003).

The Iewirokwas Program operates on the Akwesasne Reserve, located in eastern Ontario, southwestern Quebec and northern New York State. “The program aims to restore to Mohawk women their power, dignity and self-efficacy in the childbearing years and at birth in all settings” (Iewirokwas, 2002, p. 1). It is developing a community- and culture-based midwifery education program and a practical woman-centered family birth program. It offers information and support to empower women and their families during the prenatal period, to inform them of their rights, to communicate traditional Mohawk birthing rites, and to make good birthing decisions. It educates local maternity nurses, obstetricians and hospital staff about traditional Mohawk birthing practices in order to help them better support Mohawk women. The program is also involved in political action and is trying to get an exemption for Aboriginal midwives from Quebec’s midwifery law (Iewirokwas, 2002). Results of this promising approach to prenatal care have not yet been published in the peer-reviewed literature.

Based on the success of integrated approaches, the appropriateness of conventional processes and health outcome indicators (e.g., participation in prenatal education classes, low birth weight, pre-term delivery) by themselves for evaluating prenatal care in Abo-

¹¹ In response to community requests, the government returned control over the location of childbirth to the community. Community members worked with a team of health care providers to create a community-directed childbirth program that built on the traditional system of community midwives. The new system is in keeping with local values and prioritizes the role of family, culture, education, and prevention. It integrates modern medical practices where appropriate, useful, and compatible with the community-directed paradigm. Local community accountability is ensured through a variety of mechanisms. Outcomes, both in terms of culturally appropriate care, and perinatal morbidity and mortality, have improved with the new system.

iginal communities seems questionable. More research is needed to identify individual, family and community-level indicators for measuring prenatal care access, participation and outcomes based in local ways of knowing, cultural beliefs, and practices across Aboriginal populations and contexts. For example, research exploring the relationship between community efforts to restore cultural continuity (Chandler & Lalonde, 1998) and participation in and outcomes of community-involved approaches to prenatal care may identify promising focuses for community-level interventions.

Summary

This critical review of the literature has integrated evidence from a variety of populations and settings. The body of research evidence on prenatal care intervention with Aboriginal populations was relatively small, particularly for populations living in geographically isolated settings. However, Aboriginal authors, and evidence from research with Aboriginal populations has identified principles for designing, implementing and evaluating prenatal and other health care interventions. These principles closely match principles extracted from the more plentiful research evidence from other populations. Principles for design, implementation and evaluation of prenatal care with Aboriginal populations included a multidimensional holistic approach, cultural safety, continuity, trusting relationships and community involvement. Each principle was described, and strengths and gaps in research evidence supporting them were identified. Direction for further research to develop a base of empirical evidence for prenatal care interventions with Aboriginal and other communities and contexts were suggested.

A Priori Conceptual Framework

Figure 1.1 shows the conceptual framework that was developed at the beginning of the study. As Cowley (2000) suggests, “the initial [conceptual] framework will change as the analysis proceeds; it is this shift that yields information and a new model capable of explanation and potential application beyond the immediate cases under review” (p. 223). The *a priori* conceptual framework was based on the assumptions of ecological theory (Bronfenbrenner, 1979); Indigenous and critical postcolonial perspectives (Anderson, 2002; Battiste, 2000; National Aboriginal Health Organization [NAHO], 2003) and synthesis of evidence on prenatal care in the general and Aboriginal populations. Prenatal care was defined as a combination of individual, family and community-level interventions occurring from the pre-conception period until birth, aiming to improve capacity for safe and healthy pregnancy, birth and the transition to parenting.

Women of childbearing age were viewed as the key target, but fathers, families and communities were also seen as focuses of intervention. In the *a priori* framework, prenatal care was implemented to include: 1) analysis of the wider environment on prenatal health threats and capacities of women, families and communities; 2) interventions to enhance fetal development by maximizing the quality of fetal environments; and 3) action to enhance support for women, families and communities in the wider environment.

Intermediate outcomes of increased supportiveness by the family and the community, and enhanced personal capacity and coping skills on the part of pregnant women would decrease stressors and risks they experience, and ultimately reduce maternal and fetal health risks. Prenatal care also includes screening for medical and social health risks and

facilitating early access to tertiary medical interventions for medical risks to pregnant women and families (e.g., gestational diabetes and intrauterine growth retardation).

Ecological Theory

In the *a priori* conceptual framework shown in Figure 1.1, the broader ecological context is represented by the large circle, and the levels of the local ecological context are represented by the five overlapping circles.

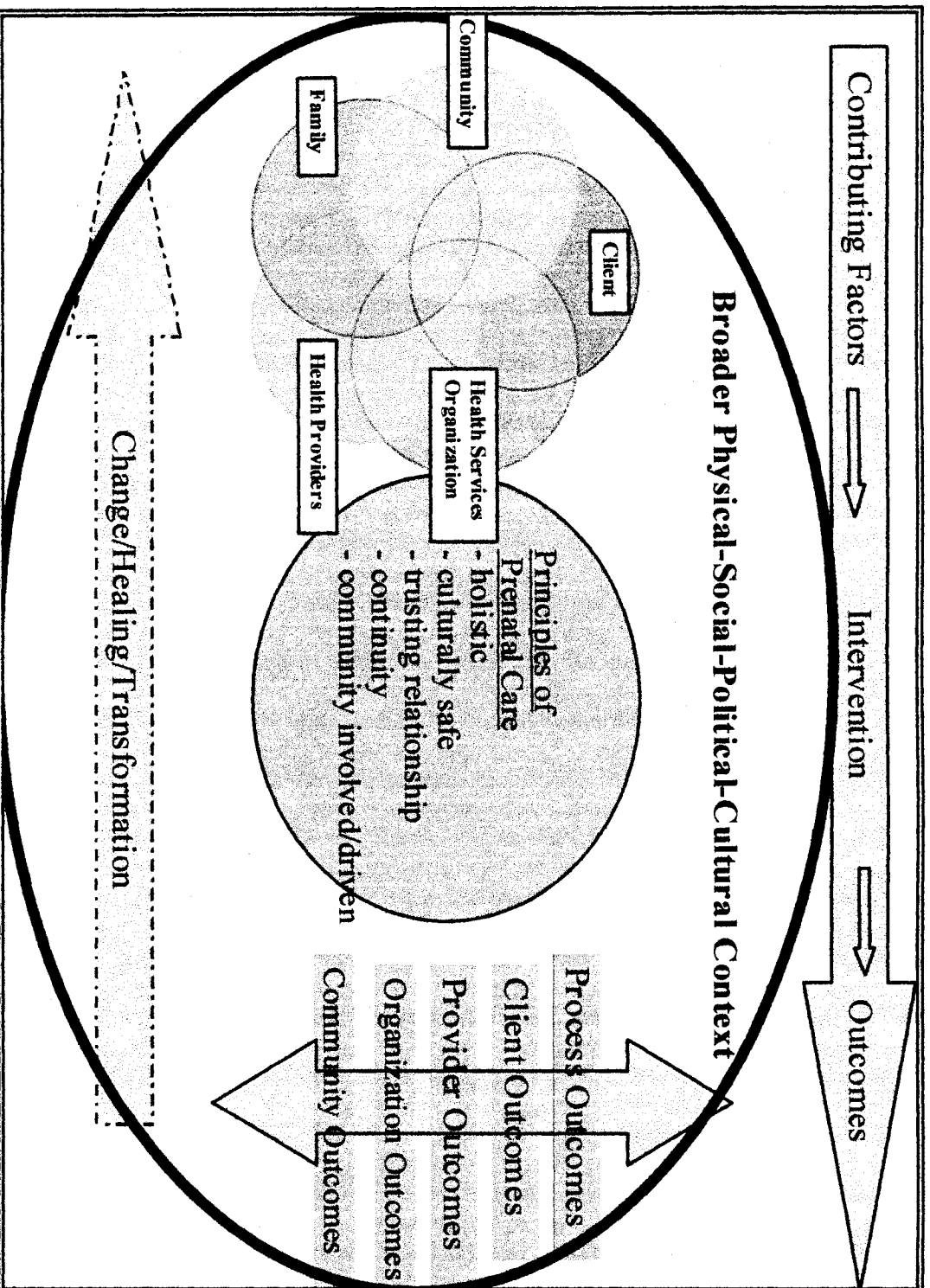
Ecological theory situates systems at individual, family, organizational and community levels within the regional, provincial and national organizational, physical, social, political and cultural contexts. Ecological theory assumes that people have the capacity to grow and become well, and that 'facts' are embedded in context in order to make sense and meaning (Bronfenbrenner & Evans, 2000). Ecological theories of human development assume that people's development and wellbeing are embedded in their relationships with the environment (Baranowski, Perry, & Parcel, 1997; Bronfenbrenner, 1979; Fong & Furoto, 2001; Greene, 1994). Ecological theory also values the knowledge embodied in or gained through experience in interacting with the environment (Bronfenbrenner and Evans, 2000).

Description of Elements in the A Priori Conceptual Framework

The three central elements in the *a priori* conceptual framework were: 1) the change process; 2) the contextual environment, and 3) prenatal care design, implementation and evaluation.

Contextual environment. The contextual environment was defined as the multiple levels of the physical, social, political, economic and cultural world (Bronfenbrenner and

Figure 1.1: *A Priori Conceptual Framework for Prenatal Care Design*



Evans, 2000; Fong & Furoto, 2001). The multiple levels were micro-, meso-, exo- and macro- environments. The micro-, meso- and exo- environments are represented in Figure 1.1 by the five overlapping circles on the left hand side of the framework, and include client, provider, organizational and community factors. Characteristics of each of these ‘contributing factors’ are seen to influence the design, implementation and evaluation of prenatal care.

The micro-environment included the linkages, processes, and face-to-face personal relationships in the immediate setting (e.g., pregnant woman and provider). The meso-environment was the linkages and processes between two or more micro-systems containing the developing person, family and health care setting. The exo-environment was the linkages and processes that occur between two or more settings, at least one of which does not contain the developing person (e.g., Tribal Council and health care settings). The *macro-environment* consists of the overall patterns of a given culture or wider social context (e.g., relations between Aboriginal people and non-Aboriginal people in Canada) (Baranowski et al., 1997; Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000).

Prenatal care process and approach. The prenatal care process in the a priori conceptual framework was adapted from Donobedian’s model of structure, process, and outcomes (Donobedian, 1966; National Nursing Centre Consortium, 2002). The a priori conceptual framework included principles, as well as implicit attributes such as knowledge and values. Prenatal care intervention principles were defined as “guides in how we live and work, and describe the essence of what we believe to be important” (NAHO, 2003, p. 8). Principles for design and implementation of holistic prenatal care in the a priori conceptual framework included: holistic, culturally safe, and based on a trusting

relationship between clients and care providers, continuity, and community involved/driven. Definitions for these principles as they pertain to the design and implementation of prenatal care were discussed earlier in this chapter and are summarized in Appendix F. The a priori conceptual framework assumed that intervention strategies or methods used to achieve the desired change would include such activities as lay or professional home visiting, public education campaigns, and peer support programs (Affonso et al., 1998; Martens, 2003). Prenatal care intervention strategies were viewed as what is actually done in the delivery of care (at all levels of the ecological system). Selection of intervention strategies would be particular to the values and knowledge of the target population within particular contexts.

A definition of *knowledge* that incorporates Indigenous knowledge as the driving perspective is an important element of postcolonialism (Battiste, 2000). Thomas Maracle's (NAHO, 2003) perspective on knowledge was the starting place for understanding knowledge in this study (see section on *Assumptions*). *Values* informing prenatal care design, implementation and evaluation were anticipated to be determined by local priorities, capacities and views of the world. Balance and respect are examples of Aboriginal values for health and healing (NAHO, 2003). The conceptual framework assumed that community stakeholders' values would inform what attributes were important, how to combine them, and how to implement them to achieve the principles of prenatal care they identified as critical to their prenatal care program's approach. Stakeholders were anticipated in prenatal care at two levels. Local stakeholders include community leaders, health care providers, and community members. Stakeholders in the broader environment include

other Aboriginal communities, Aboriginal organizations, other health care organizations, Aboriginal health care administrators and policymakers (e.g., in FNIHB) and researchers.

The categories of *outcomes* listed on the right hand side of the *a priori* framework included measures to monitor and evaluate organizational capacity, program reach and fidelity, and effectiveness of prenatal care programs. Organizational outcomes were seen as those important for optimizing organizational capacity to successfully implement and sustain programs. Process outcomes measured how accessible and appropriate the program was, and how well it reached the target population. Provider outcomes were seen as indicators for important influences on health providers' capacity to implement program design. Health outcomes were viewed as the effects of care on health status [individual and population]" (Minore et al., 2001, p. 9), and would be locally defined and congruent with the community's view of health.

Change process. The horizontal arrows at the top and bottom of the *a priori* conceptual framework represented the change process experienced by Aboriginal communities during transformation of prenatal care from models previously designed and imposed by outside health systems (e.g., FNIHB). The *a priori* conceptual framework assumed that a self-determining process of prenatal care design, implementation and evaluation would have the potential to transform participants' lived experience within the broader ecological context. These arrows were meant to reflect a cyclical process of change as it would occur in a postcolonial ecological system. Assumptions about the change process in the *a priori* conceptual framework were based on ecological theory and postcolonial thought. They included:

1. Community controlled prenatal care programs will be congruent with local values, culture and context, and will be different in design, and approach to implementation and evaluation than federally imposed prenatal care programs.
2. There is a synergistic relationship between the micro-level change process of prenatal care intervention design, implementation and evaluation, and the macro-level change process of community health, capacity and self-determination. There is a decolonizing or transformative aim in the process of changing the approach to prenatal care. The design, implementation and evaluation process will build capacity for community governance and self-determination, and improve prenatal care outcomes of individuals, families and the community.

Emancipatory Research Methodology

Emancipatory research was chosen as the most appropriate methodology for several reasons. Emancipatory research has as its central aim to unveil and transform oppressive structures (e.g., value systems, ideology, institutions) in society (Fontana, 2004), and shares similar assumptions about knowledge, values and worldviews as the postcolonial stance taken for this study. Congruent with this central aim of the study, emancipatory research *processes* acknowledge and redress the troubled history of research with or more accurately stated, *on* Aboriginal people. “Many Aboriginal people have been the subjects of research that they had little say in or no control over, that misrepresented or misinterpreted their experiences, and failed to create knowledge that was useful to the community” (NAHO, 2003, p. 4). Emancipatory research also fits well with my values and beliefs about my work as a population health research scientist.

Emancipatory research encompasses methodologies based on critical theories like feminism (Reinharz, 1992) and postcolonialism (Smith, 1999). “Fundamental to this research tradition, is the critical stance that is expected of the researcher in relation to the participants in the research and the production, use and dissemination of knowledge. Methodologies based on critical theory provide a critique of ideology, attempt to reveal hidden power imbalances to achieve emancipation, and endeavour to ensure that knowledge is available in the public domain” (Mill, Allen & Morrow, 2001, p. 114). Ontologically, critical theory focuses on solving practical problems caused by oppressive ideology and structures, and asserts that “reality exists independent of our thoughts about it, (but) empirical claims about it are (historically and contextually) situated, contingent and potentially fallible” (Mill et al., 2001, p. 113). At the level of values, a critical theoretical stance such as postcolonialism is inclusive of different value systems, but also sensitive to differences (Battiste, 2000; Mill et al., 2001). A critical theoretical stance views all forms of knowledge as valuable, but maintains that knowledge should be useful for solving practical problems and be relevant to stakeholders. Emancipatory research is a useful methodology for exploring underlying influences in poor access and use of prenatal care in Aboriginal populations. It is particularly suited to exploring the potentially disparate knowledge, values and worldviews of stakeholders (e.g., community members, providers and policy decisionmakers) for the purpose of acquiring the practical knowledge needed to improve prenatal care.

The methods and criteria for rigor chosen for the study are based on these critical theoretical values and assumptions about the nature of reality and knowledge. As well as critiquing domination in all its forms, explaining power imbalances and facilitating

emancipation, research based on critical theory emphasizes use of dialectic strategies, subject-subject relations in the focus and process of research, and includes application of the knowledge generated in the inquiry to influence change on the research problem (Anderson, 2002). Emancipatory research also tends to preserve the integrity of Indigenous knowledge (Macaulay et al., 1998; RCAP, 1996), and recognizes intellectual property rights of Aboriginal people involved in the study (Brascoupé & Endemann, 1999). Use of those principles in this study will contribute to redressing the weaknesses in current approaches to prenatal care in Aboriginal communities, avoid perpetuating oppressive research processes, and begin to close the gap in Aboriginal peoples' knowledge in the pool used to make decisions about health care for Aboriginal populations.

Case Study Design

A case-study design enabled exploration of the interplay of history, social, political and geographic contexts, and population characteristics on the research problem, and teased out "the boundaries between phenomenon and context [that were] not clearly evident" (Yin, 2003, p. 13). The case-study design expanded understanding of an issue that had been consolidated into the *a priori* conceptual framework. This permitted analytical generalization instead of trying to generalize (e.g., statistical) results from the study communities to other Aboriginal communities (Yin, 2003), as called for by Aboriginal organizations (NAHO, 2003). Case-study design enabled collection of in-depth contextual data to understand the determinants and processes of change in each of the unique study contexts and settings (Abelson, 2001; Cowley, Bergen, Young & Kavanagh, 2000;

Dopson, 2003; Langley, Denis and Lamothe, 2003)¹². In particular, the emphasis on understanding the meaning of experiences from participants' perspectives in the case study tradition (Yin, 2003; Stake, 1995) fit the purpose, postcolonial standpoint, and emancipatory methodology adopted in the study. Because case studies often use a variety of data collection methods, it was particularly suited to collecting the rich detail needed to formalize community-based stakeholders' experiential knowledge about prenatal care for pregnant and parenting Aboriginal people (Nieswiadomy, 1998). Case study methods were flexible and inclusive enough to capture the multiple and often tacit ways of knowing embedded in Aboriginal ways of being and doing. Important case study design decisions included: clear case selection criteria (Aboriginal organization/community dyad responsible for delivering prenatal care); development of an approach to care that by reputation worked well for pregnant and parenting Aboriginal people; clear distinction of case boundaries (by person, place and time), juxtaposition of perspectives from community members, providers and leaders within the case; and use of methods to develop rigor (congruent with the purpose, methodological and critical postcolonial standpoint of the study) (Dopson, 2003; Yin, 2003).

Study Setting and Population of Interest

The study setting was chosen based on: a) learning from Aboriginal organizations with successful approaches to prenatal care; b) teasing out the interplay between complex jurisdictional, administrative and governance arrangements for health care for Aboriginal people and the research problem; and c) recognition that the depth of data collec-

¹² Although details of the characteristics of the study sample and setting are included in each of the papers, Paper #3 describes the contexts of the studies in great detail.

tion and analysis would depend on development of partnerships with organizations and trusting relationships with participants.

Based on these needs, the province of British Columbia was chosen as the study setting because of its large Aboriginal population and diversity of jurisdictional arrangements within relatively small distances, diversity of access to health care services due to geography and community size, and pre-existing relationships of the researcher with several Aboriginal health care delivery organizations, and interest and support from FNIHB in that region (See *Appendix G: FNIHB Letter of Support*).

The status Indian population of British Columbia both on and off reserve was 110,529 in the year 2000 (INAC, 2002). *Appendix H* shows the geographical locations of the 198 First Nations in British Columbia. First Nation community sizes ranged from 15 to 3,500 members. There are more diverse First Nations bands, languages and societies in British Columbia than in any other Canadian province. There is a diversity of jurisdictional arrangements for governance and delivery of health services. These arrangements include: treaty, non-treaty, self-government, non-self-government, those negotiating health transfer, those not involved in health transfer (British Columbia Ministry of Health, 2001), and people living in provincial jurisdiction for health care.

Aboriginal British Columbians have identified a “lack of access to services, the lack of meaningful participation or control in how services are delivered, and the absence of working relationships with health service providers” as challenges (British Columbia Ministry of Health, 2003, p. 1). Many First Nations communities in British Columbia have such geographical barriers to accessing health services as lack of public road access, or location on islands. Many Aboriginal communities have been governing their own

health services either directly or through a multi-tribal health authority for well over a decade. Innovative approaches to the design and delivery of health programs based on local values, needs and capacities have been observed in communities in both federal and provincial jurisdictions.

Study Implementation

Emancipatory research explicitly aims to be informed and changed by participants during its conduct. In this section, I briefly outline: events and decisions made during study implementation, an account of strategies used to build rigor in qualitative postcolonial research, how the study was influenced by participants and a post-implementation critically reflexive account of my influence as research instrument.

Chronology of Events and Decisions

The study was conducted in two phases. Concurrent data collection and analysis for phase one began in February of 2004 following ethical approval from the University of Ottawa Health and Social Sciences ethics review board (See *Appendix I: Certificate of Ethical Approval for Phase One*). Sixteen key informants working in policy, leadership, and provider positions in maternal child health within the province of British Columbia were purposefully selected using network sampling techniques (Burns & Grove, 2005). Participants were sent a letter introducing the study, and requesting they contact the researcher to arrange either a telephone or face-to-face interview (See *Appendix J: Letter of Introduction for Phase One*). After completing procedures for informed consent (See *Appendix K: Text of Informed Consent for Phase One*), key informants shared their views on issues and influences on Aboriginal women and families' pregnancy experiences. They identified health care delivery organizations with reputations for high rates of early

access and participation in prenatal care by Aboriginal women (*See Appendix L: Key Informant Interview Guide*). Several Aboriginal organizations from both federal and provincial jurisdictions were suggested as promising candidates for participation in the community-based case study in Phase Two.

Criteria for inclusion in phase two were: a) reputed to have developed an innovative approach that improved early access and participation in prenatal care in an identified geographical area, and b) an adequate number of births/year (>10).

During the spring of 2004, the four organizations that met criteria for inclusion in phase two were approached about participation in the study. One of the four organizations did not respond to telephone calls or e-mail communication introducing the study (*See Appendix M: Pamphlet of Introduction*). After making telephone contact in response to the telephone calls and e-mail inviting participation, one of the three remaining organizations declined to participate.

The two organizations left expressed strong interest in taking part in the study. After face-to-face meetings with their representatives and telephone discussions over several months, the two Aboriginal health care delivery organizations (one urban and one rural) agreed to participate in phase two. During May, June and early July 2004 ethical approval for phase two was obtained from the University of Ottawa Health and Social Sciences ethics review board (*See Appendix N: Certificate of Ethical Approval for Phase Two*), from the ethical review committee of the participating Tribal Council, and from the Chief and council of the participating communities¹³. Entry to the study sites and data collection were conducted from June to September of 2004 in the two settings. The introduc-

¹³ Letters of support are omitted from this dissertation to preserve anonymity of participating communities and organizations.

tory pamphlet was circulated in both settings (See *Appendix M: Pamphlet of Introduction*). Participants in each setting were purposively selected using network sampling techniques to obtain a variety of perspectives from community members, providers and leaders (Burns & Grove, 2005). Data was collected using one-to-one exploratory interviews and small group discussions according to the preference of each participant, following completion of informed consent (See *Appendix O: Phase Two Informed Consent Forms*). An interview guide was developed to support rather than direct exploratory interviews with participants (See *Appendix P: Phase Two Interview and Small Group Discussion Guide*). Interviews were taped with participants' consent and transcribed. Supplementary documents and field notes were also included in the data set.

Data was analyzed using the interpretive descriptive method (Thorne, Reimer-Kirkham & Flynn-Magee, 2004) supported by NVIVO software. Analysis proceeded from a wholly inductive approach, and became increasingly deductive as important themes emerged. Preliminary results were drafted and enough paper copies were couriered to participating organizations to distribute to participants (See *Appendix Q: Early Results*). Participants were invited to discuss and develop the early results in a workshop and hosted luncheon held in each of the study communities in April of 2005 (See *Appendix R: Sample of Invitation to Workshop and Luncheon*).

Enhancing Rigor

At the outset of the study, I anticipated using criteria and strategies to enhance rigor from both the qualitative research tradition (Erlandson et al., 1993), as well as from emancipatory research. However, as the study unfolded criteria for scientific rigor in emancipatory research methods took primacy as the principles identified earlier took on

meaning within the real-life material contexts and relationships of the study. These emancipatory research criteria included critical reflexivity (Anderson et al., 2003; Browne, 2003), maintaining integrity of participants' voices in context (Dion-Stout, Kipling & Stout, 2001; Kirby & McKenna, 1989), and taking direct action on the research problem (Cargo et al., 2003; Fletcher, 2002). Strategies to enhance confirmability, authenticity, and fitness were used in a supporting manner (Denzin & Lincoln, 1998; Miles & Huberman, 1998; Yin, 2003). Each of these criteria for rigor and the strategies used to implement them are described below and summarized in Table 1.2.

Table 1.2: *Strategies Used to Enhance Rigor*

Criterion	Strategies
Critical Reflexivity	– <i>A priori</i> acknowledgement of assumptions/biases – Peer debriefing – Reflective journal – Secondary interviews – Making time and space for trusting relationships and critical questioning
Facilitating Participants' Voice	– Create safe and relaxed tone to encourage freedom of individual expression – Maintain integrity of voice in reporting of results (verbatim quotes)
Taking Con- crete Action	– Build relationships and maintain links with target audiences for uptake of results – Facilitate relationship-building and dialogue between stakeholders – Disseminate results to regional, provincial, national and international audiences
Confirmability	– Audit trail – Reflective journal
Credibility	– Secondary interviews during workshops and hosted luncheons – Peer debriefing – Member checks – Reflective journal
Fitness	– Thick description – Theoretical sampling for diversity

Critical reflexivity. Critical reflexivity is a process of deliberately noticing, recording and reflecting on the research process and experience, and the nature of knowledge being constructed. Critical reflexivity is the tool which enables research to transform oppressive processes and structures in research methods, outcomes and environments. It is a way of observing, making explicit and continuously revising the influence of the researcher as the primary instrument, with a particular social location that may privilege or disadvantage the researcher's voice and perspectives vis-à-vis those of participants (Thorne & Varcoe, 1998, p. 484). It is a continuous process of critically examining and uncovering the influence of oppressive processes in everyday, "taken for granted" structures, policies and attitudes. In emancipatory research, a critically reflexive researcher must be accompanied by "environments marked by respectful dialogue and reciprocal relationships that allow for the questioning of commonly held assumptions" (Reimer-Kirkham & Anderson, 2002, p. 12). Critical reflexivity is an intrapersonal and interpersonal consciousness-raising process that begins with the conception of the research and is systematically incorporated throughout implementation and dissemination of the research.

In this study critically reflexive practices were used to: 1) inform an emergent process of understanding the context and experiences of participants; 2) revise the research methods to best capture and respond to that experience to enrich the research results; 3) plan products of research that honor and best portray the perspective of participants; and 4) take action to change oppressive structures in society. Strategies to incorporate critical reflexivity into research included reflective writing and peer debriefing as a way of "mining" the subjective experience of doing the research for potential problematic situations, perceptions, values and attitudes. Critically reflective practice began during formulation

of the study, and continued through data analysis, writing and dissemination of the results. Critically reflective practice becomes a way of being, as well as a systematic process of doing, and a way of knowing or coming to understand. As a way of being, critical reflexivity shapes the relationships that evolve from the research (e.g., with participants, with community/organizational partners, with policy decision-makers using the results, with academic peers and colleagues).

Facilitating participants' voices. Time and care were taken to build trusting relationships. A relaxed and comfortable space and tone were created during interviews to encourage participants to share their experiences in their own way. Secondary interviews were conducted with participants to ensure that their voices were presented in a way that fit their perspectives. Quotes were recorded verbatim and the views of participants were carefully distinguished from those of the researcher in reporting results in order to maintain integrity of participants' voices as much as possible.

Concrete Action. Facilitating concrete change on the problem under investigation is one of the principles of emancipatory research (Mill et al., 2003). Though change to programs is a long-term endeavour, efforts were made to build relationships and maintain linkages with target audiences for the uptake of results (e.g., decision-makers in FNIHB). Relationship-building and dialogue between stakeholders were facilitated to increase access to resources needed for change (e.g., funding sources). Acknowledgement of successes by participating individuals and organizations was a natural part of the research process needed to support and sustain the long-term efforts for concrete change.

Confirmability. Confirmability is the extent to which the study conclusions can be traced to the participants and conditions of the inquiry (Miles & Huberman, 1998). The

influence of the researcher's biases is made explicit. Strategies used to enhance confirmability included: documentation of study activities and chronology, an audit trail, recording of the researcher's biases and assumptions, and data management methods that allowed results to be traced back to their source.

Credibility and fittingness. Credibility is the extent to which the study makes sense and represents participants' perspectives (Miles & Huberman, 1998). Fittingness is the extent to which the researcher has adequately described the context and conduct of the research to enable readers to make comparisons with other situations and populations. Strategies used to enhance credibility and fittingness included theoretical sampling for diversity, secondary interviews during workshops and hosted luncheons, peer debriefing, member checks during and after fieldwork, maintaining a reflective journal, and thick description in presentation of results.

Participants' Influence on the Research

The study methodology sought to have participants influence the research purpose and methods. Participants' influenced the inquiry in a variety of ways. Individual participants shaped the inquiry by sharing their personal and family healing stories, and by explaining the influence of their community's healing journey on their lives. Participants influenced the inquiry through the network sampling approach, both by whom they suggested, and through their views of why those people had important insights into the inquiry. Through example, affirmation and encouragement, participants communicated the importance of authentic engagement as fully human. The inquiry was influenced by their mentoring of me to foreground my personhood in ways of knowing, being, and doing. I

observed through their actions the importance of making time and space and using resources to develop trust and safety in relationships. I observed and came to understand more deeply the importance of acknowledging and honoring each person for who they are and their particular ways of knowing, being, and doing. Participants also influenced the inquiry by sharing their way of coming to understand their experiences. Table 1.3 shows how the study changed as a result of participants' influence.

Research questions evolved as a result of these influences, and the sequence and focus of data analysis flowed from participants' views and values. The results and implications corresponding to the research questions are reported in three papers in Part II of this dissertation.

Critically Reflexive Practice: Writing Myself into the Study

Research from a critical postcolonial standpoint requires that the social location, values, assumptions, and beliefs of the researcher be made apparent (Reimer-Kirkham & Anderson, 2002; Thorne & Varcoe, 1998). At the outset of the study, I 'wrote myself into the study' by identifying values, assumptions, beliefs and social location salient in the research problem, population and setting, and tried to make transparent how these have influenced the focus, implementation and results of the study.

I am a nurse, a mother, a student, and a health researcher. I have lived and practised community health nursing primarily in rural parts of Canada, but I now live in Ottawa. I am also a white woman, though this is not central to my personal identity. In the context of this research, I see my role as a learner and facilitator of learning from Aboriginal communities and people. I see my role in the 'postcolonial project' as building bridges

Table 1.3: *Participants' Influence on the Study*

Before Data Collection	Changed to...
Jurisdiction eligible for participation in Phase II case study. Federal jurisdiction only	Communities and organizations in provincial jurisdiction were added to eligibility for Phase II because many Phase I informants suggested that women and organizations were encouraging interjurisdictional use of services based on need rather than place of residence. Many providers in federal jurisdiction stated that 'we don't have a prenatal program in our community because we take women to the program offered by the province
Language The term <i>First Nations</i>	to ' <i>Aboriginal</i> ' to reflect diversity of population and reality of the urban Aboriginal organization.
Focus Term <i>prenatal care</i> reflected a biomedical, individual, service provider orientation bounded within medical, behavioural, and population health 'helping/intervention' models	<i>Care for pregnant and parenting Aboriginal women and families</i> to encompass the community, culture, relational nature of meaningful support; responsive to lived experience, situated within history of Aboriginal people generally, and the local community specifically.
Role of Aboriginal people, health service delivery organizations, and health providers Aboriginal people are receivers of expert- or system-directed care	Aboriginal people determine their care goals needs and are integrally involved in the process of transforming care and capacity (e.g., intrapersonal support, interpersonal support, family support...). Aboriginal parents own the experience and therefore the knowledge that is important to understand.
Responsibility for designing care Health service delivery organization	Communities and organizations seen as partners in their responsibility to create supportive environments and to support Aboriginal People's self-determined journey to heal and create a better future for their children.
Orientation of Aboriginal Organizations Meet health service delivery goals and provide best possible care according to accepted standards	Respond to and support priorities and values of Aboriginal constituents (individuals, families and communities)
Additional Research Questions	1) What are Aboriginal parents' views of the importance of pregnancy and parenting?

between the constituencies involved in Aboriginal prenatal care: Aboriginal women and communities, health care providers, policy makers and researchers (Battiste, 2000).

I believe strongly in the values of social justice, caring, respect for people as experts on themselves, and self-determination. These values underpin all of my work, whether it is community health nursing practice, research, policy or mothering. When I was a young single woman, my experiences as a community health nurse in small rural communities sparked my interest in developing the skills and knowledge to create a more just society. More recently, being a mother to children who must inhabit a world where appearance is often a basis for attitudes and decisions, I have solidified these values. I want my research to 'mine' front line nursing and community wisdom and transfer it into the pool of knowledge used to make policy.

As a nurse, I am particularly concerned with the relationship between health care providers and Aboriginal people. Nurses have an ethical and professional responsibility to 'do no harm'. Yet, the history between Aboriginal and non-Aboriginal peoples has been fraught with a great deal of harm to Aboriginal people. And nurses have colluded in that abuse, whether knowingly or not, as primary agents in colonialist health care institutions.

Specific assumptions I bring to this study include:

1. On improvement of prenatal care: changing micro-level prenatal care interventions, without changing the underlying views of reality, health, people and the environment will have limited impact on prenatal health care processes and outcomes.
2. On knowledge and its use: in a postcolonial world multiple ways of knowing would be valued and integrated by an 'epistemologically active' community of users (Bat-

tiste, 2000; Broner, Franczak, Cye & McAllister, 2001) who use knowledge in a critically evaluative, self-determined way. People would determine for themselves what knowledge could be useful and how it could be used based on their own values and priorities. Thomas Maracle's definition is the starting place for understanding knowledge in this study:

Knowledge is a community resource. It defines and drives the community. It's interconnectedness, it's multifaceted and multidimensional, it's revered, and it's language, communication and history. It's collective memory. It's captured and maintained for future generations. It's a reflection of life experience. It's acquired through listening and being empathetic. It's wisdom, strength and leadership. It's a strategic resource. It's the power of a good mind. It's imperfect. It's a gift bestowed by the Creator. (cited in Dion-Stout and Kipling, 2001, p. 4).

3. On human health: human health is interwoven with the wellbeing of the environment and of individuals from the broader social, cultural, historical and political contexts (Battiste, 2000). My personal assumptions about health are very similar to definitions expressed by Bamba, Fox & Scott-Samuel (2003). Health is:

interconnections as well as the parts, giving individual and context, process and outcome equal importance. Personal health is seen as the product of connections between mind, body, spirit, emotions, and society; population health as an emergent property arising from the interactions of individual, environmental, material and social relations (p. 6).

I believe that to reduce inequities in health and dominant social relations, change is needed at broader levels to transform colonial processes and relationships between Aboriginal people and health care organizations. I believe that 'tinkering' with micro-level processes within an inequitable macro-level policy framework based on colonialist values, assumptions, and power relations will have a limited effect on inequities in health, and is inconsistent with Aboriginal and public health ethics (Community Health Nurses'

Association of Canada, 2003; Kaufert, Commanda, Elias, Grey, Masuzumi & Young, 2001; Krieger & Gruskin, 2003; Upshur, 2002). I also believe that the potential for empowering, mutually affirming relationships between people involved in delivering and receiving health care is seriously constrained by oppressive values and assumptions embedded in colonizing health care policy. I believe further 'upstream' action is necessary to change the fundamental social structures that shape relationships between Aboriginal and non-Aboriginal people to create an equitable society. A more equitable society will lead to a reduction in the inequities in health status experienced by Aboriginal people. Research to influence change on policies that affect the relationships between Aboriginal people and health providers is a small step toward that goal.

Critically Reflective Note: Post-Implementation

Prior to engaging in fieldwork and relationships involved in this study, I wrote about how my social location and assumptions might influence the process and results of the research. During and after implementation of the fieldwork, analysis and writing of the results, I often reflected on these original assumptions, and how my experience and the study results had played out. I share below how 'right' or 'wrong' my original expectations had been compared to the reality of the experience. I share these insights both to illustrate the tensions involved in the 'bridging' work of postcolonial population health, and as an exemplar of the process of decolonizing our own minds that is necessary to this work.

Though cognizant of my privilege, and open to uncovering internalized biases and behaviours, I expected to be challenged regarding why I, as an urban-dwelling, privileged white woman was doing this research (*i.e.*, the white colonialist researcher). I was wrong.

I was not challenged so much as invited to take part in a dialogue to develop mutual understanding, and to discover shared meanings and passions. I had been prepared for my legitimacy in this role to be questioned: I was wrong in that too. Legitimacy is not the question: authenticity or genuineness was the interest.

I expected that facilitating the voice of participants would require significant energy and self-care: I was right. I had planned my fieldwork to occur Monday to Friday and I had reserved weekends to relax with family and friends. But I found the fieldwork experience was so intense, and the immersion in the world of participants so dissonant from the everyday world of my privileged middle-class social network, that I cancelled all of my visits, and used the weekends to just spend time outside with my young children walking in the woods, beachcombing, and playing with the dogs.

Finally, I had anticipated that I would require additional time and support to receive, listen to, acknowledge, and debrief from participants' stories of their lived experience in a racist, unequal society. I was right. However, I vastly underestimated: a) the magnitude of the horror of the experience of collective violence and its impact visited upon Aboriginal people by my country; b) the depth of the pain experienced and communicated; c) the incredible amount of energy and compassion that was exchanged with participants; d) the power of witnessing this reality; and e) the personal transformation and healing that I would experience as a result of engaging with my whole self.

Figure 1.2: Critically Reflective Note is an example of the reflective notes I kept while I was immersed in fieldwork. The note illustrates the themes in my experiences as researcher, and the strategies I used to manage these experiences (e.g., self-care and de-

briefing). Reflective notes also documented my thoughts and feelings as the instrument in the research, and the impact that experiences, thoughts and feelings had on the results.

Figure 1.2: Critically Reflective Note-Implementation

August 23, 2004Note to Colleen*: Post-community Immersion and Interviews

I am feeling really stuckkkkkkkkk It is hard to write about these experiences. Really my chest has been hurting and throat very full for quite a while now, and I believe that the work that needs to be done right now is not intellectual.

So why is my chest hurting and my throat full? People have put their trust in me, they have told me a lot about their personal life experiences, which by and large have not been pretty to say the least. And they have been honest: so honest and so trusting in me. I have tried to be present as myself, genuine and safe. Many people have told me they feel safe with me, and that they were surprised that they did. People were at different places on their healing journeys: it was not so hard when people had found some comfort, had found and maintained support and nurturing relationships. It is very hard when it felt pretty clear that they didn't have support, and were early on in their healing journey. I felt my purpose is very, very important to them.

The other overwhelming feeling I have is fear/worry. When I think about going back to Ottawa to do justice to the trust that people have placed in me, to tell this story and make people understand (better) what this reality is, how hard First Nations people in this community are working to heal and grow, and what they have found is necessary to do to turn things around. I am worried that I won't have support from people who get it. I think I need to start with people who get it, and as it becomes easier and clearer, my voice can be stronger, I can move on to working with people who will at least try to get it, and then move on to people who are somewhat open, and then finally to people who don't know that they don't know. So I need to feel safe too.

I am worried — or to put in a positive way — I am very committed to asserting and foregrounding the successes, the achievements, while I also want to establish an understanding of the context so that the magnitude of the successes can be appreciated. The worry part comes from thinking about the intended audiences (e.g., health providers, administrators, decision-makers, and educators) and wanting to debunk rather than reinforce stereotypes (e.g., the racializing and essentializing of peoples' experiences). So I turn to you for suggestions on how to begin with that too.

The other major reason you keep popping into my thoughts, is because of the number of stories about violence that I have heard. The number of ways that violence has become normalized, the insight that people have, the progress that individuals, families, this community are making, and the impact that the work of the Aboriginal Healing Foundation has made are incredible. The opportunity/reality when adults who have grown up with abuse are becoming parents, and want something different for their kids more than anything else in their lives, and are willing and courageous enough to do their personal healing work... I can hardly begin. I guess that is the work of my analysis. And another amazing part of it, is that for many of them, they are still totally immersed in it... it's too much for these words.

I keep thinking about the Diffusion of Innovation curve — in this community it seems like they already have the innovators and the early adopters on board to reverse the cycle (to the extent that people have done their personal healing work in their relationship with self), they have reached out and begun the healing work in their family relationships, and are using legal, political, social and organizational channels to name the violence/abuse, and to stop it.

Now I am going to go for a walk with the dogs to try and ease this knot in my chest. Let me know if you are up for a chat, or what you would recommend. And I do SO MUCH appreciate you Colleen.

* Colleen was a member of my PhD supervisory committee

Part II:

RESULTS

Researcher Critically Reflexive Note — August 9, 2004

People are talking about history, and I guess it comes from that initial interview question, 'So tell me about yourself'... They are choosing to define themselves by where they came from, by telling me about their experience as a child, their mother and father's way of being as parents, or not. Their mother's and father's experience — they are spontaneously tracing it back to residential schools, and I need to get more information about that.

Context as time: These stories are important because they are contextualizing things over time, not just in the span of a pregnancy or the span of a relationship, but in a span of generations. That fits with the way that people are also talking about telling how you have made a difference; talking about it over generations so, that makes sense too.

They are also talking about context as place. How the different places, the different houses they have lived in have influenced their choices. And they are also talking about the different communities, and how the communities and the social relationships in the community and the availability of resources, and access to support in communities have influenced their choices.

Introduction to Results

The purpose of this study was to describe community-based stakeholders' perspectives on their experience of designing, implementing, and evaluating support for pregnant and parenting Aboriginal women and families. 'Community-based stakeholders' were defined as Aboriginal people, providers and organizations mandated to provide care tailored to Aboriginal people. A critical postcolonial stance (Battiste, 2000; Reimer-Kirkham & Anderson, 2002) and participatory research principles (Cargo, Levesque, Macaulay & McComber, 2003; Fletcher, 2002; Macaulay, Delormier, McComber, Cross, Potvin, Paradis, Kirby, Saad-Haddad & Desrosiers, 1998) shaped the focus and process of the study. The study methodology sought to have participants influence the research purpose and methods. As described in Part I, participants influenced the language and focus or frame of the study, as well as roles and relationships between Aboriginal people, organizations and providers, and funders of health service delivery to Aboriginal populations. The latter change was itself a major finding of this study.

Research questions evolved as a result of these influences, and the sequence and focus of data analysis flowed from participants' views and values. The results and implications corresponding to the final research questions are reported in the three papers comprising Part II. The papers are formatted according to the guidelines of the peer-reviewed journal to which they were submitted.

Paper #1 reported on answers to the research question *What are Aboriginal parents' views of the importance of pregnancy and parenting?* Focusing on perspectives of Aboriginal parents in the study sample, these results suggest that pregnancy and parent-

ing must be understood on one hand relative to Aboriginal people's unique individual and family life experiences, and on the other hand within a broad understanding of the inter-generational impact of residential schools as an instrument of collective violence. The results highlight the need to emphasize the latter perspective as underlying inequities in health and access to services experienced by Aboriginal people, rather than enacting policies and practices that reinforce oppressive, racialized structures in society. Based on participants' views that health care interventions must flow from the perspective and values of the people they serve, the implications of paper #1 set the context for analysis and description in Paper #2 and #3.

Paper #2 reports on answers to two research questions: *'What are community-based stakeholders views on care during pregnancy and parenting?'* and *'How does (this) care make a difference to Aboriginal women and families?'*

These research questions aimed to discover community stakeholders' views on important characteristics of care, and identify corresponding indicators and expectations for care during pregnancy and parenting. These results extend the current use of the concept of safety in health care, and describe how experiences of safe and responsive care may improve early access to and relevance of care during pregnancy and parenting for Aboriginal people. Once this understanding of what was important and unique about care during pregnancy and parenting for Aboriginal people was established, the experience and contextual influences on Aboriginal health service delivery organizations transforming care from previous approaches could be explained.

Paper #3 describes results related to two research questions: *'What was the process of transforming care for pregnant and parenting Aboriginal people?'* and *'What was the*

influence of context on Aboriginal communities experience of innovating care for pregnant and parenting Aboriginal people?'

The similarities and contrasts between the two cases suggest that influences on their experiences in improving support for pregnant and parenting Aboriginal people was mediated by the governance system and stakeholder relationships in each context.

A statement of contributions of co-authors of each of these papers and the study as a whole is found in Part IV of this dissertation.

Paper # 1:

Turning Around the Intergenerational Impact of Residential Schools

on Aboriginal People: Implications for Health Policy and Practice

Dawn Smith, Colleen Varcoe & Nancy Edwards

KEYWORDS: Aboriginal People, residential schools, health impact, pregnancy and parenting, population health

RUNNING HEAD: Turning Around the Intergenerational Impact of Residential Schools

ABSTRACT

This paper reports on the first wave of results from a study exploring community-based stakeholders' views and experiences of improving care for pregnant and parenting Aboriginal people. A postcolonial lens framed the issue of Aboriginal women's and families' poor access to prenatal care within its historical and social location in a colonized society. Participatory research principles and a case-study design guided the focus and conduct of the study. Data were collected through exploratory interviews and small group discussions. The study sample consisted of purposefully selected community leaders, providers, and community members affiliated with two Aboriginal health care delivery organizations in a mainly rural region of a Canadian province. Results showed that participants from all three stakeholder groups felt that care must be based on understanding of the priorities and experiences of the pregnant and parenting Aboriginal women and families themselves. Therefore Aboriginal parents' views on the importance of pregnancy and parenting was brought into the foreground of the study results. Turning around the intergenerational impact of residential schools was identified as pivotal to a successful approach to care. Results suggest that pregnancy and parenting must be understood on one hand respective to Aboriginal people's unique individual and family life experiences, and on the other hand within a broad understanding of the intergenerational impact of residential schools as an instrument of collective violence. The results show the need to take into account the intergenerational impact of residential schools as one of the major factors underlying the inequities in health and access to services of Aboriginal people. Failure to do so may further the enactment of policies and practices that reinforce oppressive, racialized structures in society.

Introduction

Two thirds of that last generation to attend residential schools has not survived. It is no coincidence that so many fell victim to violence, accidents, addictions and suicide. Today the children and grandchildren of those who went to residential schools also live with the same legacy of broken families, broken culture and broken spirit (Chief Councillor Charlie Cootes, cited in Royal Commission on Aboriginal Peoples [RCAP], 1996, p.22)

From the mid-1800s until as late as 1996 an estimated 100,000 Aboriginal¹ children, ages four to 18 years old, were removed from their families and placed in residential schools as part of the federal government's assimilation plan, to "deal with the Indian problem" (Indian and Northern Affairs Canada, [INAC], 1998; RCAP, 1996). As well as enforced separation of children from their family and community at an early age, residential schools involved deliberate suppression of language and culture, substandard living conditions and second-rate education, and widespread physical, sexual, emotional and spiritual abuse. (Aboriginal Healing Foundation [AHF], 2002; INAC, 1998; NuuChahNulth Tribal Council [NTC], 1996; RCAP, 1996; United Church of Canada, 1998;). "Disclosures of abuse, criminal convictions of perpetrators, and findings from various studies tell of a tragic legacy... that leave former students, their families and communities to deal with issues such as physical and sexual abuse, family violence, and drug and alcohol abuse" (INAC, 1998; p.1). As a result of residential schools,

Aboriginal children learned to despise the traditions and accomplishments of their people, to reject the values and spirituality that had always given meaning to their lives, to distrust the knowledge and life ways of their families and kin. By the time they were free to return to their villages, many had learned to despise themselves" (RCAP, 1996, p.57).

¹ The term Aboriginal "refers to organic political and cultural entities that stem historically from the original Peoples in North America, rather than collections of individuals united by so-called 'racial' characteristics" (Royal Commission on Aboriginal Peoples, 1996). These include the First Nations, Inuit, and Métis peoples of Canada.

The residential school system and its enduring impacts are a complex historically situated phenomenon. “While it is not uncommon to hear some former students speak about their positive experiences in these institutions, their stories are overshadowed by disclosures of abuse, criminal convictions of perpetrators and the findings of various studies such as the Royal Commission on Aboriginal Peoples, which tell of the tragic legacy that the residential school system has left with many former students. They, and their communities, continue to deal with issues such as physical and sexual abuse, family violence, and drug and alcohol abuse”(INAC, 2004, p.1). Aboriginal people have asked for an approach to healing that would address the needs of individuals, families and communities arising from the legacy of physical and sexual abuse at residential schools. In response, the Government committed \$350 million in support of a five-year community-based healing strategy and has recognized that it is in Aboriginal and non-Aboriginal peoples’ interests to support individuals, families and communities in their efforts to begin the healing process (INAC, 2004).

Though there has been legal and political recognition and a beginning process for retribution for the enduring and intergenerational impacts of residential schools (Government of Canada, 1998; United Church of Canada, 1998), the implications of the health effects of residential schools for health services policies and programs have received limited attention. Qualitative and quantitative research has begun to describe the long-term health impacts of residential schools (Dion-Stout & Kipling, 2003; NTC, 1998; Tait, 2003). For example, a qualitative study exploring the experience and impacts of a residential school with close to 100 survivors from one region in BC noted: 93% of former residents reported extreme loneliness and feelings of abandonment, 91 % reported loss/oppression of language and culture, 92% witnessed abuse of other students; 90%

disclosed being abused in one or more ways (e.g., sexual, physical, emotional); 76% reported losing their self-respect or feeling inferior; 84% reported problems with relationships, family, parenting and communication (NTC, 1998).

Within the context of a study focusing upon learning from successful care for pregnant and parenting Aboriginal women, the critical importance of the Aboriginal participants' vision for turning around the intergenerational impact of residential schools (IGIRS) became central. Participants viewed pregnancy and childrearing as a window of opportunity for turning around the IGIRS for Aboriginal individuals, families and communities. Orienting care for pregnant and parenting Aboriginal people within this understanding will require a significant shift in the roles, relationships and intended outcomes of care. Understanding IGIRS as one of the root causes of the inequitable health and social conditions experienced by Aboriginal people has implications for the underlying purpose and rationale for health policy, programs, and the practices of health care providers more generally.

This paper focuses on that central finding from the study and describes participants' vision for *Turning it Around*. Participants' experience of pregnancy and parenting, and therefore their care needs and priorities, could only be understood within their experiences of and efforts to change the IGIRS and other related colonizing influences and structures. Participants felt that understanding and acknowledging the IGIRS as a root cause of the poor health and social conditions, such as poverty, addictions and violence, was imperative to healing and building strength.

Background

The federal government has had jurisdiction over health services for First Nations and Inuit People living on reserves since the 1876 passing of the *Indian Act* (Government of Canada, 1985). Since that time, services have been provided through the First Nations and Inuit Health Branch, formerly known as Medical Services Branch of Health Canada. At present, a growing majority of First Nations communities have transferred, or are in a multi-year process of transferring, administration and delivery of on-reserve health care services from the federal government to First Nations control (First Nations and Inuit Health Branch, 2005). Health services for Aboriginal people living off-reserve are the responsibility of provincial governments, and are regionally administered in most provinces.

On-reserve maternal-child health care is comprised of pre- and post-natal care, evacuation from rural but not necessarily remote settings, to provincial tertiary-care facilities for birth (Smith, 2002). Primarily Registered Nurses deliver pre- and post-natal programs in partnership with community health representatives and alongside several related programs such as Canada Prenatal Nutrition Program, the Fetal Alcohol Syndrome/Fetal Alcohol Effects Prevention Program, and the Aboriginal Head Start On-Reserve Program. Services vary considerably across the regions and among communities in presence, size and scope (Health Canada, 2000). This variety of services results in a collection of programs with independent administrative, governance and implementation systems, rather than a coherent integrated system of care. Further, continuity and depth of care over the childbearing continuum are disrupted by evacuation for birth, high rates of

nursing staff turnover, and difficulty integrating the various programs offered on-reserve (Smith, 2002).

Anecdotal and research evidence suggest that this model of maternal child health care has contributed to the inequities in health and social wellbeing of Aboriginal women, children, families and communities (Adelson, 2004; Dion-Stout & Kipling, 1999a; Dion-Stout & Kipling, 1999b). Aboriginal people have emphasized that new health and healing systems must embody equity in access to services as well as health status outcomes, holism in approaches to interventions, Aboriginal authority over health systems, responsiveness to differences in cultures and community realities and, where feasible, community control over services (RCAP, 1996). This need for change has been publicly acknowledged. For example, Romanow (2002) asserted that “action must be taken to create new models to co-ordinate and deliver health services”, address health needs further upstream, adapt health services and programs to each community’s unique cultural, social, economic and political circumstances, and “give Aboriginal people a direct voice in how health care services are designed and delivered (p. 212).

While the need for change is being recognized, descriptive studies of the problems related to maternal child health care far outweigh studies describing appropriate alternatives for Indigenous² populations globally. For example, the problem of late or no access to and poor use of care, and poor pregnancy outcomes in Aboriginal women is well documented (Baldwin, Grossman, Casey, Hollow, Sugarman, Freeman, and Hart, 2002; Bridge, 1999; DeCosta & Child, 1996; Goldman & Gleib, 2003; Hoyert, Freedman, Strobino & Guyer, 2001; Heaman, Gupton & Moffat, 2005; Humphrey & Holzheimer,

² The term Aboriginal is used primarily in some contexts (e.g., Canada and Australia), while the term Indigenous is more globally inclusive.

2000; Luo, Kierans, Wilkins, Liston, Uh & Kramer, 2004; Luo, Wilkins, Platt & Kramer, 2004; Public Health Agency of Canada, 2005). Evidence suggests that Aboriginal women and families require more culturally appropriate care relevant to their needs and strengths (Battiste, 2000; Browne & Smye, 2002; Long & Curry, 1998; Powell & Dugdale, 1999; Sokolowski, 1995; Westenberg, van der Klis, Chan, Dekker & Keane, 2002). Evidence has shown that Indigenous women's satisfaction with care, early initiation of care, increased rates of breastfeeding initiation and duration have been improved by culturally appropriate prenatal services, however definitions and interventions for 'culturally appropriate' vary (Affonso, Mayberry, Inaba, Matsuno & Robinson, 1996; Affonso, Mayberry, Inaba, Robinson & Matsuno, 1995; Buchareski, Brockman & Lambert, 1999; Nel & Pashen, 2003). Research and evaluation studies (Affonso et al., 1995; Buchareski et al., 1999; Fisher & Ball, 2002; Martens, 2002; Nel & Pashen, 2003) have shown that community involvement in program design, implementation and evaluation improved participant satisfaction, early access and participation in care, and enhanced women's health behaviours such as improved nutrition, and decreased tobacco and alcohol consumption, and feelings of mastery concerning infant care.

However, programs of research were conducted in single settings, close to urban centers, and/or with particular populations. Given the gap in knowledge to inform a responsive and sustainable approach to care for pregnant and parenting Aboriginal people, research exploring the views and experiences of Aboriginal and community-based stakeholders is needed.

Method

The overall purpose of this study was to describe community-based stakeholders' perspectives on their experience designing, implementing, and evaluating care for pregnant and parenting Aboriginal women and families. As the study progressed it became clear that participants felt that care must be based on the priorities and experiences of the pregnant and parenting Aboriginal women and families themselves. Therefore, the focus of the study brought into the foreground the views and life experiences of the Aboriginal parents in the study sample, to answer the research question, '*What are Aboriginal parents' views of the importance of pregnancy and parenting?*'

The study takes a critical postcolonial stance (Battiste, 2000; Reimer-Kirkham & Anderson, 2002) and uses participatory research principles (Cargo, Levesque, Macaulay & McComber, 2003; Fletcher, 2002; Macaulay, Delormier, McComber, Cross, Potvin, Paradis, Kirby, Saad-Haddad & Desrosiers, 1998). Participatory research principles include explicating power imbalances, subject-subject relations in the focus and process of research, and application of the knowledge generated in the inquiry to influence change on the research problem (Anderson, 2002; Mill, Allen & Morrow, 2001). Methods used to enact these principles in the study included critical reflexivity (Anderson, Perry, Blue, Browne, Henderson, Khan, Reimer-Kirkham, Lynam, Semeniuk & Smye, 2003; Browne, 2003), maintaining integrity of participants' voices in context (Dion-Stout, Kipling & Stout, 2001; Kirby & McKenna, 1989), and taking direct action on the research problem (Cargo et al, 2003; Fletcher, 2002).

Participants' experiences were viewed through a critical postcolonial lens to explicate their efforts to understand, deconstruct, resist and transform the impact and institutions of colonialism (Battiste, 2000; Reimer-Kirkham & Anderson, 2002).

Postcolonial and participatory research perspectives include diverse value systems, are sensitive to differences (Battiste, 2000), value all forms of knowledge and seek to generate knowledge relevant to stakeholders that is useful for solving problems (Mill et al., 2001). Collection of in-depth contextual data to understand the determinants and processes of individual and organizational participants' experience in improving care for pregnant and parenting Aboriginal people in each setting (Abelson, 2001; Cowley, Bergen, Young & Kavanaugh, 2000; Dopson, 2003; Langley, Denis and Lamothe, 2003) was enabled by a case-study design (Yin, 2003). The University of Ottawa Health and Social Sciences ethics review board, the ethical review committee of the participating Tribal Council and the Chiefs and Councils of the participating communities granted ethical approval for the study.

In Phase One, 16 participants from provincial, regional, and community-based organizations responsible for services for pregnant and parenting Aboriginal people were selected using snowball sampling techniques, and interviewed by phone or in person. Participants were asked to share their perspectives on issues and influences on Aboriginal women and families' pregnancy experiences, and identify health care delivery organizations with reputations for having developed prenatal care services with high rates of early access and participation by Aboriginal women.

In Phase Two, one urban and one rural Aboriginal health care delivery organization located within one region in a Canadian province agreed to participate in the

community-based case study. Research partnerships were initiated and research agreements were developed with the two partner organizations to identify ownership, control, access and possession of the research process and products. Formalization of the agreements followed the protocols and requirements of the partner organizations and communities. For example, a description of the study and cost/benefits to the community was presented to local Chiefs and Councils, and necessary adjustments made to receive their support to conduct the study. Once ethical approval was obtained, participants in each setting were purposively selected to obtain a variety of perspectives. Clients, family members, providers, managers and administrators, policy decision-makers, and community leaders were interviewed. Table One shows the composition of the study sample for Phase One and for each of the community settings in Phase Two.

Over 60% of the total study sample self-identified as Aboriginal and 90.4% were women. Many of the Aboriginal participants chose to share their personal experiences growing up as children, becoming parents, grandparents, aunts and uncles. For many participants, it was imperative that their perspectives were understood and acknowledged within personal, historical and social contexts. Describing the experiences and importance of those experiences is the focus of this paper, and thus draws extensively on the interviews from Aboriginal community members, providers and leaders.

Data were collected by the first author using one-to-one exploratory interviews and small group discussions during field work for a period of three months in the two settings. Many participants chose to share their personal experiences growing up as children, becoming parents, grandparents, aunts and uncles, in response to the opening question, 'Tell me a bit about yourself and your experiences related to pregnancy and

Table 2.1: *Sample Composition by Phase, Setting, Aboriginal Identity and Gender*

Study Phase and Setting	Total	Aboriginal Identity		Female	
	#	#	Percent	#	Percent
Phase One	16	8	50 %	15	93.75 %
Phase Two-Isolated Community	29	21	72.4%	25	86.2 %
Phase Two-Urban Community	28	15	53.6 %	26	92.9 %
Phase Two Totals	57	36	63 %	51	89.5 %
Study Totals	73	44	60.3 %	66	90.4 %

parenting'. Although it was not a planned area of exploration, residential schools emerged as central in participants' experiences and efforts to make a difference for the children of the future. Supplementary documents and field notes were also included in the data set. Interviews were taped and transcribed by a third party.

During a prolonged period of immersion in the data the first author used NVIVO software and an interpretive descriptive method to analyze the data (Thorne, Reimer-Kirkham & Flynn-Magee, 2004). "The intellectual task of the analyst (was) to engage in a dialectic between theory and the data, avoiding theoretical imposition on one hand and atheoretical description on the other, in the quest for a coherent rich interpretation that allows *a priori* theory to be changed by the logic of the data" (Thorne et al., 2004, p. 4). In light of this analytic task, it became clear that turning around the IGIRS pervaded

participants' experience of being and becoming parents, and therefore was brought into the foreground in the purpose and ontological landscape of this study.

Findings

'Turning it around' was one of the most central and overriding themes in the entire project. That central theme is described in this paper. Turning it around was primarily concerned with a sense of hope for the future based on understanding and confronting the IGIRS.

We are turning it around ... We are going to be better parents for our children because we are healing. And our children won't experience the legacy. I mean that is my hope, that my children won't experience the pain and things like that. That they will have an understanding and what they will acquire is the gift of the resiliency and the gift of survival, but not the pain of the abuse and everything else (Parent & Provider & Leader).

Turning it around involved three sub-themes: understanding the IGIRS, healing, and building strength and capacity. A fourth cross-cutting subtheme of turning it around, 'rebuilding our cultures in contemporary contexts', was interwoven within participants' journey through successive cycles of understanding the IGIRS, healing, and building their strength and capacity.

Understanding and Acknowledging the Intergenerational Impact of Residential Schools

Turning it around starts with and depends on *understanding and acknowledging the IGIRS*. Participants described many levels of disconnection and alienation resulting from the IGIRS. Because children were removed from their families over multiple generations, cultural teachings, parenting skills, and community identities were disrupted. As one participant said:

It's so intergenerational. You have generations of people who have been affected by the trauma. ... I have talked to people who have got 5 generations of trauma coming down. So you have 4 or 5 generations of people who haven't been able to connect,

who haven't had a sense of spirituality, who haven't been able to make firm attachments with their caregivers. It is a direct result of residential school violence (Provider).

Participants described how residential schools shamed and belittled Aboriginal values, beliefs, practices and people. In students attending residential schools, this resulted in disconnection or dissociation from painful feelings, poor self-esteem, negative identity as Aboriginal people, and disrespect for traditional beliefs and practices. Because these residential school experiences occurred during a very formative period of emotional and moral development, they became encoded into identity, beliefs and behaviour patterns.

As one participant explained,

They all went to residential schools, except the youngest. And again that's when we are starting to work on the child's confidence and esteem, too. Them being told — the older kids in residential school are told, "You are good for nothing, you are just an Indian. You will never amount to anything" (Parent & Provider).

Participants made sense of the powerful influence of this encoding process through their stories of the role of 'teachings' in human social, emotional and moral development. Participants described teachings as how children learn to make sense of the world and their place in it. *Teachings* are the values, beliefs, knowledge and practices that make up a person's culture. As a child, teachings shape identity and ways of being in relationships. Participants described how residential school survivors pass on to their children the residential school 'teachings' with which they grew up, such as described in the quote above. The cycle continues as their children take up residential school 'teachings' and then they pass them on to their children in an unconscious way. The quote below is one example of how participants described the process of becoming aware of passing on the ways their parents had learned in residential school to their children:

To be really perfectly honest, for years we weren't even considered citizens — or people for that matter. There were certain things that... stereotyping — we were this and we were that. So that attitude, I went through that and I think in a sense I passed that on to my kids. You know, without me really saying it so much, and anyway I think that is where it comes from. It's hard to see. Sometimes I don't notice it until I start talking about it. Sometimes we have to forgive ourselves for what we did to our kids, for what we passed onto them (Elder & Parent).

Participants described the IGIRS as the root of a downward *spiral of addiction, violence and poverty* in individuals, families and communities

The IGIRS is seen as underlying a lot of the substance abuse issues, the sexual abuse and the physical abuse. So to get the root of the problem, there was more attention put on the experience of residential school (Provider).

As emotional, spiritual and social wellbeing were compromised by IGIRS, and people were caught in the downward spiral of addictions, violence and poverty, their strength and capacity to successfully manage life challenges diminished. For example, many participants described leaving home as a pre-teen or teenager to escape the chaos and interpersonal violence in their family, home and community. This often meant dropping out of school to find work, looking for work in unskilled or seasonal jobs, and difficulty finding adequate housing. These difficulties further alienated them from family, community and culture, perpetuating the downward spiral.

Healing

Healing from the trauma brought on by the IGIRS is the second major sub-theme of *Turning it Around*. Participants explained that if things are to be different for their children and grandchildren, if the cycle is to be broken, then they have to use the understanding of IGIRS to face and heal their own trauma resulting from the intergenerational transmission of residential school teachings, and downward spiral of behaviours and ways of coping with life challenges. They described healing as a self-

determined process for individuals, families and communities. Participants described their healing journey as a gradual, back and forth process of facing up to and forgiving oneself and others for the hurts, changing beliefs about oneself and others, and accepting responsibility for oneself and one's choices. Healing requires courage, determination, persistence, and support. As one participant explained:

People need to do their own work. You know, they get to do their own healing work: develop the skills, the life skills, the decision-making skills, the comfort with themselves. And that's one part. But then another part is the relationships thing... the relationship with self, the relationship with family, relationship with community. And I think number one is that you really have to get your relationship with yourself sorted out (Grandmother).

Participants described how forgiving self and others for past hurts, and acknowledging strengths was identified as an important part of healing.

I am afraid to admit when I am wrong. I am afraid, but I have the ability to forgive (Parent).

Participants stated that part of healing is changing personal core beliefs, particularly the need to regain and act with *respect* for self and all living things. For example,

We don't need to be powerful; we just need to be equal — to respect each other. Letting it all go to hate, that is not good for your insides. You gotta think about your own body, deal with it, heal it and not fill it with hate. Turn things around. Let's do it with love and respect for each other as women and in turn feed it to our children (Parent & Community Member).

Building Strength and Capacity

Building strength and capacity was described as a significant priority for individuals, families and communities, to address the deficits resulting after decades of the IGIRS. Healing was a process of going back to make sense of, to accept and to heal the losses and hurts resulting from the IGIRS. Building strength and capacity was about equipping themselves with the skills and resources for moving forward toward their

vision for a better future. Participants described their efforts to develop the knowledge, skills, confidence, and networks of support required to work toward their vision for strong and healthy people, families and communities. Developing goals according to their own priorities, beliefs and vision for the future was described as a necessary and significant part of capacity-building.

Participants' strength and capacity-building experiences and efforts were focused at individual, family and community levels. Examples of building personal strength and capacity included going back to school, reaching out and developing healthy support networks, or renewing spiritual practices. Community capacity building was reflected in many participants' stories, such as this description of a community's experience of coming together, talking and building capacity to set goals, and take action to meet them:

It [treaty negotiations] brought the community together to talk about the problems, to talk about the issues, to talk about what we wanted. And really, what they did in the development of treaty negotiations is they said; "This is what we want in economic development, this is what we want in education, this is what we want in social development". They went through everything, and what they did without realizing it is that they just did their long-term goals. And then once they realized what they wanted, then of course, they started doing things about it (Leader).

Parents and community leaders described collective efforts to rebuild a strong infrastructure and a positive social environment to support parents to make better choices.

One community leader described years of commitment and tenacity on this issue:

I will always stand for making this community safe for women and children. And I need the support of everyone here. I can't do it myself. I can't be everywhere. When you see something, you have to speak up about it. I am always telling people that we all have responsibility for making this a safe, healthy community. Like, if you see someone molesting a child over there, it is your responsibility to speak up (Community Leader & Parent).

The emphasis on rebuilding positive parenting capacity and skills cut across many programs and sectors. Initiatives that were successful worked on all three subthemes — *understanding the IGIRS, healing and building strength and capacity* — to create an environment of support for individuals and families as they moved through their own *turning it around* process.

There's more linkage there now. They [have] a lot of parenting initiatives that they did at a school level, which would get the kids before they were pregnant actually, and then they [have] a lot of parenting support for young parents, or teen parents themselves. And they [have] a lot of professional workers who had been given training in developing parenting programs and parenting support programs and stuff. So I think that the issues that relate to residential schools that affect a person's ability to parent in a healthy way were probably addressed in those programs. In addition, there was a program that is called the [residential schools] survivor program (Provider).

Role models, mentors and support people were emphasized as important to building capacity. Many participants described the importance of having even one person who believed in you and showed you that it was possible to build toward your goals and dreams. For many participants even a single person — a sister, an aunt, a grandparent — believing in them, and witnessing their struggles and achievements — played a significant part in turning childhood adversity and trauma into resilience, positive coping and life skills.

There is a lot that happens in our communities and I think one of the big challenges for me was getting past that whole idea that there was no way I could be successful and be a mother. And I think that one of the things that greatly helped me was the fact that my mom was a teen mom. She was 16 when I was born, 15 when she got pregnant. And everyone said that she should either have an abortion or give me up for adoption, and you know. When I was born her doctor said to her, "There's no way that you are going to provide her with a good life. And you are going to be condemning this little girl to a horrible life and she will never amount to anything". And my mom did not stop working her butt off to make sure that I had a really good life, and I did. And so, I guess from seeing her, I knew that all hope was not lost. I knew that if I just worked really, really hard, I

could get there. Unfortunately, I think, not everybody grows up being able to see that (Parent).

Rebuilding our Cultures in Contemporary Contexts

Rebuilding our cultures in contemporary contexts is a sub-theme that cuts across all aspects of *turning it around* because it is a healing, reconnecting activity in itself, and because it was viewed as the root of strong people, families and communities. *Rebuilding our cultures in contemporary contexts* reconnects people with their culture and the roots of a strong positive identity.

How do you change society? But that's where the cultural pride comes in. To have strong cultural teachings and strong pride in who you are [and] to really give children a sense of pride in who they are (Parent & Provider).

Reconnecting with culture and nourishing a strong, positive cultural identity was viewed as a positive opportunity for participants to reconnect with themselves.

Participants described how the process of rebuilding their culture also reconnects families and provides them with positive opportunities to heal their relationships. Family members reach out to learn, discuss and make decisions about how to practice traditional ways and teachings. They described how reclaiming their culture was an affirmative process that engaged them in the upward spiral of turning it around: understanding how the IGIRS influenced parenting behaviours; forgiving; accepting and healing from past hurts; and coming together to work on a different future for themselves and their children.

However, participants acknowledged that reconnecting with their culture meant that they must work through multiple impacts of the IGIRS simultaneously. They must reconnect relationships; learn how to engage with each other in a healthy way; identify lost cultural teachings and work out how they will be practiced today; and help the person and family reframe their cultural identities and beliefs.

There's a lot of disjoining in our communities. We talk about how we have these strong family bonds, we have these strong cultural bonds, but quite honestly, I don't believe they are there, altogether. For instance, if we were to sit down and talk about a practice such as a coming-of-age ceremony, truly people would like say: "You're doing it wrong, and you're doing it wrong". There is no appreciation for the real differences between people. We are really, really focused on making sure that everybody does it right — our way. There's a huge cultural loss and a huge problem of identity, both culturally and as a family (Parent & Leader).

Rebuilding our cultures in contemporary contexts was often described as challenging as people debate how to manage, grow with, and live traditional cultural teachings in today's social, geographical, occupational realities. It is more than a simple matter of reclaiming traditions, but rather creating a new culture that honors tradition and identity.

For example,

It depends if you're in more of an urban area; maybe you will draw on, say, the Cree cultures and a mix of cultures, Métis cultures. Whereas, you know, from like say [large First Nation] who are really strong and they're feeling comfortable, they draw maybe more from one culture. But if you go outside of the [large First Nation] tribe group, to say a Friendship Centre, it's quite different how they might approach it. So I think that diversity exists: how they do their teachings and how they involve the family and the mother (Leader).

Discussion

According to international law, “forcibly transferring children of the group to another group”, is a form of genocide or state-perpetrated form of collective violence intentionally targeting a population group with the aim of destroying it (*Convention on the Prevention and Punishment of the Crime of Genocide*, 1951, cited in Krug, Dahlberg, Mercy, Zwi & Lozano, 2002, p. 216). The long-term individual and population health effects of genocide have been well documented. Health impacts of genocide include: increased rates of depression and anxiety; psychosomatic ailments; suicidal behaviour; intra-familial conflict; substance abuse; and anti-social behaviour (Krug et al., 2002, p.

216). “Intergenerational transmission of mental health *sequelae* (of collective violence) has also been documented, with offspring of holocaust survivors reporting higher rates of current and lifetime post-traumatic stress disorder symptoms than control subjects, despite similar self-reported rates of traumatic experiences in both groups (Yehuda et al., 1998, cited in Krug, 2002). Thus an extended burden of disease may be conferred on communities already coping with a multiplicity of genocide-related health consequences (Adler, Smith, Fishman & Larson, 2004). In the case of Canada’s Aboriginal peoples, residential schools were just one part of a collection of human rights abuses such as being required to stay on reserve (written permission was required to leave until the mid-1960’s), the loss of work through traditional activities, such as fishing, hunting, denial of rights of citizenship (e.g., voting, owning land) and a host of other factors (Furniss, 1995, 1999; NTC, 1998; RCAP, 1996).

Aboriginal participants’ experiences of and explanations for intergenerational transmission of the traumas of residential school policies are congruent with evidence on the impact of childhood trauma on neurobiological (National Clearinghouse on Child Abuse and Neglect, 2001), moral and emotional development (Tangney & Dearing, 2002). Trauma during childhood often results in withdrawal and disassociation, cutting people off from their feelings (Dion-Stout & Kipling, 2003; Tangney & Dearing, 2002). Unhealthy relationship behaviours such as coercion, abuse and neglect modelled in residential schools, and dissociation from feelings, constrain opportunities for affected children to develop the skills for healthy relationships (Dion-Stout & Kipling, 2003). These problems are further complicated by learning dysfunctional coping behaviours to escape from the spiritual and emotional pain, loneliness and isolation modeled by

residential school staff, such as alcohol and drug use (AHF, 2005; Dion-Stout & Kipling, 2003; NTC, 1996; RCAP, 1996). The resulting identities, beliefs and patterns of social behaviour then get passed on by survivors.

Participants' experiences and successes with turning around the IGIRS extend the evidence on resilience, recovery from trauma, and cultural continuity into the domain of care during pregnancy and parenting. For example, participants described the powerful impact of having at least one person who witnessed either their painful experiences or their successes as critical to their progress to turn around the IGIRS. This echoes many studies concluding that having at least one other person to whom one is connected is a significant protective factor for the health of survivors of trauma such as severe violence and child sexual abuse (Brown, Henggeler, Brondino & Pickrel, 1999; Gilgun, 1990; Hall, 1996; Rew, 2002; Testa & Miller, 1992; Wilcox, Richards & O'Keeffe, 2004). Dion-Stout and Kipling (2003) have synthesized the potential contribution of evidence on resilience to the experience of residential school survivors, and their family members. The results from this study suggest that understanding the IGIRS may help tap into sources of resilience that help transform parenting and family relationships and avert intergenerational transmission of patterns set up by residential schools.

Participants' experiences of *rebuilding their cultures in contemporary contexts* resonates with evidence on the positive impact of First Nations' community-based efforts to rebuild cultural continuity devastated by decades of colonizing policy (Chandler & Lalonde, 1998). The results of this study extend the significance of this work on cultural continuity into the domain of pregnancy and parenting.

The findings reported here also contribute to the emerging body of evidence on cultural safety (Browne, 2001; Browne & Smye, 2002) by raising the issue of safety in the context of care during pregnancy and parenting. Culturally safe care involves understanding the history of colonization, its impact on Aboriginal People, attention to power relations in health care relationships, and competencies for facilitating safe supportive relationships (Polashek, 1998; Wood & Schwass, 1993). The findings of this study add to the cultural safety literature by emphasizing the importance of bringing these issues into the foreground of design and delivery of safe and supportive policy and programs.

Implications

Understanding and acknowledging the IGIRS emerged as central to participants' vision for a better future for their children, thus salient to safe and supportive health care relationships. *Understanding and Acknowledging the IGIRS* requires understanding the pathway of devastation resulting from multiple levels of disconnection and alienation when people undergo decades of genocidal policy and relationships in society. The resulting downward *spiral of addiction, violence and poverty* is often racialized as being an Aboriginal "characteristic", rather than being recognized as the consequence of collective violence (Browne, 2001; Reimer-Kirkham & Anderson, 2002).

Silence on residential schools within and outside of Aboriginal communities, and racialized explanations for the inequitable health and social conditions experienced by Aboriginal people reinforce colonialist relations in general, and in health policy and practice (AHF, 2005; Adelson, 2004). Health policy and programs may inadvertently reinforce oppressive stereotypes, if addictions and violence rather than IGIRS are

conceptualized as the root cause of health and social inequalities. The unacknowledged assumption is that the characteristics of Aboriginal people themselves explain increased rates of problems such as addictions and violence. Basing policy and practice on racialized explanations for health and social conditions experienced by Aboriginal people creates unresponsive and unsafe services, and may explain the pattern of poor access and use of mainstream pregnancy and parenting programs. Recognizing and respecting the views and experience of Aboriginal people and bringing their views and vision for change into the foreground of maternal child health policy and practice is needed to reverse the health and social conditions resulting from the IGIRS.

These results suggest that community-based stakeholders' understanding of both root causes and acceptable approaches to safe and supportive care in Aboriginal communities must be added to the discourses shaping both related health policy and programs, and health professional training programs. Health status and experiences such as pregnancy and parenting must be understood within a broader understanding of the impacts of colonization on Aboriginal People, while also acknowledging the unique life experiences and meanings of individuals, families and communities. Practitioners must on one hand develop a critical understanding of the impact of colonization as a program of collective violence to 'deal with the Indian problem'. On the other hand, safe practice also requires respect and responsiveness to individual differences in experiences of the IGIRS that is shaped by the interplay between diverse personal, family, and community contexts. Further, system differences related to geographical location, population size and governance arrangements also contribute to variations in experiences and meaning between individuals and communities.

Conclusion

Foregrounding Aboriginal parents' explanations of root causes of poor health and social conditions in the orientation and purpose of health policy and programs, represents a paradigm shift for current maternal child health policy and programs, and professional practice that have positioned Aboriginal people themselves as 'the problem', and focussed efforts on the downstream effects of residential schools. The sub-themes in the participants' stories offer a prescription for action by both Aboriginal and non-Aboriginal people in relationships, programs and policies to support bringing the culture back through understanding the profound effects of IGIRS, emphasizing healing and focusing upon strength and capacity. Such a perspective would enable health policy, organizations and providers to work in closer harmony with Aboriginal People toward their vision, rather than reinforcing the colonizing relations that are a legacy of our past and an ongoing feature of daily practices. Such a shift will require nurses to develop our understanding of how to build individual competencies for culturally safe nursing practice. Further research is needed to explicate competency development processes that build partnerships between Aboriginal organizations and communities, and to identify implications and actions for nursing education, and professional practice organizations overseeing our professional responsibilities to the public.

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Paper # 2:

Bringing Safety and Responsiveness into the Forefront of Care

for Pregnant and Parenting Aboriginal People

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KEYWORDS: Indigenous Peoples, pregnancy and parenting, safety, responsiveness, intervention design, evaluation, perinatal programs, participatory research

RUNNING HEAD: Safe and Responsive Care

ABSTRACT

Poor access to prenatal care for Aboriginal people is well documented. A postcolonial standpoint, participatory research principles and a case-study design were used to investigate two Aboriginal organizations' experiences in improving care for pregnant and parenting Aboriginal people. Data were collected through exploratory interviews and small-group discussions with purposefully selected community leaders, providers, and community members. The study found that safety in health care relationships and settings, and responsiveness to individual and families' unique experiences, capacities must be brought into the forefront of care. Results suggest that the intention of care must be situated within a broader view of colonizing relations to improve early access to, and relevance of care during pregnancy and parenting for Aboriginal people.

Introduction

There was always... a worry that in the past decade, the emphasis had always been on perceived rigid rules and regulations coming from the outside. And so (as nurses), I guess the anxiety was... we don't want to continue to do that...we wanted to honor our professional code (i.e., standards for practice), but also wanted to honour the cultural codes and protocols of the [local] people., and the professional code was the add-on piece, rather than the other way around We needed to understand the [local cultural] code, to respect it, to abide by it, and to be guided by it. So that the cultural code was the main code [emphasis added] (Provider #P2-A4).

Late or no access and poor use of prenatal care, as well as poor pregnancy outcomes among Indigenous^a women globally^{1,2,3,4,5} demonstrate the problems and lost benefits incurred by colonial style health care delivery systems. Many health care programs and practices continue to reflect the oppressive values and attitudes that underlie colonization⁶ and create demeaning, disrespectful or dismissive environments and interactions between providers and Aboriginal people⁷. This has created a dynamic in health care in which Aboriginal^b people may avoid health care services or use services only at the point of crisis. As a result, benefits to individuals and populations through preventive interventions during pregnancy and parenting are lost.

Many Aboriginal health care organizations position their work in the broader project to transform the inequities imposed by colonialism and the resulting hegemony of Western knowledge and social systems⁸. In an earlier paper⁹, we described participants' views of pregnancy and childrearing as a window of opportunity for Aboriginal people to

^a The term Indigenous is a globally inclusive term, while the term Aboriginal is used primarily in Canadian contexts.

^b The term Aboriginal "refers to organic political and cultural entities that stem historically from the original Peoples in North America, rather than collections of individuals united by so-called 'racial' characteristics" (Royal Commission on Aboriginal Peoples, 1996). These include the First Nations, Inuit, and Métis Peoples of Canada.

turn around the intergenerational impact of residential schools^c and create a better future for their children. Results suggested that pregnancy and parenting must be understood within the context of the intergenerational impact of residential schools, as well as *respective* of Aboriginal people's unique individual and family life experiences.

This article describes community-based stakeholders' views on Aboriginal organizations' approaches to care during pregnancy and parenting; and their understanding of how the difference this care makes for Aboriginal women and families can be incorporated into indicators and expectations for evaluation.

Background

Inequities in health between Aboriginal and mainstream Canadian populations have been well documented.^{10,11} Since the *Indian Act* of 1876¹², the federal government has had jurisdiction over health services for First Nations and Inuit People living in First Nations and Inuit communities^d. The First Nations and Inuit Health Branch [FNIHB] is the 5th largest health services delivery organization in Canada, and delivers primary health care services to First Nations communities either directly, or through transfer agreements with First Nations controlled health authorities. Problems with FNIHB controlled services have been attributed to inequities in access to services, an imposed biomedical rather than holistic approach to interventions, federal government rather than Aboriginal authority and community control over health systems, and lack of

^c From the mid 1800s until as late as 1996 an estimated 100,000 Aboriginal children, ages four to eighteen years old, were removed from their families and placed in residential schools as part of the federal government's assimilation plan. Residential schools involved deliberate suppression of language and culture, substandard living conditions, second-rate education, and widespread physical, sexual, emotional and spiritual abuse, and is an internationally recognized form of genocide (Convention on the Prevention and Punishment of the Crime of Genocide, 1951, cited in Krug, Dahlberg, Mercy, Zwi & Lozano, 2002, p. 216).

^d Health services for Aboriginal people living off reserve are the responsibility of provincial governments.

responsiveness to differences in cultures and community realities¹³. This legacy has contributed to creating and sustaining individual-focused, bio-medically oriented services, and a top-down system of maternal child health care^{14,15}.

The FNIHB's maternal child health program is comprised of pre- and post-natal care, including evacuation from rural and remote settings to provincial tertiary-care facilities for birth¹⁶. Pre- and post-natal programs are delivered primarily by registered nurses who work with community health representatives, alongside several related programs such as the Canada Prenatal Nutrition Program, the Fetal Alcohol Syndrome/Fetal Alcohol Effects Prevention Program, and the Aboriginal Head Start On-Reserve Program. The presence, size and scope of these services vary considerably across the seven FNIHB regions and among the 602 First Nations communities. The result is a collection of programs with independent administration, governance, and implementation systems. Further, service continuity and depth of care over the childbearing continuum are disrupted by evacuation for birth, and high rates of nursing staff turnover. This model of maternal child health care has contributed to the inequitable health and social conditions experienced by Aboriginal women, children, families and communities^{17,18}.

The need for more culturally-appropriate maternal child health care that is relevant to the needs and strengths of Aboriginal women and families has been identified^{19,20,21,22}. From a cultural safety perspective, which takes into account any factors that disempower Indigenous people, barriers to health care for Aboriginal people will remain "until the effects on the health care system of inequalities in power between groups in society are addressed"^{23 (p.453), 24}.

Some evidence for intervention suggests that culturally appropriate perinatal services improved Indigenous women's satisfaction with care and early initiation of care, and increased rates of breastfeeding initiation and duration, though interventions deemed to be culturally appropriate varied. Two programs of research^{25,26} and several evaluation studies^{27,28} with Indigenous communities found that community involvement in program design, implementation and evaluation improved participant satisfaction, early access and participation in care, and enhanced women's health behaviours such as improved nutrition; and decreased tobacco and alcohol consumption, and feelings of mastery about infant care.

In Canada, a growing majority of First Nations communities have transferred, or are in a multi-year process of transferring the administration and delivery of health care services from the federal government to First Nations' control. Innovations by First Nations communities and organizations to improve care for Aboriginal women and families during pregnancy in some communities have been noted. However, researchers have not yet systematically documented what features of these prenatal programs are salient. Thus the purpose of this study was to describe innovations developed by Aboriginal health care delivery organizations to improve care during pregnancy and parenting for Aboriginal people.

Methods

A critical postcolonial stance and participatory research principles^{29,30} shaped the focus and methods of the study. Critical postcolonial perspectives located participants' experiences within the struggle to understand, deconstruct, resist and transform the impact and institutions of colonialism^{31,32}. Both postcolonial and participatory research

perspectives are inclusive of different value systems, sensitive to differences, view all forms of knowledge as valuable, and seek to generate knowledge that is relevant to stakeholders and useful for solving practical problems. A case-study design³³ enabled collection of in-depth contextual data to understand the determinants and processes of individual and organizational participants' experiences in improving care for pregnant and parenting Aboriginal people in each setting^{34,35}. Peer debriefing, member checking, prioritizing trust and relationship-building in research encounters, reflective writing and engagement, and thick description were used to bring critical reflexivity, integrity of participants' voices in context, and direct action on the research problem into the forefront of the research process, as well as to maximize confirmability, credibility and fitness of research results.

Concurrent data collection and analysis for phase one began in February of 2004 following ethical approval from the University of Ottawa Health and Social Sciences ethics review board. Sixteen key informants working in policy, leadership, and provider positions in maternal child health in the province of British Columbia were purposefully selected using network sampling techniques³⁶. During either telephone or face-to-face interviews, key informants shared their perspectives about issues and influences on Aboriginal women's and families' pregnancy experiences, and identified health care delivery organizations with reputations for having high rates of early access and participation in prenatal care by Aboriginal women.

One urban and one rural Aboriginal health care delivery organization geographically located in one region were then invited to participate in the community-based case study in phase two. Ethical approval was obtained from the University of

Ottawa Health and Social Sciences ethics review board, the ethical review committee of the participating Tribal Council, and Chief and Council of the participating communities. Field work was conducted from June to September of 2004 in the two settings.

Participants in each setting were purposively selected using network sampling techniques to obtain a variety of perspectives from community members, providers and leaders. Sampling decisions were made to juxtapose stakeholder group (i.e., leaders, providers, and community members) perspectives on the research questions. Data was collected by the first author using one-to-one exploratory interviews and small-group discussions according to the preference of each participant. Interviews lasted from 45 to 120 minutes depending on the communication style, stories and perspectives the participant wished to share. Time was taken at the beginning of the interview to create a safe, trusting, respectful environment and dynamic in the researcher-participant relationship, and emphasize the importance of many ways of knowing, particularly feelings or embodied knowledge^{37, 38}. Many participants held multiple stakeholder positions, such as parent, provider and community leader, so a longer period of time was required to discuss their related experiences. Interviews were taped with participants' consent^e and transcribed. Supplementary documents and field notes were also included in the data set.

Data were analyzed by the first author using an interpretive descriptive method³⁹ supported by NVIVO software during a prolonged period of immersion in the data. Analysis proceeded from a wholly inductive approach, and became increasing deductive as important themes were identified. Analysis included iterative cycles of coding, collapsing and reorganizing coding structure, and consideration of thematic patterns

^e Three participants preferred to have notes taken during the interview.

across different sites, and different participant groups (e.g., community members, providers and leaders). Throughout the analysis, integrity of participants' sense of importance across themes was examined and maintained through peer debriefing, member checking, reflective writing and consultation with relevant documents such as those suggested by participants. Once preliminary results were drafted, all participants were invited to discuss them in three-hour workshops held in the study communities in April of 2005.

Results

A total of 73 key informants and community-based leaders, providers and community members participated. Table 2.2 shows a profile of participants in each phase of the study. Over 60% of the sample self-identified as Aboriginal and 90% were women. Most participants had multiple roles (e.g., were leaders, providers, and community members).

Participants were assigned to the group based on the criterion for which they were to chosen to participate. Nearly half of phase-two participants were providers ($n = 25$); and 20 of these had more than 10 years ($n = 20$) of experience working in an Aboriginal health service delivery organization. Providers included registered nurses ($n = 9$), lay providers ($n = 7$) such as nutrition counselors, community health representatives or family support workers, and other health and social service professionals ($n = 9$) such as nutritionists, social workers, and professional counselors. The remainder were community members, including mothers, fathers, grandparents, and Elders; and leaders such as band administrators, chief and council members, health centre administrators or advisory committee members.

Table 2.2: *Sample Composition by Phase, Aboriginal Identity and Gender*

Study Phase and Setting	Sample Sub-group	Total*	Aboriginal Identity # (%)	Female # (%)
<i>Phase One</i>		16	8 (50)	15 (93.7)
<i>Phase Two</i>		57	36 (63)	51 (89.5)
<i>Case A: remote setting</i>		29	21 (72.4)	25 (86.2)
	Leaders	8	7 (87.5)	6 (75)
	Providers	10	2 (20)	9 (90)
	Community Members	11	11 (100)	9 (81.8)
<i>Case B: urban setting</i>		28	15 (53.6)	26 (92.9)
	Leaders	9	4 (44.4)	9 (100)
	Providers	15	7 (46.7)	14 (93.3)
	Community Members	4	4 (100)	3 (75)
Study Totals		73	44 (60.3)	66 (90.4)

*Though many participants fit into more than one category, they are only counted once in this profile

Pregnancy as an Opportunity for Change

‘Successful’ intervention approaches were described by participants as acknowledging individual and collective history, and responding to pregnancy and parenting as a significant opportunity to facilitate and support Aboriginal peoples’ efforts to create a better future for their children. Respondents described pregnancy as a

powerful opportunity to support and facilitate people in choosing a healing path.

Participants indicated that pregnancy was often a time when prospective parents examined the influence of the intergenerational impact of residential schools on their values, beliefs and capacity for healthy parenting. Speaking from her experience as a parent, this provider explains:

I've found having children really makes you question the spiritual, your spirituality... So if you're ambiguous before, you weren't sure what you believed, it's pretty hard to talk about that with your kids. ...I think questioning as you become a parent is a normal part of becoming a parent, but there probably are a lot more conflicting issues I think, if you have the residential school issues. Even if you weren't there yourself, but a child of someone who went to residential school because it's passed down for sure. But they were never taught how to be a parent. They were never parented (Provider #P2-A3).

As well as revisiting a painful childhood, becoming a parent represented a time of significant hope for a better future for their children.

I was abused. I was neglected, I was physically abused by my parents, by my friends. This is something I don't want to happen to the next generation of children. I want things to be different for my kids. I want them to succeed — I can see they are going to succeed. They are doing well in school and they are going to have a chance (Community member #P2-A10).

Participants described the high value placed on children by families, culture and community as an “enormous” motivator for parents to make and sustain healthier choices.

The real cultural belief is that all children are a gift from God. So no matter what the circumstances... if the woman is drinking, if she's doing drugs... it doesn't matter [to the importance placed on the child], that child is a gift. And that has an enormous influence on the women (Provider #P2-A2).

Safe and Responsive Care

Safety and responsiveness were seen by participants as central to an approach to care that fundamentally changed the nature of their relationships with health care

organizations and providers. They saw attention to safety and responsiveness as enabling health care to facilitate Aboriginal peoples' efforts to turn around the intergenerational impact of residential schools. The sub-themes involved in design, implementation and evaluation of safe and responsive care for pregnant and parenting Aboriginal people are described below.

Safe Places and Safe Relationships

Safe places and relationships were described as essential to support Aboriginal parents in their efforts to turn around the intergenerational impact of residential schools.

Safe places are important from multiple perspectives. Participants described how mainstream health care environments were often perceived and experienced as unsafe.

Speaking about experiences in mainstream health care setting, one leader said:

Lots of the time they don't feel comfortable [at the mainstream health agency]. It's not a culturally acceptable place. The rules are very rigid. You have to come at a certain time. They [agency staff] don't understand the difficulty of getting rides, they don't understand how appointments can be missed ...and also [Aboriginal parents] they feel they're being judged on the way the baby looks, or how they talk or ... health nurses assume they're stupid or they're slow and they can't read, or, you know, these sorts of things (Leader P2-B1b).

Participants described how the risks associated with past care-seeking experiences have made safe places and safe people in the Aboriginal health organization critical:

It took a long time for trust to be established. That this was a safe place and that it had benefits versus the risks of coming into this place. I think we have to acknowledge for people who have been marginalized, the risks need to be weighed out versus those benefits. And you know, some of the risks might be that it puts on the table that you are using a substance that could cause harm to the fetus or if you have other children at home and you identify that you are using a drug of some sort..., I mean just coming out of the closet and telling people that you have a problem has its own risks. And that's where the trust factor comes in. You know if, if the way that that problem solving is handled is respectful, effective and client-focused, then that's why people will come. The word of mouth is going to put it out there that it's okay to take that risk (Leader #P2-B6).

Participants described the characteristics of a safe place, emphasizing the importance of the energy — or the feeling of a place:

It's also the environment, the place; it's warm, friendly and caring and we have time for people. There is a different energy in programs built from an Aboriginal perspective... the pace is different... the environment is more relaxed, friendly, casual... it is a comfortable place to be, with couches and the coffee room. There is a mix of staff that is similar to the mix of participants [including some] First Nations staff. We dress differently..... I don't dress up to see participants ... We are people-friendly, not appointment book-friendly ... it feels like home here.... It's built more around creating a home-like atmosphere for participants, and not on an appointment book (Provider #P1-16).

Safe places were also seen as requiring a nonjudgmental attitude on the part of the whole program and organization:

And we want them to know that parenting isn't easy. Parenting doesn't come naturally for everyone. You are not always going to know how to do it, what to do, why to do it, when to do it. That everybody needs help and support, and if you don't have someone, then you have us; especially for young people that don't have family around or who have a fractured family and can't rely on their family. We let them know right from the beginning that it is okay to be overwhelmed and you don't have to be ashamed to ask for support (Leader #P1-10).

Aboriginal parents said that to heal, you have to face up to the pain, to the weaknesses and the problems, which can be very difficult. Therefore, you need supportive relationships with people who will not judge you, but will walk beside you, who will listen and acknowledge your pain and your strengths along with the mistakes you may have committed as a human being. Respect in everything that is said and done, whether consciously or unconsciously, influenced people's feelings of emotional safety.

But I think the more First Nations groups I know, the more I know just to treat everyone like individuals. It truly is. You know, you make these assumptions based on what they should be culturally and then you get challenged and told that's wrong. So, I find it's always best to work with them as individuals and say... and treat them as people, with respect, and then you get amazing results (Provider #P2-B1a).

The client-provider relationship was seen as an opportunity to build understanding and capacity for healthy relationships. Participants emphasized facilitating healthy reconnection and relationships with self, significant others and family, rather than creating dependencies on providers.

You have to have, I feel, for me to even connect with them and to be open and honest so that we can work with that, is to say, "What has life shown you?" "What's your biggest issue, what's your biggest concern?" And when it's coming from them, then probably 95% of the time, people come out and say what their issue is... whether it's to try to quit pot smoking or trying to quit cigarette smoking or working on their partner to do that, or having a healthy relationship... because I've had that too. That was their concern, they wanted a healthy relationship and they wanted to treat each other respectfully so that their children could come into a world where they were treated respectfully (Provider #P2-A22).

Safe relationships mean providers being open, and seeking to understand and acknowledge, rather than to judge. Along with acknowledging the pain and struggles people have experienced, the participants thought it critical to recognize the gifts and assets that people have developed through their struggles.

That's all people want, is that acknowledgement. I think we all want that as people, trust that I can make my own decision and trust that I will do the best that I can with the skill set that I have. And when you give me that credit... then I'm going to aspire for more (Provider #P2-A22).

Connecting with people at a 'heart' or 'spirit' level through developing safe, trusting relationships was described by all groups of participants (i.e., leaders, providers, community members) as the most important difference between the approach developed by the Aboriginal health organizations compared to conventional care. This became increasingly clear as the interviews progressed, so the question was posed, "What happens if you don't connect with people at a heart level?" Responses to this question

ranged from “*You might as well pack your bags and head home*”, to “*Nothing. Absolutely nothing happens*”. One participant put it like this:

If [connecting at heart/spirit level] isn't there, they're not there. That's what happens. People just don't feel comfortable. My take... is that they're not going to come back, because that's the feedback that I have got from people ... when they feel respected and when they feel accepted, when they feel that you care and they'll test you out... and they know... they've been through an experience for so long that they know from their teachings and also from their experience and all the kinds of painful things that have happened what works and what doesn't (Leader #P2-B7).

Responsiveness

Responsiveness encompasses being holistic, being client-directed, and integrating ways of knowing into relationships and care. Participants in this study described holistic as:

There is that kind of spiritual dimension in everything that takes place ...the spiritual, mental, emotional, physical aspects of life all need to be considered and in balance for us to really be able to participate fully in who we are and in our families and in our communities. And that's a juggling act. Anybody who has tried to become balanced knows that. But, so we need all kinds of support to do that... we need understanding, we need encouragement... (Leader#P2-B7)

Client-directed care was differentiated from client-centered care and was described as the client setting the agenda, making the decisions and taking responsibility for living with the consequences. For example,

Most of it, I truly believe, if I look back over the years... it's about 50-60% emotional support. I might have an agenda that I'd like to talk about breastfeeding today, but that might be the last thing on their agenda, so if we can't do what's on their mind and their focus, then how can we really reach what we need to do (Provider #P2-A22).

Responsiveness means that many ways of knowing are respected and integrated into care. Ways of knowing included the traditional knowledge, experiential knowledge, ‘heart knowledge’, and clinical knowledge from both clients and providers. However,

there was a consistent emphasis on bringing traditional knowledge, experiential and 'heart knowledge' into the forefront of care. Participants explained why:

We're trying to work with women to invite them to explore some of the traditional practices. Like before they give birth and try to incorporate it into a birth plan. And even through the pregnancy, to try to use some of those belief systems and have that guidance instead of white society telling you what you should and shouldn't do (Provider #P2-A3).

An emphasis on personal and cultural knowledge reverses the pattern of care, from imposing and shaming based on mainstream knowledge and practices, to connecting with clients, and acknowledging and affirming their cultural knowledge and identity:

Well I think that to be strong on the culture is such a good tool to try to turn it around because, you know I talked to a lot of women and there's a lot of anger, there's a lot of being made to feel ashamed of yourself that sort of results in sex and abuse issues. And I think going back to the traditional ways of giving pride and food can help to undo some of that. I see that as the answer. And I think it will come. It's going to be slow. But I think that's the answer, going back to the traditional teachings and beliefs (Provider #P2-B16).

The importance of an approach that incorporates many ways of knowing is evident in descriptions of experiences moving back and forth between living in small isolated First Nations communities and larger mainstream communities. The difficulties of trying to fit into the values and lifestyle of mainstream society, heightened some participants' awareness of their unique way of being and knowing as an Aboriginal person:

It was like two collisions... this world with that world... and it took many years to realize... how do I fit into this society? How do I adjust to this society? How do I meet up to their standards, their education, their lifestyle, their raising of their children was so different from the way ... we were raised as children... and ah, it was hard. It took me many years to adjust (Community Member # P2-B3).

Providers, leaders and community members were clear that up-to-date scientific and expert clinical knowledge is important, and integrated as needed. Providers indicated that deciding how and when to use different ways of knowing comes from reflective

engagement with their own emotional wisdom, as well as being emotionally “tuned-in” and respectful of the choices and priorities of the people with whom they are working.

Making Intervention Strategies Safe and Responsive

There was always... a worry that in the past decade, the emphasis had always been on perceived rigid rules and regulations coming from the outside. And so (as nurses), I guess the anxiety was... we don't want to continue to do that...we wanted to honor our professional code (i.e., standards for practice), but also wanted to honour the cultural codes and protocols of the [local] people., and the professional code was the add-on piece, rather than the other way around We needed to understand the [local cultural] code, to respect it, to abide by it, and to be guided by it. So that the cultural code was the main code (Provider #P2-A4).

Safe and responsive care for Aboriginal parents during pregnancy and parenting involved a collection of innovative strategies that are qualitatively different from conventional care. These elements of care were identified as critically important by all three groups of participants in both communities (i.e., community members, providers and leaders). Examples illustrating this difference include: reaching out and being visible; empowerment education; inclusion of fathers and families; and an emphasis on the role of food. Examples highlighted below demonstrate how the imperatives of safety and responsiveness shaped providers' practice.

Reaching out and being visible. Reaching out acknowledges the barriers that the history of unsafe environments, people and relationships may have on care seeking. Reaching out was also seen as an indication of being with people because you genuinely cared about them. Reaching out was an example of following the local cultural codes, rather than imposing or limiting care to the norms of mainstream society. Reaching out was the ‘way we do things around here — it's our way’. For example:

There is, I think, very positive support with [the community health nurse], who is able to get out into the homes and do a one-on-one, and that's what really works.

There is a very big weakness, in a sense, with people and their safety and their issues to walk into the health clinic. They don't feel safe. They don't feel that they can trust the staff [who] work there. They don't feel trust in, not just the people, but in the whole entire government structure. ... fear is a big thing. Fear to talk to somebody about sex and sexual education...[for example] (Provider #P2-A9).

Being visible went hand in hand with reaching out.

To me, one of the most important things is being visible. I found that being visible in the community, consistently... I'll see Elders, I'll work with the mothers, I'll go to the school, I'll do baby shots... a lot of stuff, where people come in and they're looking for something or they want some screening done, and then I'll talk to them about that.. about anything. I found that the women come much earlier. And as they've gotten to know me I've found that some of the women have actually come within the first five weeks [of their pregnancy] (Provider #P2-A2).

Empowerment education. In contrast to the straight information-giving approach of conventional and less well received programs, an empowering approach to education was a distinct aspect of supportive programs. Providers described a one-to-one responsive style of teaching and learning that was noticeably different than simply providing people with oral or written information. They described an ongoing dialogue with clients that integrated client's knowledge of themselves, and their goals and constraints, with provider's knowledge of such things as bodily functioning, the health care system, and client's rights.

Now they're thinking about it. They know that if they want to get pregnant they want to be healthy. They want to have healthy babies. ... I teach them [about their menstrual cycle]. ... Pretty much all those women know when they are ovulating now. And we all should. I tell them, don't feel bad if you don't know, 80% of the population doesn't. I mean, it's the truth. So, they all know. To me, that's empowering them. They are empowering themselves with that awareness of when they need to... not have sex when... you know, if they are going out for the weekend, there is more planning involved than I have ever seen before (Provider #P2-A22).

Including fathers and family. Safe and responsive care recognized the disconnections resulting from the intergenerational impact of residential schools, and

seized the positive opportunity presented by pregnancy and parenting to encourage families to develop stronger connections and build healthy relationships. Providers encouraged family members to participate directly in care. For example:

When [the nurse] is doing the prenatal, she welcomes them... I don't think I've seen a dad come through here who wasn't just beaming when he left after the prenatal session. I think that even that early involvement and that early education about what's happening with the wife's body is an important step for, for men to have, for all people to have. And it's teamwork, it's not just all mom's job because the baby's in mom... you need that support (provider #14).

Participants also described how clients were encouraged to reach out to family members to explore how the tasks and issues of pregnancy and childbearing, such as dietary habits and naming have been managed in previous generations. This served to reconnect family members over a positive common interest that often provided an opening for healing past hurts.

Feeding the body, mind, and soul. Food was described as a positive, culturally-based method of connecting, building relationships and passing on knowledge, and a traditional way of imparting knowledge.

Culturally our way is to, when you feed someone, what you're feeding them is, you're feeding them information once you're feeding them nutritionally also. You know, what I mean, is you're feeding their mind. You're feeding their body and you're feeding their soul when you're giving them the respect. And you're giving them the honor that they deserve. Everybody needs to be well-respected when they walk in that door regardless of who they are. That's the way I envision it. Feed the mind. Feed the body. Feed the soul (provider #15).

However, food security and food literacy were also described as urgent concerns for pregnant and parenting families. Food insecurity was identified as a consequence of poverty, and a gap in knowledge and skills resulting from the loss of traditional food sources and the consequences of the intergenerational impact of residential schools:

We also have to recognize that the parents of today's pregnant women may have been in residential schools. And so they didn't learn how to cook. Therefore, they didn't do what you're doing with your family. They didn't make from scratch or teach their children what is a balanced meal. So we've got some [food] illiteracy (Leader #P2-B6).

Participant's described weaving together food as a need and as a solution in their programs:

One of the things that we do a lot of at [our organization] is to have gatherings and, culturally when people have gatherings, they eat. So people have the opportunity to come together and eat in a social kind of a way that I think provides a lot of good nourishment... besides food, it nourishes the soul and just provides people with just those kinds of things that maybe they don't have access to in their every day life... Things like a sense of community... enough food. You know, we have women coming in there sometimes, that haven't eaten for three days because they've been feeding their kids... And then we have the cooking classes and things like that (Provider #P2-B5).

Expectations and Indicators for Evaluation

The second research question asked, '*How does (this) approach to care make a difference to Aboriginal women and families?*' Participants situated their views of how this approach to care made a difference relative to community/clients' unique experiences of the intergenerational impact of residential schools, and from an appreciation of each individual, family and communities' unique experiences in the process to turn around these impacts. Sub-themes for evaluation included a seven-generation perspective on expectations for change, appreciating client and community progress, and recognizing individual and collective level indicators of how supportive intervention can contribute to Aboriginal peoples' efforts toward their vision.

A seven-generation perspective. In this view, expected outcomes are longer-term, and fit with facilitating clients' and communities' work to turn around the intergenerational impact of residential schools.

This healing will take seven generations. It won't take four generations...It will take seven. It's the generations, and that's what's hard for us as nurses too, to really... when you feel disappointed, then it's... it's like remembering that. It's not about me or my disappointment, it's about the seven generations down the road. And that's where their healers and their visionaries... that's the way they view it, that's the patience that they have (Provider-#P2-A2).

Crucial to appreciating how this approach to care during pregnancy makes a difference, is understanding where each person is starting from, what their goals and priorities may be, and how the current challenges and tasks of pregnancy may fit into their lives.

During pregnancy is the time that I see women most likely to make a change. Sort of as an observation... if someone is having a lot of alcohol or drugs involved with their life or is not really very healthy, I find that when they find out they're pregnant, it tends to turn them around and they tend to work very hard to do the best they can for that pregnancy. And often I'll see that it lingers on. You know, that change of the nine months will have been so great, that after the baby's born, they are able to continue on a healthier way. So I think it's a really great opportunity(Provider #P2-B1).

Participants were unanimous in the view that their expectations of positive changes are not necessarily within the nine-month span of pregnancy but over consecutive pregnancies, and even generations.

Participant: They can come to me, and I can teach them about...you know, the early stages of pregnancy and conception and what it means, about development... and [about] how important it is to be sober, and that's I think the knowledge that the women are gaining. In the next pregnancy, it makes it difficult for them [to know] whether to keep the baby or not, or go through the pregnancy, because they already now know... they have prior knowledge, but actually this is the development stage. And if this baby... if I'm drinking heavily at this stage then my baby could be born with FAS.

Interviewer: So it might not have a big influence on their (current) pregnancy but it would maybe change their behavior with subsequent pregnancies.

Participant: And that's the point (Provider #P2-A2).

Rather than comparisons to externally imposed measures of short-term success, evaluation needs to be tailored to individual and community realities and expectations, and focused upon appreciating the magnitude of positive changes over time. For example,

indicators of infant attachment can be used as an indicator of both individual and community progress, rather than just against objective standards:

I guess it's a disappointment in a way... Because you're sort of hoping, wishing for these parents to really get what it's all about. Now, that being said, it is happening... they are bonding at a completely different level than they were probably bonded with ... and they are aware of what's available for their babies... like the hopes and dreams... they're just aware of that... And so even if the time spent with their babies isn't always 100% positive... it is 100% more positive than it was, say, 20 years ago. I think there is a shift happening (Provider #P2-A9)

Thus participants described how expectations are situated in an understanding of how much change can be expected from one generation to the next. For example:

They make huge strides. I think that's where the difference is. This is where... they actually stop drinking... and as one of the healers said to me one day, 'You know they were out there drinking and they've come in to you... Think about that one. They are sitting in your office... they've stopped drinking at three months. Think about that one.' So maybe some of these children will grow up with a snippet of self-esteem and they'll actually not... they'll do it less. So basically you're talking... again it goes back to the seven generations (Provider #P2-B13).

Appreciating client and community progress. Appreciating client and community progress is built on an understanding of differences in where communities/clients are starting from, as well as the energy and effort it may take to start and maintain the healing, and capacity building process. Communities' efforts to improve health and social conditions must be evaluated within an understanding of how the history of colonization interacts with geography and population density to influence community capacity and access to resources. For example, small remote communities may have had a greater proportion of children forcibly attending residential schools over a longer period of time. Thus there is significant diversity between communities in terms of a) degree of impact of colonization such as residential schools; b) access to resources both inside and outside

the community; and c) progress with healing and turning around the intergenerational impact of residential schools and other instruments of colonization.

Many leaders and providers talked about the reality of trying to run programs that are funded on a *per capita* basis, when living in a small isolated community.

My experience is from small towns and one of the things that I really feel strongly is, in these small communities we only have 100 or so people or 200 people. Your pool of what programs we get to run gets so much smaller. And you've only got a few, like a handful of really good resource people (Provider #P1-3).

Many participants talked about how the cyclical nature of recognizing, deconstructing, and transforming program structures often starts out as *de facto* adoption of old programs:

Adoption of FNIHB structures happens a lot right now, because of lack of models, lack of leadership and governance capacity. So people ended up adopting or using what they know or what is available...[and] that ends up to be FNIHB programs (Leader #P1-10).

Thus where communities may be “starting from” must be understood and acknowledged.

The level of effort required to leave behind the dependency models of the past, and make incremental gains in building leadership and governance capacity must be appreciated.

We [a large First Nations community] went through health transfer relatively early, back in [the early 1990's]. Which means we started the process in the mid-80's. Other communities, especially smaller communities were very very afraid of health transfer agreements because they thought that the government is going to set us up; they would be abandoned, the rug pulled out from under them. Now that I am in this position, I see the small struggling communities that do have a lot less resources (Leader #P1-10)

Recognizing relevant indicators. How does this approach to care facilitate

Aboriginal peoples' efforts to turn around the impacts of colonization/residential schools and build health and capacity? Safe and responsive approaches to care were credited with positive outcomes on both collective and individual levels. When asked how safe and

responsive approaches to care make a difference, participants described indicators of positive outcomes such as *“the number of people who are on a healing path”*, *“the degree to which abuse is talked about”*, *“leaders carrying the hurt — [an important indicator would be] that the leaders are able to be on a healing/forgiving path”*, *“a lot of [mothers] are back to breastfeeding”*, *“they are really aware of the dangers of drug and alcohol during pregnancy”*, *“there are less addictions, the rate is down”*, *“the rate of teenage pregnancies would go down”* and *“if a baby was conceived in a happy way — not a rape — the family and grandparents relate to the baby as a human — this is getting better — before it wasn’t so good. Now people are more able to let the hurt go and not take it out on the baby”*. Many of these indicators of progress relate particularly to childbearing, but also are more general indicators of progress with turning around the impacts of residential schools (e.g., number of people on a healing path). These indicators were discussed as relevant to both collective and individual levels.

At a collective level, participants talked about indicators of the community believing that the health care organization and providers were safe, and would respond to their concerns. Thus indicators of *trust* are important to evaluate:

And when the word gets out, I mean you can talk about advertising in newspapers and what have you, but the best promotion of (our program) has been word-of-mouth. So until the word gets out that you can trust this program, they aren’t going to come. And it’s one by one by one that that happens. And we miss that. We don’t measure that Aboriginal people [are] not accessing prenatal care? A paramount indicator is that they came (Leader #P2-B6).

Significant to both collective and individual progress, all groups of participants (i.e., providers, community members, leaders) also described *“speaking up”*, *“speaking out”*, and *“finding a voice”* as an indicator of progress along a healing path. All stakeholders

saw finding their *voice* as an indicator of increasing strength that improved individual and collective capacity to name and take action on issues.

Things are changing: more women are speaking up, more people are coming out and speaking about their experiences [with interpersonal violence]; trust is growing, but there is still lots of work to do (Leader #P2-A12).

Participants talked about collective level indicators such as *improved access and participation* in educational programs, drug and alcohol services, domestic violence and child apprehension support services as important program outcomes. For example:

Even in the junior high, graduation has increased. I believe health has increased... I think there are probably fewer FAS children because of the pregnancy outreach program... and the Healthier Lifestyles. And the knowledge, the education... I believe that there are fewer women caught in domestic violence than there were before, because they didn't feel like they had any alternative... again, it was education... I think there is less alcohol. I think another battle that we have to deal with is drugs. ... but if we didn't have the workers there I think it would be far worse than it is (Leader #P2-B19).

Patterns of *who* is receiving care is an important indicator of how safe programs improve access. Care accessed by the very vulnerable, exploited and marginalized is an indicator of the safety and responsiveness of the organization and providers. This leader goes on to say:

And there are sexually exploited youth/children... [and] we are getting the street workers coming in for their AIDS testing and various testing and some of them actually ended up going to other programs... a few actually started coming into Adult Basic Education (Leader #P2-B19).

As the relationship between the local people and the health care organization and providers grows, another important indicator at both individual and collective levels is *when* care is accessed. Many participants described a pattern of increasingly *early access* to care and education as a choice, rather than as a reaction to problems or crisis: For example:

I actually had a lady two weeks ago who came in to me and she has actually decided to plan a pregnancy... She's been in a new relationship for a while and they are actually talking about having a family together. She already has, actually, two older children, so she really wants to plan this one. This is pretty awesome. This is awesome stuff (Provider #P2-A2).

At an individual level, the most commonly expressed positive indicator described by participants was the set of changes they attributed to people developing self-esteem and pride as an Aboriginal person. For example, they would say, *"It's been really something, watching the breakthroughs. You can see the shoulders come up, and the head come up"*. Many providers described watching these changes in body language and eye contact as *"the best part about my work"*.

Providers identified individual level indicators of improved personal capacity and coping skills:

A young woman, 19 years old, first baby... and she came in to me consistently for prenatal care. Anything I said to her, she heard. And we watched some of the preparation videos and stuff... she took it all in... And she would come back to me and say... 'Well I bought this crib and it's standard. So I know immediately that she's heard everything that's said on that video, because she's following through with the necessity of providing good safe care to her baby (Provider #P2-A2)

Many providers described how safe places, as well as safe people, can result in gradual improvements in access and use of care as people move through different aspects of their healing journeys. For example, they described an unfolding process of increasing access to relevant services:

Eventually they started to come up to my office for counseling and then eventually they started to see other counselors... so it just became comfortable. It took I would say, probably just a couple of years... two or three years (Provider #P2-B5).

They talked about how increased knowledge led to a decrease in risk behaviors:

And I think this knowledge, the minute they find out that they're pregnant, they stop the alcohol, they stop the drugs... that's the time when they begin to come for

care then, because they're sober and they'll be open as long as they're sober (Provider #P2-B1).

Discussion

Results have expanded notions of patient safety and cultural safety currently used in health care. Patient safety broadens the concepts of medical or physical safety as criteria for quality in health care⁴⁰. Patient safety is defined most broadly as follows: a “major objective of any health care system should be the safe progress of consumers through all parts of the system. Harm from their care, by omission or commission, as well as from the environment in which it is carried out, must be avoided and risk minimized in care delivery processes”^{41(p.2)}. This definition includes the concept of harm due to negligent or intentional action or inaction⁴². However the risk of *emotional* harm in health care settings and interactions has yet to be discussed as a patient safety issue. Results suggest that emotional safety is an important dimension of patient safety for Aboriginal people in health care interactions and settings and warrants further attention.

Results identified the emotional dimension of safety as having a crucial influence on *access* to prenatal care. Emotional safety has been discussed in the context of mental health care, and as an issue in care and healing from interpersonal and collective violence, rather than as a patient safety issue *per se*. This study suggests that both internal and external dimensions of emotional safety may be issues for Aboriginal people in health care interactions. Internal safety is the extent to which you *feel* safe when the situation you are in is safe.

Internal safety is affected by past experiences with safety or lack of safety.

Participants commented about the importance of word of mouth and trust in the

organization as a safe and caring place. This may reflect the influence of past experiences with unsafe health care interactions or other social institutions⁴³.

External safety refers to actual facts about whether people or situations are safe. As described in the cultural safety literature, some health care settings and interactions *are* unsafe for Aboriginal people. Unexamined, demeaning and disrespectful attitudes, values and beliefs of health care providers and organizations of colonized societies have created behaviors that are hurtful for Aboriginal people⁴⁴. Transforming this systemic impact of collective violence on Aboriginal peoples' experiences of both internal and external safety in health care has been termed *culturally safe care* and is described as "actions which recognize, respect and nurture the unique cultural identity of [Aboriginal people], and safely meet their needs, expectations and rights"⁴⁵. Identifying safety as an important influence on early access and use of care during pregnancy and parenting is an important finding, and complements the emerging body of evidence on cultural safety.

Interestingly, emotional safety is a well recognized and supported concept in the education sector, and has been identified as an important influence on both learning experiences and outcomes. Educators and schools recognize that "emotionally unsafe situations *shut down* the learning process for children", and work to create "supportive learning environments that meet both the academic and emotional needs of children"⁴⁶ (p.1). This perspective resonates with the findings of this study, and suggests the need for further research to understand the influence of emotional safety on both access to and experience of health care interactions and settings.

Results suggest that Aboriginal people are working on understanding, healing and transforming their sense of safety and well being in interpersonal relationships, including

relationships in the context of health care. Participants described the approach taken by both providers and organizations to work *in partnership* with Aboriginal people to create relationships, places and interactions that feel safe. Further, health care organizations and providers must develop the skills and understanding to assess the extent to which they *are* providing safe care. The extent to which basic preparation of health professionals, such as undergraduate schools of nursing are equipping graduates with the skills to understand and develop safe care must be examined. Research and education could build on the work of nursing organizations and educational institutions in New Zealand to develop competencies, and organizational support for culturally safe practice⁴⁷.

Responsiveness. Findings highlight the importance of sensitivity and responsiveness to the diversity of individual and families' lived experiences, and the need to provide care that respects these differences. The underlying reasons for late access and lack of participation in prenatal care identified elsewhere⁴⁸ were explicated. Further, a strengths-based orientation to intervention and evaluation seems critical to improve real access to care and to facilitate women's choices related to family planning and timing of pregnancies. These results illustrate how safe, trusting relationships are prerequisite to understanding individual circumstances and needs for things such as housing, food, advocacy with mainstream health and social systems, and encouragement to start and sustain further education. Results exemplify *how* the approach to care can enhance Aboriginal peoples' feelings of safety and relevance, thereby increasing early access, participation and outcomes of care.

Expectations and indicators for evaluation. Health indicators have often been derived from populations and contexts external to Aboriginal communities and may not reflect

community knowledge and values. Furthermore, existing indicators often emphasize 'downstream' late stage, disease-oriented outcomes rather than measuring 'upstream' opportunities for early intervention. Results introduced a set of qualitatively derived indicators that reflect the values and priorities of Aboriginal participants (e.g., number of people who are on a healing path). It also identified ways to use more common indicators for maternal and child health programs (e.g., infant attachment, uptake and duration of breastfeeding) in ways appropriate to Aboriginal communities and contexts. The research also suggested indicators that providers can use to reflect on the safety of their care (e.g., *word of mouth that provider is safe*) and the evolution of a trusting relationship (e.g., *finding and using voice, speaking up*), as well as an outcome of clients' journeys along a healing path (e.g., changes in body language such as "*the head, the shoulders coming up*").

Table 2.3 summarizes indicators for use in evaluation of programs for pregnant and parenting Aboriginal people that could be applied at individual and population levels. Important actions of safe and responsive health care include: formally acknowledging and 'registering' the pain and trauma resulting from the intergenerational impact of residential schools; recognizing and celebrating strengths and progress; making space for many ways of knowing to be expressed and respected; facilitating voice and encouraging dialogue; and working toward creating new relationships between Aboriginal communities and health care organizations and providers. Evaluation methods must assess, acknowledge and facilitate growth of new 'partnership' relationships between communities, clients and health care organizations and providers. Indicators must be selected, used and interpreted to acknowledge the significant efforts of individuals and

Table 2.3: *Promising Indicators for Individual and Population Level Evaluation*

Indicators	Individual Level Use	Population Level Use
Healing - # of people on a healing path - # of leaders on a healing path	- Progress along healing path over time	- #/% on a healing path - #/% describing leaders as role model for taking healing path
Interpersonal Violence - degree to which abuse is talked about	- Individual and family report discussing awareness and behavior to improve interpersonal relationships	- #/% talking openly about abuse/interpersonal violence - frequency of individual and collective action related to abuse awareness
Access to & Participation in Services - Education - Drug and Alcohol - Interpersonal Violence - Child Protection	-	- Availability - Early Access - Use - Word of Mouth referral - Cross Service uptake
Tobacco, Drug & Alcohol Addiction - Dangers of tobacco, drugs and alcohol during pregnancy - Aware of dangers of tobacco, drugs and alcohol during pregnancy - Decrease tobacco, drugs and alcohol use during pregnancy	- Presence/severity - Improvement over time - Improvement over consecutive pregnancies - Improvement over consecutive generations	- Change in #/% with addictions - Change in rates over time - % with low, med, high awareness - % of expectant mothers & fathers decreasing use - % of expectant mothers & fathers abstaining
Care during Pregnancy & Parenting - Come early for care - preconception → first weeks; first trimester... - Come regularly for care - Develop trusting relationship with care giver - Express satisfaction with care	- Change over consecutive pregnancies; - Development of relationship over course of pregnancy & parenting - Describes relationship as safe	- #s/% coming at points along preconception to birth continuum - #/% expressing satisfaction with care - #/% describing caregiver relationship as safe
Relationships with Extended Family - Strength of connection with extended family - Heal family relationships	- Initiate connections with extended family (e.g. mother, grandmother, aunt) - Participate in family healing activities/services	- #/% families reconnecting and healing relationships - #/% participating in family healing services
Connection with Family and Local Cultural Teachings - Knowledge - Practice/Behavior - Identity	- Knowledge of family and local cultural teachings - Practice family and local cultural teachings - Express family and local cultural Identity	- #/% demonstrating interest in and knowledge of family and local cultural teachings - #/% participating in family and local cultural practices - #/% expressing positive family and cultural identity
Planned Pregnancies - planned pregnancies - teenage pregnancies	- Change over consecutive pregnancies	- change in #/% of teenage pregnancies over time - Change of #/% of total pregnancies that were planned
Breastfeeding - Knowledge, support, initiation and duration of breastfeeding	- knowledge & confidence - family support for breastfeeding - breastfeeding duration	- #/% initiating breastfeeding - #/% maintaining breastfeeding for _____ length of time

communities to turn things around, rather than used in colonizing ways which attribute positive changes solely to health service organizations and position Aboriginal communities and individuals as passive objects in care.

Results suggest that program impact can be measured at individual and collective levels. In particular, results underscored the importance of a longer-term, prospective and longitudinal evaluation across the experience of pregnancies rather than the more usual cross-sectional approach to measuring indicators. Measuring the extent to which care during pregnancy and parenting is making a difference will require a combination of quantitative and qualitative indicators, and triangulation with viewpoints of stakeholders. Furthermore, perspectives of community and client stakeholders must take priority in evaluating their experience of safety and responsiveness of care. Methods for obtaining internally located measures puts citizens or clients in the role of partners in evaluation, as recommended in current evaluation methodology^{49,50}.

This qualitative community-based study of the innovations developed by Aboriginal organizations in two unique geographical, jurisdictional and demographic contexts explored perspectives of providers, leaders and community members to describe their views of care during pregnancy and parenting. Though several strategies were used to capture the richness of their experience, and differentiate researcher and participant voice and interpretation, these results represent only a beginning understanding of community-based perspectives. Further research is needed across a greater number and diversity of settings to confirm or add to our understanding of salient aspects of approaches to and evaluation of care during pregnancy and parenting for Aboriginal people. Adequate time and resources are required to enable community-based participants with long standing

trusting relationships to take a more active role in research design and implementation, thus enabling more Aboriginal voices to be heard.

Conclusion

Pregnancy and parenting represent a culturally and developmentally significant opportunity for Aboriginal people to turn around the intergenerational impact of residential schools. Results highlight the critical importance of building successful programs on an understanding of the history of colonization, and its impacts on Aboriginal people's relationships and experiences in health care. Results describe how the approach to care positions providers and organizations to work in partnership with Aboriginal people toward their vision to transform both the impact of this history, and the nature of relationships. Situating care within a wider historical timeframe profoundly influences the goals, roles and relationships, resources and expected outcomes of care. This study also underscores the importance of planning and evaluating programs to recognize and respond to the unique experiences of individuals, families and communities. These results warrant further exploration of the notion of safety in health care, particularly how experiences of emotionally safe care may improve early access to, and relevance of care during pregnancy and parenting for Aboriginal people. We conclude that to be viewed as 'successful', health care providers and organizations must work in closer harmony with Aboriginal people toward their vision, rather than reinforcing the colonizing relations that are a legacy of our past and often an ongoing feature of daily practices.

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Paper #3:

**The Influence of Governance Systems on Aboriginal Organizations' Experiences
Improving Care during Pregnancy and Parenting**

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Colleen Varcoe & Barbara Davies

RUNNING HEAD: Paper #3: Influence of Governance on Organizations' Experiences Improving Care

ABSTRACT

Problem: There are widespread patterns of late access and low use of prenatal care among Aboriginal women in Canada. System and historical factors have impeded efforts to improve this care. The purpose of this study was to describe the influence of contextual factors on organizations' experiences improving care for pregnant and parenting Aboriginal people.

Methods: Participatory research principles were used in a comparative case study design with two Aboriginal health care organizations in British Columbia, Canada. Case A was a small, geographically isolated and culturally homogeneous community serviced by the health care organization of a transferred First Nations Tribal Council. Case B was an urban Aboriginal health center serving Aboriginal and non-Aboriginal people. The sample consisted of purposefully selected leaders, providers, and community members. Data were collected through exploratory interviews, small group discussions, document review and researcher field notes. Data analysis described the history of each case, and identified how contextual factors influenced the cases' experiences improving care.

Results: Although the two cases shared similar visions and views of their role, their experiences improving the responsiveness of care were quite different. Major influences on their experiences were policy changes at broader levels of government, societal attitudes towards Aboriginal people, and the governance model that organizations operated within. *Implications:* Changes to the health system, without attention to governance, negatively influence Aboriginal organizations' experience and efforts to improve responsiveness of programs for Aboriginal people. Participatory approaches to governance and health system change appear to have a positive influence on Aboriginal organizations' experiences improving care for pregnant and parenting Aboriginal people.

Introduction

Many of the health problems of Aboriginal^a Peoples have been attributed to the history of oppressive relations and current social conditions that resulted from colonialist policies (Aboriginal Healing Foundation, 2002; Battiste, 2000; O'Neil, 1995; Royal Commission on Aboriginal People [RCAP], 1996; Waldram, Herring, & Young, 1995). Resulting weaknesses of health services include inequities in access to care, an imposed biomedical rather than holistic approach to interventions, federal and provincial government jurisdiction rather than Aboriginal authority, and community control over health systems, resulting in lack of responsiveness to differences in cultures and community realities (Romanow, 2002; RCAP, 1996). These complex system issues impede efforts to improve responsiveness of health care programs, and move forward from the legacy of colonization ingrained in current systems.

A review of the international literature on maternal child health care interventions of relevance for Aboriginal people covering the period from 1990 to 2004 identified a total of 82 reports inclusive of 15 systematic or comprehensive reviews; eight narrative reviews; 13 quantitative studies; 6 program evaluations; 15 qualitative studies; and 15 reports from programs of research. Of these, 44 included Aboriginal populations and 13 were conducted in isolated settings. Evident in this review was a long-standing, widespread pattern of late or no access and poor use of prenatal care, and poor pregnancy outcomes in Aboriginal women (Bridge; 1999; DeCosta & Child, 1996; Goldman & Gleib,

^a The term Aboriginal "refers to organic political and cultural entities that stem historically from the original Peoples in North America, rather than collections of individuals united by so-called 'racial' characteristics" (Royal Commission on Aboriginal Peoples, 1996). These include the First Nations, Inuit, and Métis Peoples of Canada. Use of the term Aboriginal does not intend to negate the uniqueness the three groups, but to be inclusive and reflective of the diversity of the populations being served by the organizations involved in this study.

2003; Hoyert, Freedman, Strobino & Guyer, 2001; Humphrey & Holtheimer, 2000; Luo, Wilkins, Platt & Kramer, 2004; Luo, Kierans, Wilkins, Loston, Uh & Kramer, 2004; Public Health Agency of Canada, 2005). The need for more culturally-appropriate care that is relevant to the needs and strengths of Aboriginal women and families was also clearly identified (Browne & Smye, 2002; Long & Curry, 1998; Powell & Dugdale, 1999; Sokolowski, 1995; Westenberg, van der Klis, Chan, Dekker & Keane, 2002). No studies examining the influence of governance and jurisdictional factors on the relevance of prenatal care interventions for Aboriginal were found. However, governance is a prominent issue in the literature on general health care serving Aboriginal people (O'Neil, 1995; RCAP, 1996; Romanow, 2002; Smylie, 2000; Waldram, Herring and Young, 1995).

Aboriginal health service delivery organizations play a key role in improving health care programs, given their position between macro levels of health policy design, and the more micro-level realities of its implementation and evaluation. *How* Aboriginal organizations have improved timely access and responsiveness of care during pregnancy and parenting has not yet been systematically studied. An examination of contextual influences on Aboriginal organizations' experiences transforming programs would add to an understanding of factors influencing organizational capacity to improve access to and responsiveness of health care for Aboriginal people.

These issues were examined in a qualitative study describing innovations to improve care during pregnancy and parenting that were developed by two Aboriginal health care delivery organizations. The organizations were operating under different systems of governance and administration within one region of British Columbia, Canada.

Previously reported results of the study found that Aboriginal organizations based their approach to care on stakeholders' views that the instruments and relations of colonization were roots causes of the inequities in health and social conditions of Aboriginal people (Smith, Varcoe & Edwards, in press). A second report described how community-based stakeholders put safety and responsiveness in the forefront of their approaches to care for pregnant and parenting Aboriginal people (Smith, Edwards, Varcoe, Martens & Davies, under revision). This paper describes the cases on the basis of governance models that construct their role and relationship with broader levels of decision-making, and suggests that greater attention to governance models is needed to improve the responsiveness of health programs serving Aboriginal people.

Background

There are well-documented health inequities between Aboriginal people and the general Canadian population (Canadian Institute of Health Information, 2004; Federal/Territorial/Provincial Advisory Committee on Population Health, 1999; First Nations and Inuit Regional Health Survey National Steering Committee, 1999). Anecdotal and research evidence suggest that poorly designed and weakly integrated health care interventions have contributed to the inequities in health and social well being of Aboriginal women, children, families and communities (Adelson, 2004; British Columbia Vital Statistics Agency, 2002; Dion Stout & Kipling, 1999a; Dion-Stout & Kipling, 1999b). Furthermore, centralized control by the federal government has removed health planning from the unique cultures, contexts and experiences of communities widely dispersed across urban, rural and remote locations. These historical and structural

remnants of colonization continue to influence the extent to which care for pregnant and parenting Aboriginal people are relevant to community needs and priorities.

Administration and Governance of Health Care for Aboriginal People

The policy legacy and lingering presence of colonization is further complicated by complex governance and administration of health services for Aboriginal people. In essence there are two separate health systems delivering care for Aboriginal people. Aboriginal people access primary and preventive health care services based on their place of residence in either federal or provincial jurisdiction. They use both federal and provincial systems for their specialized medical and tertiary health care needs. Aboriginal health service delivery organizations are embedded in either the federal or provincial system.

Federal jurisdiction. About 410,645^b (41.1 per cent) of the nearly one million people identifying as Aboriginal live in First Nations or Métis communities located in areas under federal jurisdiction for provision of health services (Indian and Northern Affairs Canada, 2004). Health care services have been delivered through the First Nations and Inuit Health Branch [FNIHB] of Health Canada, formerly known as the Medical Services Branch. Primary health care services in First Nations communities were governed, designed and implemented by the FNIHB mostly by registered nurses who work in collaboration with community health representatives.

However, since the mid 1980's, a growing majority of First Nation's communities have transferred, or are in a multi-year process of transferring the administration and delivery of health care services from the federal government to First Nations' control

^b Differences in population estimates may be explained by inaccurate enumeration due to Aboriginal communities choosing not to participate in the census, and population growth between 2001 and 2003.

(FNIHB, 2004). In many areas, First Nations bands with common social, cultural, geographical and/or economic interests voluntarily joined together under legally incorporated non-profit organizations called Tribal Councils. Tribal Councils are mandated by their member band councils to “provide advisory and/or program services to member bands”, and to represent the interests of member Nations with other levels of government (e.g. provincial and federal). “Advisory services are defined as the provision to member bands of specific knowledge, expertise and/or assistance” in areas such as band government, financial management, community planning, health care, technical services and economic development” (Indian and Northern Affairs Canada, 2005, p. 1).

Many First Nations communities and Tribal Councils have now had over 20 years of experience renewing governance systems and innovating programs formerly controlled by FNIHB. This transfer of control has enabled health service delivery organizations of First Nations bands or Tribal Councils to innovate programs and services in an effort to better fit the values, priorities and concerns of their constituent populations. In some communities greater congruence between health care services and local values and beliefs, increased emphasis on the role of family, culture and prevention, and more effective integration between traditional and western approaches have been observed (RCAP, 1996; Smylie, 2000). However, significant obstacles and concerns about delivery of services in federal jurisdiction remain, including health information system weaknesses, community capacity for effective management and governance of services (Auditor General, 2000), adverse socioeconomic conditions (Boyer, 2003; Waldram, Herring & Young, 1995), and failure of transfer agreements to consider emerging needs (O’Neil, 1995).

Provincial jurisdiction. The majority (67 per cent) of Aboriginal people in Canada live in areas where health care provision is a provincial responsibility (Statistics Canada, 2003). In the province of British Columbia, health care was regionalized in 1993 based on recommendations from the British Columbia Royal Commission on Health Care and Costs (1991). Specialized services such as support for women at risk during pregnancy remained the responsibility of the British Columbia Ministry of Health Services, who worked with regional health authorities to plan and co-ordinate services. In addition, some services, such as public health programs were transferred to the Ministry of Children and Families at the same time.

The majority of health services in British Columbia are managed by regional health authorities. Fifty two health authorities of various size and mandates (11 regional health authorities, 34 community health councils, and seven community health service societies) were formed in 1993 and revised over the next six years to bring governance of health care "closer to home". Implementation included legislation to transfer governance to the newly formed regional health authorities, a health labour adjustment strategy, education and orientation of health authority boards and councils, and development of health management plans. Health service plans were the key accountability mechanism between the Regional Health Authorities, and the provincial Ministry of Health (Canadian Centre for Analysis of Regionalization and Health Care [CCAHR], 2005). Though many of these potential advantages were recognized, providers and policy advisors expressed concerns that regionalization would weaken the provision of important preventive health programs or threaten their accessibility for marginalized women (Benoit, Carroll & Kaufert, 2000).

Then in 2001, with the intention of “stream lining the system, improving its efficiency, strengthening its accountability and allowing better planning and co-ordination of services” (CCAHR, 2005, p.3), the newly elected provincial government again changed the regional structure. The 52 health governance structures were changed into five regional health authorities, each governed by a board of six to nine members who were appointed by the Minister of Health Planning.

Thus in the province of British Columbia, health care for Aboriginal people during pregnancy and parenting is governed either: a) through a RHA accountable to the province; b) by the British Columbia Ministry of Health Services; c) through a transferred health authority such as a Tribal Council accountable to the federal government through the regional office of FNIHB; or d) directly by the regional office of FNIHB. In addition, women in rural and remote areas are evacuated for birth, which further complicates integration of care both within and between jurisdictions (Benoit, Carroll, & Millar, 2002; Gryzbowski & Kornelson, 2004; Smith, 2002). All of these issues create considerable challenges to the development of a flexible and responsive system of care for pregnant and parenting Aboriginal people. Yet, this diversity of governance, administration and service delivery arrangements also provides an opportunity to explore contextual influences on the experiences of Aboriginal organizations to improve responsiveness of care during pregnancy and parenting for Aboriginal people.

Methods

The purpose of this study was to describe community-based stakeholders' perspectives on their experiences designing, implementing, and evaluating care for

pregnant and parenting Aboriginal women and families. This paper describes Aboriginal organizations' experiences improving care during pregnancy; and the contextual influences on Aboriginal organizations' innovation experiences.

The focus and the process of the study were shaped by a critical postcolonial stance (Battiste, 2000; Reimer-Kirkham & Anderson, 2002) and participatory research principles (Cargo, Levesque, Macaulay & McComber, 2003; Fletcher, 2002; Macaulay, Delormier, McComber, Cross, Potvin, Paradis, Kirby, Saad-Haddad & Desrosiers, 1998). Details of the study methodology, design and methods have been discussed in our earlier reports (Smith, Varcoe & Edwards, in press; Smith, Edwards, Varcoe, Martens & Davies, under revision). The study was conducted in two phases. In phase one, following ethical approval from the University of Ottawa Health and Social Sciences ethics review board, sixteen purposively selected key informants shared their perspectives on issues and influences on Aboriginal women and families' pregnancy experiences, and identified possible cases for phase two. Cases were defined by *place* (geographical, governance and administrative boundaries of the participating service delivery organization), *persons* (leaders, providers and community members involved in the program change), and *time* (from program initiation to end of data collection in 2004).

In phase two, several cases or organizations identified by key informants as having high rates of early access and participation in prenatal care by Aboriginal women were invited to participate. One urban and one rural Aboriginal health care delivery organization, both geographically located in the same health region, agreed to participate. Approval for phase two of the study was obtained from the University of Ottawa Health and Social Sciences ethics review board, the ethical review committee of the participating

Tribal Council, and chief and council of the participating community. Phase two field work was conducted from June to September of 2004 in the two settings. Participants in each setting were purposively selected using network sampling techniques (Burns & Grove, 2005) to explore diverse perspectives among stakeholder groups (e.g. leaders, providers, community members) (Yin, 2003), and to describe the innovation process over time (Langley et al., 2003).

Interviews were used as the principal data source. Documents provided by participating individuals and organizations were reviewed, including policies, program descriptions, utilization statistics, audits, and utilization records. Documents were scanned, and proxy documents created and added to the database. The background information obtained from documents was then used to develop critical questioning (Yin, 2003). One-to-one exploratory interviews and small group discussions were conducted by the first author according to the preference of the participant. Field notes kept by the researcher were also included in the data set.

Primary analysis occurred during the interviews to allow participants to validate and clarify how their perspectives were being understood and recorded (Kirby & McKenna, 1989). Interpretation of participants' perspectives was made transparent during interviews by probing for how participants located their stories and experiences in a particular social, historical, political, cultural or geographical context (Reimer-Kirkham & Anderson, 2002); and sharing with the participants the similarities and differences between perspectives gathered in the inquiry. Transcripts of interviews were entered into NVIVO software and analyzed by the first author using constant comparison (Guba & Lincoln, 1985) and an interpretive descriptive approach (Thorne, Reimer-Kirkham &

Flynn-Magee, 2004), during a prolonged period of immersion in the data. Descriptive analysis separately pieced together a history of each community's experience improving care, and identified factors that seemed prominent from the perspective of participants. The interpretive analysis identified how contextual factors contributed to similarities and differences between the cases' innovation experiences. Data from both phases of the study were used to enrich descriptions of contextual influences, and to juxtapose perspectives from stakeholders in different parts of the health planning and delivery system. Participants joined in a critically reflective discussion of results in workshops held in the study communities in April of 2005.

Results

Sixteen people participated in phase one and 57 people participated in phase two. Over 60 percent of the total study sample self-identified as Aboriginal and 90.4 percent were women. The types and availability of documents collected and reviewed in the study is summarized in Table 2.4. Types of documents rather than actual document titles are used to protect anonymity of the study participants. Documents describing the two events (program innovation and health system change) identified as central in these findings were not evenly available across the two cases because of their different administrative and jurisdictional locations and the timing of these two central events in their history. For example, transfer to First Nations control in Case A occurred in the mid 1980's so fewer documents were available at the time of the study. In Case B's history, documents describing the health system changes were more readily available, whereas documentation of the program innovation in the 1980's was fairly scarce.

Table 2.4: *Summary of Reviewed Documents**

Type#	Documents Describing...	Case A	Case B
	Health System Change		
I	Health system change process (e.g. minutes of meetings, government reports, research reports, proceedings from community meetings, health transfer process; health transfer agreements, written input into government policy documents)	+	+++
II	Health authority strategic policy directions (e.g. memorandum of understanding, logic models, strategic policy documents)	+	++
III	Organization mission and mandate (e.g. published materials, websites)	++	++
IV	Terms of reference for stakeholder relationships (e.g. for tribal council, board and advisory committees; memorandum of understanding; legislation)	++	++
V	Community perception of organization/program (published reports; newspaper articles; letters; annual report; community meetings)	++	++
VI	Community health and social factors (e.g. newspaper articles; reports of community health, economic development and social development; local statistics)	+	++
	Program Design and/or Innovation Process		
VII	Program development process (e.g. consultant reports, pilot project reports)	+++	+
VIII	Program description (e.g. website and published materials)	+++	+++
IX	Utilization statistics and records (e.g. from administrative records on programs and related programs such as education, child protection, counselling/mental health/abuse prevention)	+	+++
X	Staff job descriptions (e.g. from human resource departments)	+++	+++
XI	Accountability measures and expectations (e.g. from published program manuals, forms, reports of audits and external evaluations)	+	+++

*The documents for each type listed in the table were '+' (limited availability) to '+++ (readily available).

Description of Cases and Their Experience Improving Care

The two cases varied in terms of date of program initiation, population size, geographical remoteness, jurisdiction, and model of governance and administration (See Table 2.5). Each case had a distinctive theme that captured both the influence of the broader societal context and the influence of the respective governance systems and

relationships. The experiences of the cases are described below. Participants' views are illustrated with quotes from both cases. Examples of how the types of documents described in Table 2.4 were used to develop and support this analysis are indicated in brackets (*e.g. Supported by Document [SBD] Type__*).

Table 2.5: *Highlights of Case Descriptions*

	Case A	Case B
Start of the Program	-began in mid 90's	-began in mid 80s
Community Size	Small (population < 1000)	Larger (population > 80,000)
Aboriginal Population Demographics	Stable, culturally homogenous community within small geographical area (within 0.5 km from health center)	Transient, culturally diverse population, geographically dispersed over large area (up to 25 km from health center)
Geographical Location	Remote-2 hours by private gravel road from hospital	Urban –located in downtown core of a mid-size city
Jurisdiction	Transferred First Nations Tribal Council under federal jurisdiction	RHA under provincial jurisdiction
Relationship between Innovation of Program Approach & changes in Governance/ Administration	Prior to mid 1980s-FNIHB controlled program -mid 1980's –mid 1990's- Transferred to First Nations control, maintained FNIHB program approach -mid 1990's-began developing partnership and new approach -2004-new approach and well established partnership between community, health service delivery organization, & Tribal Council	-mid 1980's –organization developed program for high risk pregnant women in collaboration with community stakeholders and the RHA. -late 1980's –program approach adopted and (partially) funded by British Columbia Ministry of Health as the Pregnancy Outreach Program . Reports directly to Ministry; works in collaboration with other community-based agencies. -2001: administration of all Pregnancy Outreach Programs moved to Regional Health Authorities -2004: RHA-multi-sectoral Memorandum of Understanding on early childhood development

Case A. Case A was a health service delivery organization governed by a transferred First Nations Tribal Council. Participants in Case A were from one of the small, geographically isolated, culturally homogeneous communities comprising the Tribal Council membership, as well as leaders and providers working for the Tribal Council. Case A was recruited because of its reputation for having developed an innovative approach to care during pregnancy and parenting that was based on local communities' values and practices, and was positively received by the community. Pregnant and parenting families received their preventive health and social services from Tribal Council administered and governed service organizations, but also accessed high risk prenatal care services, tertiary care (e.g. hospital care during birth) and midwifery and medical care services (e.g. hospitals, physicians, obstetricians) from organizations operating under the RHA of the provincial health system. In addition, given the mobility of community members on- and off-reserves, high risk prenatal care services offered by the provincial health care system, and governed through the RHA were also used. Therefore, Case A leaders and providers were influenced indirectly by the activities, policies and changes within the health region in which they were geographically located.

As shown in Table 2.4, the innovation to improve care for pregnant and parenting First Nation's community members began in the mid-1990's as a result of the change in governance structure following transfer of health care to the First Nations Tribal Council in the mid 1980's (*Supported By Document [SBD] Type I*). The terms of reference of the Tribal Council (*SBD Type IV*) mandated a partnership approach that was markedly

different from the FNIHB health service provision model that came before (*SBD Type VIII*).

In Case A, community-based organizational stakeholders (e.g. leaders, providers, community members) were included in the change from the previous FNIHB governance and program models, to a partnership model of governance and program delivery between the Tribal Council, the community governments (e.g. Chief and Council), and the health service organization and providers. Participants' stories communicated a sense of ownership, commitment, and optimism about the change and the opportunities it represented. The new governance and program delivery model (*SBD Types I & VIII*) was built on a common understanding of the problem and vision for change. Leaders, providers and community members had the autonomy and support from the Tribal Council to build capacity needed to work through multiple challenges over a 10 year period to improve program responsiveness (*SBD Type VII*).

The predominant experience of Case A can be described as *Growth/Innovation through Partnership*. Case A used a partnership model that focused on the positive, developed their innovation by tapping into community strengths, hopes and dreams, and working as partners.

Everything is evolving, and growing. I think that is true with some of these programs. The nursing program, the USMA program (USMA means precious little ones), and the education program. They have all had their ups and downs. But I think that is recognized, and that is to be respected as well. It's reality. I think if you can build on success, it is good to build on the positive. You have to recognize the negative, be honest and face it, but I think your chances of building for the future are greater if you can build on strengths (Case A provider).

Growing in partnerships was an upwardly spiralling growth experience for all partners: providers, organization, and community and clients (*SBD Types VI & IX*).

Ten years ago I never felt that I would be able to do anything. So, not only have I seen them grow, I've seen myself[grow], as a professional, both professional and personal growth... Because I wouldn't have stood up for a lot of things, either, ten years ago, and now I do. So, I think it's [our experience has been] about working and growing together (Case A provider).

Case B. Case B was recruited into the study because of its reputation for having developed a program approach that improved early access and participation in care for pregnant and parenting Aboriginal people in an urban setting (*SBD Types V & VII*). Case B is a Native Friendship Center^c in operation since the late 1960s. It operates an urban Aboriginal health center under provincial jurisdiction for health care. Case B serves both Aboriginal people living both on- and off-reserve, and non-Aboriginal people. The catchment area extends up to 25 km from the Friendship and Health Center and includes rural communities as well the urban population (*SBD Type III*). Case B was integrally involved in developing the program that would later be adopted as the model for the provincial Pregnancy Outreach Program (*SBD Type VII*). There are now over 46 Pregnancy Outreach Programs in British Columbia (*SBD Type III*). In Case B, the Friendship Center started out in a leadership position within collaborative relationships with other community and regional agencies involved in the program. The program approach was developed based on the Friendship Center's understanding of the issues and needs of pregnant and parenting Aboriginal people (as well as other high risk populations being served^d), and their vision for change. A community development approach was used to design the program. Once the program was adopted and in part financially supported by the Ministry of Health in the late 1980's, Case B reported

^c Native Friendship centers provide health, social, cultural and recreational services to urban, Aboriginal populations (National Association of Friendship Centers, 2005).

^d The pregnancy outreach program serves all pregnant women in need for additional support to manage unmet nutritional, alcohol, drug and tobacco, and social support needs during pregnancy.

directly to a provincial program co-ordinator (*SBD Types I & III*). The program continued to grow over the next decade within this collaborative model of governance with the British Columbia Ministry of Health and other community-based agencies. The pregnancy outreach program was one of a growing number of Case B's programs (e.g. educational laddering programs, supportive housing, family support and sexual abuse intervention programs) (*SBD Type VIII*).

In 2001, governance and administration of the Pregnancy Outreach Program was moved to the regional health authorities, and a hierarchical relationship between Case B and the RHA was legislated by the newly elected provincial government (*SBD Type I*). Other changes to governance and administration of services were imposed by the provincial government in 2001 including dissolution of Aboriginal governance structures in the Ministry of Health; and greater centralization of regional planning processes (*SBD Type I*). As a result, 2001 to 2004 was a period of alienation and instability for Case B and a period of adjustment and change for the RHA. In 2004 the RHA reached a multi-sectoral memorandum of understanding for a strategic plan for services for children aged birth to six years in the region (*SBD Type IV*).

Case B's experience can be described as *Growth/Innovation through Persisting and Resisting*. Case B persisted toward their vision through waxing and waning periods of support and hostility in the environment, and through alternating periods of collaboration and resistance from local, regional, and provincial stakeholders.

I think it's important to be able to put across the difficulties that we experience in continuing to provide the services that we do. Sometimes it's just like, you go, go, go and troubleshoot, troubleshoot... and all your energy goes into troubleshooting. It would be nice if we didn't have to use up all that energy overcoming that resistance and we could use it for moving on (Case B leader).

Case B's continuing growth and innovation was enabled by ingenuity, resourcefulness and tenacity. Growth was sustained by genuine relationships among stakeholders, strong beliefs and being grounded in their culture, family and community.

What keeps me going is seeing some of the changes that happen and knowing that there are many people... their lives wouldn't be the way they are if it wasn't for some of the programs that were built here. The spirit is in my own family and what they are doing. And their value is not just for themselves, although that is very important. But their value is also for the community (Case B leader).

Comparing Cases: Contextual Influences on Organizations' Experiences

Two levels of influence were apparent in the cases' experiences of improving care for pregnant and parenting Aboriginal people. Provincial and federal level health system changes had a significant influence on both cases' experiences improving care. At the societal level, the past and ongoing influence of racist attitudes was a negative influence on organizations' efforts to improve care, and also profoundly influenced how changes at other levels were experienced. The most predominant contextual influences on organizations' efforts to improve care were stakeholders' more immediate, day-to-day experiences of the dimensions of governance. In this section each of the broader level influences are briefly summarized. This is followed by a more detailed description of community-based stakeholders' perspectives on the influence of governance on their experience improving care.

Processes of Health System Change

Provincial and federal level health system changes had a significant influence on both cases' experiences of improving care. These changes included federal-provincial joint planning tables, and centralization or decentralization of health care governance and administration (*SBD Types I, II & IV*).

Federal-provincial joint planning. Federal-provincial joint planning in British Columbia was described as particularly strong by many participants in both cases. The joint planning committee began when Health Canada funded the Canadian Prenatal Nutrition Program programs about 10 years ago. Joint planning tables linked federal and provincial jurisdictions, and brought together different ministries and departments from both levels of government (*SBD Types II & IV*). Many participants in both phases emphasized that many of the First Nations people in British Columbia spend part of their time on-reserve and part of their time off-reserve.

People [moving] back and forth is common, it's normal. So to have the different pots of money [restricted by where people live] sometimes can be quite frustrating. There's supposed to be a joint planning committee in every single province since Health Canada is giving money for services which are really the province's jurisdiction. So in order for them to play in our playground, as I often tell the federal government, we needed to do joint planning, evaluation and management (Phase One #5).

Enhanced federal-provincial co-ordination resulted in greater freedom for organizations and providers at the community level to access funds, collaborate and facilitate access to health care services for Aboriginal people regardless of where they lived.

The Tsawwassen Accord [a provincial-federal agreement] symbolizes a shift away from the jurisdictional [planning] barrier. All the Aboriginal leaders came together and signed a Memorandum of Understanding with our provincial government to work together for the safety, health and well-being of Aboriginal children, and the goal of moving towards Aboriginal governance at the regional level. So that caused quite a big shift. Because that was the first time that Aboriginal groups came together with a common goal. The Early Childhood Development Agreement in the Province of British Columbia is across seven child-serving ministries. We have the Aboriginal Early Childhood Development Round Table. We also have a multi cross-ministry plan around [Fetal Alcohol Syndrome]. So I think that there's a lot more joint provincial-federal tables that are sitting down and collectively talking about how do we serve the community better (Phase One #6).

Case B's experience demonstrated how federal-provincial joint planning enabled on- and off-reserve health service organizations to work together. For example, the on- and off-reserve organizations scheduled their programs and food supplements to be complementary, and provided transportation so that pregnant and parenting women had more opportunities to attend prenatal classes, gatherings and other services (*SBD Types VIII & X*).

There's lots of examples around the province where they were able to share resources-money from on- and off-reserve sources ... a counselor, and do joint things together as well. They work the system to their advantage. Bravo to them (Phase One #5).

Because the study site for Case A was in a remote geographical area under federal jurisdiction, the impact of joint planning of services between federal and provincial jurisdictions was less direct. However community members, leaders and providers in Case A described how services were more readily available for clients when they moved back and forth between the closest urban center, and their home community.

Greater centralization of health care services. The regional health authorities experienced increased autonomy and flexibility in health planning as a result of greater centralization of health care services. As a RHA leader explained:

There was a lot of complexity in the system around pregnancy because of primary care with physicians, and hospital system, and community systems. There are so many different systems that Aboriginal women could be part of because the system's so complex. So a piece of work that is ongoing for us is integration of the service with the other health, the other parts of the system. So it's been good with regionalization as we have made changes in our practice to support a real system of care. There is more local decision-making. We can actually make a decision and move. I would hate to go back to being part of a government-run health system because it was so hard to make a difference, to make any changes. Whereas now we have autonomy. So that if there is a sound plan, you can move resources around to make it happen (Case B leader).

The RHA has used this increased autonomy to tackle the jurisdictional and administrative barriers to care during pregnancy. They brought together regional level health, education, and social service sectors under a single early childhood development framework agreement (*SBD Types IV & V*).

We developed a framework on early childhood development. It's called "Building Together". We actually signed a memorandum of understanding, it's a tripartite agreement in terms of pregnancy and childbirth and a whole continuum of family health that identifies what we believe are the core components of the service. It's a framework with an agreed on vision and mission and goals and a mechanism, which is the early childhood development services committee that is the monitoring piece for us to all move forward. It really puts us on the same page and provides a really strong foundation for moving forward together and being efficient with our resources, trying to avoid that one of our system get to set up to compete rather than work on a common goal (Case B leader).

Closure of the Aboriginal Health Councils. Since 1992 the British Columbia Ministry of Health's Aboriginal health division provided funding through six regional Aboriginal Health Councils for addictions, mental-health and family violence prevention programs (*SBD Type VIII*). Its closure by the newly elected provincial government in 2001 (*SBD Type I*) was experienced as a significant barrier to improving health care for Aboriginal people. The Aboriginal Health Council had six Council members, three representing on-reserve, three off-reserve organizations. The closure of the Aboriginal health council, in tandem with greater centralization of health planning to five regions from the 52 health service societies, community health councils and regional health authorities (*SBD Type IV*), signalled to participants an intention to remove control from Aboriginal people.

The government shut down all the Aboriginal health councils, which funded a lot of programs and then there seemed to be that move to take the pregnancy outreach programs from Aboriginal organizations. The Bands have federal dollars they access so they seem to be okay and they model their programs after ours, too. So their

funding seems to be more secure, but in the urban [off-reserve] areas it just seems to be going backwards [with Aboriginal people having less control over their programs], and that's a concern (Case B leader).

The Pervasive and Draining Influence of Systemic Racism

Past and ongoing experiences of racism against Aboriginal people pervaded participants' day-to-day efforts to improve care for pregnant and parenting Aboriginal people. Many participants in both Cases A and B viewed the health system changes, as well as interactions at the local level, as indicators of an enduring and pervasive racism that were a constant drain on their efforts to improve care for pregnant and parenting Aboriginal people. For example, Case B participants described how individual attitudes about Aboriginal people that came with the health system changes were a drain on their energy:

To me it is a systemic racism that is really ingrained. I don't think people really realize when they are being that way, because it's just a part of what's been ingrained and learned and they feel that they are doing a good deed and there's no way that Aboriginal people can run a program, or have any skills or knowledge or whatever... and that they [RHA employees] can do it better. And that's really apparent. I felt the only reason they wanted to move in was because if they were there, they would keep finding fault with anything we did [because] they are still looking at trying to take those funds out. So those are the kinds of things we are constantly [dealing with] (Case B leader).

However Case B participants described how the word 'racism' was an emotional and attitudinal barrier, and suggested using the term "prejudice" as more conducive to influencing change:

How about letting go of the word "race" and use different words such as prejudice. 'Racism' is another label and we should let go of labels. The word "race" sets off a lot of [defensive reactions], and it's hard to get beyond that (Case B provider).

Systemic racism was also experienced by Case A participants, though with less direct implications. The following quote echoes comments made by participants in both cases:

There's still times when I feel that because it's my choice to work for a First Nations organization, nurses at the mainstream public health unit thought it was because I wasn't able to get a job elsewhere or I wouldn't be able to. That's sometimes the impression I get, but then I think, "well, why am I even worried about it, it's not an issue to me... so why would I even let that worry me, right?" (Case A provider).

Influence of Governance on Experiences Improving Care

The governance models influenced both organizations' experiences improving programs for pregnant and parenting Aboriginal people. Dimensions of governance described by participants in both cases included: view of root causes of health and social conditions; approach to care; vision for the future; voice; autonomy, view of accountability, approach to decision-making; view of fairness; and stakeholder relationships. Table 2.6 compares the influences of these dimensions for the two cases.

Historically-situated view and vision. A historically-situated understanding of root causes for health and social conditions, approach to care, and vision for the future was central to the work of both Aboriginal organizations (*SBD Type VIII*). Organizations and providers in both cases shared and constantly renewed their understanding of communities' and clients' vision for a better future, based on an understanding of the past and the impact of collective violence on Aboriginal people. In particular, understanding and acknowledging the intergenerational impact of residential schools as a root cause for health and social conditions and capacity for healthy parenting, was described as crucial (Smith, Varcoe & Edwards, in press). Participants in both cases described their goal as providing safe and responsive programs that build Aboriginal people's capacity to

manage their own lives in a healthy, productive and meaningful way for themselves and their children (Smith et al, under revision).

Table 2.6: *Influence of Governance Systems on Improving Care in Case A and B*

	Case A	Case B
Historically-situated view of health & social conditions ^c	Tribal Council and Case A held similar views	RHA and Case B held different views; impact of colonization on Aboriginal people not acknowledged by RHA; racialized explanations for health and social conditions implicit among mainstream providers.
Vision	Tribal Council, community/band council and Case A organization developed vision together	RHA and Case B approaches developed separately, and focused on different but not incompatible visions. Complementary and/ or competing aspects of visions were observed, rather than explicitly described by participants from Case B and RHA
Voice	Making space and building capacity for stakeholders to exercise voice in decision-making at multiple levels was a priority to both Case A and the Tribal Council	Making space and building capacity for stakeholders to exercise voice in decision-making at multiple levels was a priority for Case B, but not understood or formally supported by the enlarged regional health board. Formal structures for Aboriginal voice in health planning lost with centralization of health planning in 2001.
Autonomy	Tribal Council and Case A use a partnership model, and have invested in developing trusting relationships. This increased the autonomy of the organization and providers, and has enabled greater responsiveness to clients.	Case B experienced autonomy to develop programs and care in response to community/client needs and priorities until 2001, when autonomy was constrained by management of program by RHA.
View of Accountability	Case A and Tribal Council similarly felt that first accountability is to the community, and that funding and program delivery be tailored to be congruent with community needs and priorities	Case B and RHA held different views of accountabilities, with Case B feeling the programs must be responsive to community/client needs and priorities, but had to 'make up for' shortfalls between program accountabilities and community needs.
Approach to Decision-making	Tribal Council, community and Case A organization agreed on and used a consensus model of decision-making	Collaborative decision-making was used initially. Decision-making processes were suddenly changed in 2001.
View of Fairness	Similar views of root causes, vision for change and approach to care creates similar view of fairness	Different views of root causes precipitates perceptions of unfairness, especially when historical impacts are not recognized
Stakeholder Relationships	Tribal Council and Case A stakeholders invested in trusting relationships as primary medium for achieving vision	Both positive and negative relationships among RHA decision-makers and Case B shaped the experience of Case B, and impact of changes imposed by the provincial government in 2001.

^c See Smith, Varcoe & Edwards (in press) which describes participant's views of root cause of inequities in health and social conditions of Aboriginal people as rooted in the instruments and relations of colonization.

Case A stakeholders described how the historically situated vision and understanding of leaders was essential to starting and sustaining initiatives to improve care:

Well I think (name withheld)'s type of leadership – It's just kind of a quiet leadership. She's always very creative. [She understands] the historical context, the current political context of the tribal councils, the culture and the differences in the culture. She understands all of that. It's (the) understanding and appreciation and respect.' So that's sort of grounding in First Nations and then she's very grounded in professional nursing and committed to improving the health of the people (Case A provider).

Case B stakeholders described a similar visionary leadership grounded in an understanding of history, political contexts, and diversities among cultures of Aboriginal people.

The way forward, the innovation comes from having a vision. The vision is just knowing the history of Aboriginal people and knowing what there was then and the strength that was there and a way of life. I'm not saying it was perfect, but it was certainly productive and self-governed for Aboriginal people. Then working from that is looking at holistic health and making sure that there is education... that we get through the impacts of residential school. I guess you know about the seventh generation. They say whatever you do in this lifetime effects seven generations after you. And it's having people look at what they need to do to create a healthier community, individually and community-wise. The [pregnancy support] program is a big part of that holistic health creating healthier babies, addressing alcohol and drug issues, and gradually rebuilding the strength in the community; not only a few individuals here, but whole communities (Case B leader).

Case A and B differed in that Case B stakeholders and the RHA did not share a similar vision and understanding, whereas Case A and Tribal Council stakeholders did (*SBD Types II, III & V*).

Voice. The issue of voice was prevalent across categories of participants in both organizations. It involved developing processes and infrastructure for people to have a voice in decision-making, as well as building capacity and space for people to exercise

voice in decision-making at all levels. Providers, leaders and community members described a process of creating spaces and opportunities for citizens and the community to have a voice in how programs were designed and delivered (*SBD Types I, IV, V, VI*). Voices and representation of Aboriginal organizations in broader policy decision-making were described as critical to both cases' experiences improving programs.

In Case A, the terms of reference of the Tribal Council recognized the importance of stakeholder voice in decision-making at multiple levels, and formal structures such as health advisory committees, were put in place to accommodate that priority (*SBD Types IV & V*). One provider described the emphasis placed on creating space and opportunity for community voice in decision-making during development of the new approach to care:

I think what is important to me about that whole process is that, or the model itself, is the process that went together to build it. And it maybe wasn't maybe perfect, but it was, I think, a very strong and very honest attempt to build that model with the community base, as well as having professional input (Case A provider).

Because they are under provincial jurisdiction, the changes in provincial government policy had a direct effect on Case B's experience of having a voice in planning. Case B described loss of processes and infrastructure for voice in governance of health services for Aboriginal people when the provincial government dissolved the Aboriginal Health Planning Councils (*SBD Types I & VI*).

There's a little unit left in the provincial government. We thought we would be proactive and we pulled everyone in and worked on input to the [Aboriginal Health Plan]. They had an original plan that was done by, I think, one or two nurses and I think they had a couple of native people that they had talked to, but it didn't include some of the really important issues and things that needed to be included. So we had [well respected Aboriginal leaders representing different Nations and areas of the region] and people that had been really involved in health and social services for years do a lot of work redoing that document. We turned it in and they didn't use any

of our information. They never talked to us. We finally called them in for a meeting. They went with this skeleton thing that they did, which I felt wasn't even reflective of the needs of the community (Case B leader).

Autonomy. Organizational, provider and client autonomy appeared to be a critical factor in capacity to improve care for pregnant and parenting Aboriginal people. In Case A, the Tribal Council buffered macro level policies in order to allow communities and organizations to have the autonomy to respond to community needs and priorities (*SBD Types I*):

There is a health transfer agreement with the Tribal Council [which is] this umbrella administrative body that looks after 14 First Nations. They understand completely what is in the Health Transfer Agreement at their level. They understand it inside and out. And from there, the money just gets divvied up to each First Nations. They send you this budget that says you've got a \$100,000 for health. Spend it on health, but there's no restrictions on it. So, it's kind of like, you spend it where you need it. But in health transfer agreements, there are targets that you have to meet. They say some things, you know... it's for this, this and this... but I guess why they're doing that is to allow for flexibility for the needs (Case A leader).

In Case B, the process of health system changes was experienced as a loss of autonomy and voice in governance of services for Aboriginal people.

They [the RHA] might have their own opinion of how we operate. Pushing back, we're trying to meet our mandate in accordance and keeping in mind our own policies and procedures, right. So we find sometimes the health authorities will impede or impose. They think that they know how things should be found and they have told us [how to do our business] (Case B leader).

This perception of RHA interference was shared by decision makers from the RHA, who acknowledged that in fact, there had been a sudden change in the relationship between Case B and the RHA as a result of transferring administration of the pregnancy outreach programs to the regional health authorities in the province. As one key informant explained:

The history about those services [the pregnancy outreach programs], a lot of them really started because there was a community development process with key people, who worked in those health units, nurses and nutritionists connecting with their friendship centres and Aboriginal partners. [Prior to 2001] the relationship between the pregnancy outreach coordinators and agencies were directly to the Ministry of Health, with the health unit over here [motions to the side] even though they were often very involved. So then regionalization happened and health authorities were responsible, and even though there had been a contract relationship between the pregnancy outreach providers and the RHA, it really was a rubberstamp. But now, there are other questions asked and direction given like 'Why don't you think about this in this way' and 'maybe you should shift services'... there's a real change in control. I don't think any of the agencies in the province would have had a different experience. They would have felt "What's going on here, this is ours!" (Phase One #5).

The increased autonomy and flexibility in health planning that the RHA experienced as a result of decentralization, was initially experienced by the Case B organization as less autonomy, less voice in health planning, and as a result less freedom to be responsiveness to the community (SBD Types I & XI).

We [the case B organization] have phone calls [from the newly appointed RHA contract manager] asking what we're doing and... I said, "Why are you doing this? I would never dream of phoning [another organization] and asking why you are making those kinds of decisions. Because I don't work in a day-to-day situation to know what's going on and (I can't) even pretend that I would know what was going on. So I would never interfere with your [business], with what you're doing" (Case B leader).

View of accountability. Both cases believed that their first accountability was to the community, and that they were also accountable to administrative authority. In Case A, the conflicts between these two accountabilities had been clearly identified early on, and precipitated the need for change:

We were all finding our way [as individual nurses, as administrators and leaders]. I felt like I was on a teeter totter in a way.... with directives from community and directives from the Tribal Council. Plus there was the other layer, which many of us were always talking about, the layer of our nursing standards of practice. So there are really 3 layers there (Case A provider).

Over several years they developed a framework for building a model of care based on accountability to the community's values and priorities, and then finding the common ground that met the accountability requirements of all stakeholders (*SBD Types VII & VIII*).

There were really broad opportunities for people to talk about what health meant to them, what health workers meant to them. And then they looked at different programs for various populations... And then they gathered those into themes and then went from the themes to the development of cultural meetings and then it was from all that, that the mountain itself developed. So it really has... there was an enormous attempt to have a grassroots based [approach] (Case A provider).

In their newly configured relationship as a subordinate to the RHA, Case B's formal accountability was to program goals and deliverables set by funding organizations. However, trying to be accountable and responsive to community priorities, and program goals and deliverables put them in a difficult position. The following comment from a leader in Case B demonstrates fractured accountability to micro-goals from multiple funding sources, and potential conflict if contractual commitments were not congruent with community needs:

We receive different sources of funding for different programs, health, education and social services, that each have criteria and contractual commitments we have to abide by. We train the staff to understand each of their positions, to stay within the boundaries of each of the programs, and to listen to what the community needs are (Case B leader).

This fractured accountability was evident through examination of published program deliverables and accountability requirements (*SBD Types VIII, IX & XI*). The differences in how program utilization statistics were collected and analyzed demonstrate how the governance models in each case facilitated capacity to manage potential conflicts in accountabilities. In Case A, the partnership governance model enabled the problematic of

the old charting and measurements systems to be identified, and an alternative developed that fit the community-tailored program approach (*SBD Types VIII, IX & XI*).

It [the charting system] came about because we didn't really have any standard forms. It was just a compilation of everybody else's forms and nobody was standardized and it just depended on if it was this nurse's passion and she excelled or if it wasn't her passion, then there was no [real documentation of care]. Because it was a new program that we had developed we really just wanted to standardize [our practice]. So then all nurses coming in, whether they had worked with us for awhile, they knew they had the tools to do the practice that fit with the community. And that was different; it was different than most other practices (Case A provider).

During the same time as Case A was developing their new charting system in Case A, an independent chart and record audit (MacDonald, 2003) by the Office of Nursing Services of the FNIHB identified that nurses were completing no less than 232 separate forms, often with little understanding of why, and no feedback of results from broader levels once forms were sent "up the system" (*SBD Type VII*). In contrast with these problems, Case A's new charting and record system strengthened the program approach, and enabled provider practice and measurement of program impact that matched the new program model (*SBD Types VIII & IX*).

So we had the visual framework. That was really nice but then we had this medical model charting. So like we're trying to do this traditional holistic nursing that really values the culture and yet all of our charting was medical model that totally didn't fit. So you couldn't really practice your nursing as you wanted to. So we had to develop new charting systems (Case A provider).

In contrast, Case B's fractured accountability was further complicated by the huge burden of reporting requirements demanded by a plethora of contractual relationships. When asked if there was anything that made it harder to do their work, the time that reporting requirements consumed was often described:

Paperwork, deadlines, reporting, right, you know like there's lots and lots of reporting. Any program, anything funded from the government, there are reports (Case B provider).

This provider described the details of the reporting requirements (SBD Types IX & XI):

1. *Annual reports- which is the IPQ (Individual Participant Questionnaire). IPQ counts the number of pregnant women, the number in the program, the number of lost, number of breast-feeding, number of, you know. It's a big; it's a book that I have to fill out at the end of the year for them...*
2. *The quarterly Canadian Prenatal Nutrition Program ICQ2 (Individual Client Questionnaire) -that measures each client but they're a statistic, right. We don't submit names. We submit numbers. So I go through charts and am just picking, picking, picking. Counting. Counting from the front page as to how many times they've come in the program. How many times they've been seen. Did they breast-feed? Did they stop? How long they were in the program. Did they quit before they delivered their baby? Stuff like that.*
3. *The quarterly United Way reports- They want to know what we do with the funding. How many meal vouchers we gave out. How many clients we've seen....*
4. *Monthly board reports...*
5. *Weekly report to the management team just so they know what you do during the week. How many clients you've seen that week. How many phone calls you made. How many referrals you made...*
6. *Quarterly Report to [the RHA] (Case B provider).*

Not only were there considerable reporting requirements, but also the piecemeal contractual relationships with multiple funding sources did not provide infrastructure funding to develop skills and resources for efficient management of health information.

So can you imagine the statistics that I have to keep? I have all of this upstairs in the filing cabinet in the reception area. And every time I want to record something, I have to go upstairs, go through to the filing cabinet in that front office and record it by hand. It's not on computer, none of this. It is sort of a capacity thing. We have a disk upstairs, right. And we have the how-to manual. We just don't have the computers or the people, or the time (Case B provider).

The incongruence between contracted program objectives, activities, and measurement of outcomes, with Case B's vision and mandate to support the community was captured in a statement made after discussion of all these monitoring and reporting requirements:

Do I make a difference in their lives, in their choices? I don't know how we would be able to monitor that because, you know, I only know how I made a difference in other girls' lives because they've told me personally, right, and it's not recorded on paper (Case B provider).

Approach to decision-making. One of the most important differences between the experiences of Case A and Case B was the way that decisions about care were made, and the degree of congruence between decision-making approaches of the stakeholders (e.g. RHA, organization, providers, community/clients). In Case A, the tribal council, the community, and the nursing department believed in and used consensus decision-making. This is evident from the emphasis on involvement of all stakeholders in their mandate (SBD Type IV):

Mandate: For the benefit of present and future generations of [our people], to encourage the greatest possible communication, commitment and involvement of community members, service providers and leaders to facilitate the holistic application of human, natural and financial resources toward the goal of having healthy people living in healthy communities in a healthy environment (Excerpted from the Terms of Reference of Case A's Tribal Council).

The mandate and terms of references such as for the board and advisory committee spelled out a similar approach to decision-making in Case B (SBD Type IV). However, the new regulations for Regional Health Boards (SBD Types III) that came with the enlarged RHA became another layer of bureaucracy that discouraged community stakeholders from having a voice in decision-making. Participants perceived that Aboriginal people were further marginalized (e.g. no representation on board, too many barriers to come to the table to speak & no monetary payment for their expertise). The challenges of community participation in health planning in the much larger health

regions made the relationships at local levels of planning and administration even more important.

With the Regional Health Boards and then the Aboriginal dollars that are sitting there, if you go to a meeting you have to put a brief in. I don't know how many weeks ahead... and if they don't like what's in there, they take it out and you can't bring that forward and you've only got so many minutes to speak. And we did that for 10 years for nothing, for free, sat on those boards and developed all these things that needed to be developed and now the Health Board's they get \$3,500 a day the members, whether it's a whole day, or two hours, for every meeting... each member. And I don't think we're getting anything out of it, for the average person in the community for those Aboriginal dollars (Case B leader).

View of fairness. Delivering care according to people's values, beliefs and priorities was foremost in the innovation of program approaches of both cases. However, the extent to which governing organizations (Tribal Council for Case A; RHA for Case B) understood the significance of this approach to both community and the organization differed.

In Case A, removing from health care the imposition of values and beliefs of dominant society on Aboriginal people was central to the reason for change.

There was always a worry that in the past the emphasis had always been on perceived rigid rules and regulations coming from the outside. The anxiety was "we don't want to continue to do that". We wanted to honour our professional code [e.g. standards for practice], but also wanted to honour the cultural codes and protocols of the [local] people. We needed to understand the [local cultural] code, to respect it, to abide by it, and to be guided by it. So that the cultural code was the main code, and the professional code was the add-on piece, rather than the other way around (Case A provider).

An RHA stakeholder in Case B explained how these same values and vision were not well understood by most staff and decision-makers within the mainstream RHA health service delivery organizations.

Most of our staff are non-Aboriginal people, who don't have that context. They come from white middle class backgrounds, and feel that [colonization] was years and years ago and it doesn't affect our relationships in the present; [they feel that the past] doesn't affect us across this table and our relationships. Whereas conversations with my Aboriginal colleagues, they'll say, "You can't do that, that's impossible. You need to acknowledge the history and [the impact of] all the triggers and words that you would use".... So I think it's really important that our staff who work in communities where there are high Aboriginal populations need to understand that. We need to do a better job. It should be a core part of our orientation and staff training (Case B leader).

Relationships among stakeholders. At the very centre of organizations' innovation experience are the relationships between all levels of stakeholders. Relationships are in the forefront of Aboriginal organizations experiences improving programs, but also to create change in the broader social environment. Participants' in both cases described respectful, trusting, safe relationships as a vehicle for developing understanding, healing and building strength and capacity to work toward the shared vision. For example, providers from both cases described the understanding and empathy that were essential to developing constructive relationships with clients.

I only used my experience in life to work with all these families, because I understand how they felt. I knew in my heart how painful it is to go through a loss and I knew in my heart how it is to grow up in a violent environment. And I knew in my heart how it was to be stuck in a relationship that was so familiar inside and feel how can I go out there and trust everybody? How can I trust anybody? It's so... the world is so mean...it's not safe. (Case B provider)

Similarly, the character of organizational-health authority relationships (e.g. the Aboriginal health service delivery organization and the Tribal Council in Case A and the Aboriginal health service delivery organization and the RHA in Case B) were a critical influence on the meaning of participants' everyday experiences with racism, and profoundly influenced the implications of changes in the health system. Respectful,

mutually supportive relationships between organizational leaders and decision-makers from the governing/administering health authority facilitated Aboriginal organizations' experience improving care. Positive, respectful relationships helped to bridge negative encounters in the broader environment, and to overcome the turmoil caused by health system changes imposed by the provincial government. However, disrespectful and dismissive attitudes of individuals in positions of authority profoundly shaped the meaning of experiences of these system changes. Participants from both cases described "finding people with the right attitude" as critically important to both delivery of care, as well as building bridges between Aboriginal and mainstream health organizations.

Summary of Results

In Case A's experience, community-based organizational stakeholders (e.g. leaders, providers, community members) were included in the change from a top-down externally imposed governance and program model, to a partnership model of governance and program delivery. Participants' stories communicated a sense of ownership, commitment, and optimism about the change and the opportunities it represented. The new governance and program delivery model was built on a common understanding of the problem and vision for change. Leaders, providers and community members had the autonomy *and* support for capacity building that enabled them to work through multiple challenges over a 10-year period to improve program responsiveness.

Case B started out in a leadership position within collaborative/partnership relationships with other community agencies/stakeholders to develop a new program congruent with their view of the issues/needs, and vision for change. The program continue to grow and evolve over the next decade within a collaborative/partnership

model of governance with the British Columbia Ministry of Health Pregnancy Outreach Program Co-ordinating Office, and as part of a growing network of in-house programs to provide better access to the determinants of health (e.g. educational laddering programs, supportive housing, family support and sexual abuse intervention programs). Case B experienced a period of alienation and instability when roles and relationships with the RHA were suddenly changed by a unilateral decision by the provincial government.

Discussion

Simply put, governance describes the process of making decisions about direction and roles in any form of collective action. Governance has been defined as “the ways in which organizations and the people in them relate to each other” (Davies, Anand, Artigas, Holloway, McConway, Newman, Storey & Thompson, 2004, p.1), and “comprises the traditions, institutions and processes that determine how power is exercised, how citizens are given a voice, and how decisions are made on issues of public concern” (Graham & Wilson, 2004, p.1). Though the concept suggests that not only governments govern, there remains substantial confusion about governance (Davies et al., 2004; Edgar & Chandler, 2004). Furthermore, there are a diversity of views, values about how decisions are made and by whom (Edgar & Chandler, 2004; Graham & Wilson, 2004). Failure to explicitly and deliberately sort out governance arrangements between stakeholders creates almost inevitable contention and conflict between stakeholders.

Governance occurs in four zones or spaces: ‘global space’, ‘national space’; ‘organizational space’; and ‘community space’ including activities at a local level where the organizing body may not necessarily assume a legal form (Graham & Wilson, 2004). These results relate to governance in organizational and community spaces. Newman

(2001) discusses four types of organizational or community governance: hierarchical models, rational goal models, open systems models, and the self-governance model. The hierarchical or bureaucratic management model is oriented towards predictability, control and accountability, and is criticized for being inflexible, slow and reluctant to change. In the rational goal model governments exert power through managerial means (e.g. through contracts). Compared to the hierarchical model, the rational goal model is less oriented to control, focuses on shorter time lines and attempts to maximize outputs. The experience of Case B after the legislation changes of 2001 is an example of the rational goal governance model. Rational goal models are incongruent with Aboriginal views of governance, which put voice, strategic or historically-situated vision, and respect for autonomy and self-determination to the forefront in governance (Graham & Wilson, 2004).

The open systems governance model is oriented towards networks, where power is dispersed and relationships constantly adapt to meet changed demands. The open system model is "fluid, fast and highly responsive" and "accountability is low but sustainability is high" (Newman, 2001, p. 35). The self-governance model is oriented inwards, focuses on peer accountability among a company of equals and on fostering relationships of interdependence and reciprocity. Case A's experiences appears to fit with the open system, network and relationship centered model of governance.

More recently, mixed models for governance have emerged which combine self-governing organizations in market or network-based relationships with each other, yet maintain hierarchical relationships to government. The mixed governance model uses delegated responsibilities through hierarchical relationships with government to enhance

accountability to governments' priorities, but enables self-governing organizations considerable autonomy for delivering outcomes (Davies et al., 2004). The governance models in both cases in this study share similarities with a mixed model.

Our results suggest two critical issues of concern with use of mixed governance models in health care for Aboriginal people. First, mixed governance models are especially important in a context where multiple layers of decision-making about care are involved. For example, decisions to change the delivery of prenatal care in Case A involved the community and individual clients, providers delivering care, organizations implementing care, the Tribal Council and the federal government. Similarly, many layers of decision-makers were involved in decisions about program changes in Case B. These multiple layers produced significant barriers to making changes, often extending the time period involved in implementing the change and threatening the sustainability of programs particularly in Case B. Mixed governance models that explicitly attend to how historically-situated vision, stakeholder voice, and autonomy are preserved in decision-making about care would remove many of the current barriers to improving care. However, our results suggest that greater attention must be paid to how, and by whom, mixed governance models and relationships are constructed during large health system change (Mhatre & Deber, 1992; Lewis and Kouri, 2004).

Newman (2001) also acknowledges cultural governance as a "social and cultural as well as an institutional practice. Cultural governance "concentrates on the kinds of knowledge and power through which social activity as a whole is regulated. It draws on the Foucauldian notion that power is constitutive and that it constructs and normalizes practices" which are viewed as "new strategies of control" (Davies et al., 2004, p. 74).

Given the legacy and enduring presence of influential instruments of governance such as the *Indian Act*, the interdependencies between Aboriginal and non-Aboriginal players in governance systems must be explored, and mutually agreed on principles identified (Graham & Wilson, 2004). For example, how governance dimensions such as voice, autonomy, views of accountability, strategic vision and fairness (Graham & Wilson, 2004) among community-based organizations and Aboriginal populations will evolve must be discussed.

Implications

The results focus attention on the influence of governance models and health system change on Aboriginal health service delivery organizations experiences improving care for pregnant and parenting Aboriginal people. These findings highlight issues related to integration of Aboriginal governance values and orientations within socio-political contexts with different values and orientation to governance. From a postcolonial perspective, the Aboriginal organizations in this study strived to shape care that supported Aboriginal people to live by their own values and beliefs. This is a complex endeavour in a societal context: a) that for decades denied people the right and dignity to live by their values and beliefs; b) that deprived people of their cultural heritage, values and beliefs; and c) that operated from a 'health professional knows best' rather than a human rights orientation in health care-Aboriginal relations. Indeed this was the essential difference between the vision and approach to care driving the Aboriginal organization in Case B and the program approach of the mainstream RHA. This difference was a source of much stress and angst for Aboriginal leaders and providers. Working within mutually respectful relationships could facilitate intervention approaches

that tackle the root causes of inequities in health and social conditions experienced by Aboriginal people.

In health policy and planning, accommodating understanding of the impact of governance on care would involve taking the time and making funding available to explore and discover common ground and/or potential conflicts between stakeholders. Health care decision-makers must consider and support stakeholder involvement in health system change processes as a worthwhile investment in responsive care. Building healthy and constructive relationships, and developing consensus on governance is prerequisite to developing programs that address population priorities, and ultimately reduce inequities in health. Measuring progress with indicators such as capacity and opportunity for voice among stakeholders, and congruency between program aims, measures and stakeholder vision would be consistent with this approach. Because health system change seems to be a norm rather than an exception (Lewis & Kouri, 2004), health professionals should become familiar with basic governance concepts and processes, develop competencies to identify when governance issues are influencing their practice, and acquire skills for full participation in health system change processes in the best interest of clients. Ideally, these competencies would be introduced during undergraduate health professional education programs.

Research could examine the influence of governance on organizations' efforts to improve access to, and responsive of health services for Aboriginal populations. For example, research and evaluation methodologies that closely involved stakeholders to deepen understanding of their worldviews and priorities may illuminate relationships between program innovation and governance systems (Davies et al., 2004). Because this

study explored organizations' experiences improving care, the significant influence of health system change processes was not anticipated. Had a governance question been part of the original objectives, a richer description and more detailed documentation of the health system changes may have been obtained. Further research is needed to examine in greater depth the impact of processes used in health system change on organizations' capacity to improve care. Experts on Aboriginal governance and system change should be included on future investigative teams. Such multidisciplinary research could examine the process of large health system changes on community-based stakeholders' capacity to improve care, such as how different change processes impact stakeholder relationships, voice, and/or autonomy.

Conclusion

This comparative case study used emancipatory research principles from a postcolonial standpoint with participants from two Aboriginal health care delivery organizations in the province of British Columbia, Canada. Despite their differences, the small, geographically isolated, culturally homogeneous case under federal jurisdiction, shared a similar vision, view of their role and relationship to their constituent population with the urban Aboriginal health center under provincial jurisdiction. Findings highlight that care for pregnant and parenting Aboriginal people involves multiple stakeholders who may hold different views of roles, relationships and how decisions will be made. Our analysis illustrated how differences in 1) processes used to change governance systems; and 2) the governance model structuring roles, relationships and decision-making about care, profoundly impacted the Aboriginal organizations' experiences improving care for pregnant and parenting Aboriginal people. We suggest that greater attention to

governance is needed when designing health systems serving Aboriginal people.

Specifically, more explicit recognition of stakeholders' views and values related to governance, greater stakeholder involvement in health system change, and participatory governance models may enhance Aboriginal organizations' capacity to improve care.

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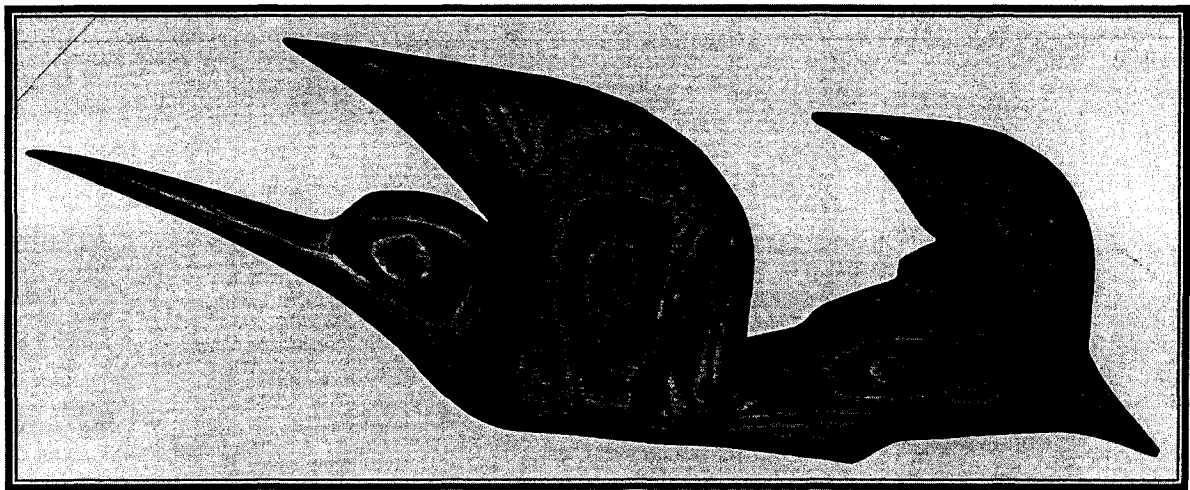
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Part III:

INTEGRATED DISCUSSION

“We are at a moment of both profound changes in the scientific concept of nature and of the structure of human society. As a result there is a need for new relations between man and nature and between man and man. We can no longer accept the old a priori distinction between scientific and ethical values” (Prigogine and Stengers, 1984, p.312).

Figure 3.1: *Critically Reflective Note-Implications*

Carving by Charlie George, Heiltsuk Nation, Bella Bella, BC. Used with Permission.

Notes to myself -Aug 24, 2004

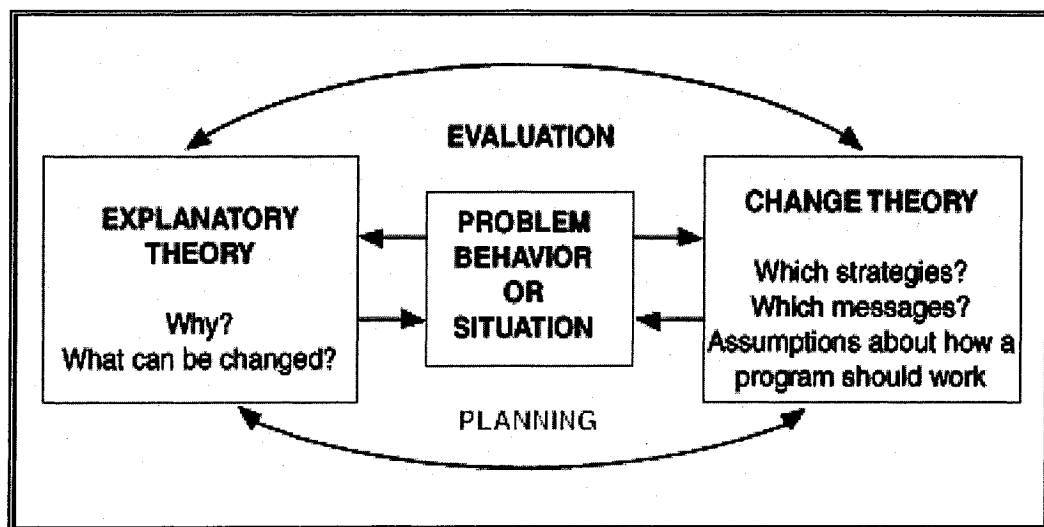
I have been thinking about the raven in Charlie George's carving. Charlie explained that the raven is a trickster that can change/transform his shape. I think that is one of the themes I am going to have to be aware of as I move into knowledge translation of my findings, and helping people understand what it is Aboriginal people and organizations are trying to achieve, what their visions are, what their challenges are, what their strengths are, and how to work from those strengths. So when I write up the results, I am going to have to speak from the providers' perspectives, who are so grounded in supporting individual Aboriginal people. I will also try to describe the leaders' perspectives, who have the vision and think from a Nation perspective. Yet, I am also thinking about the issues from funders' perspectives, who may be seeing this through a health services lens. So I think that's why the Raven is in Charlie's carving. This teaches me that we need to be able to switch back and forth and change from one mindset into another. To incorporate all of these different perspectives into the planning of care.

I was also thinking about people who have a foot in both worlds, like the community health representatives and the lay health workers. They are really important to the bridging process, because they can see and understand things from more than one perspective. They can change their lens back and forth in order to facilitate communication. They are like interpreters. So those people who have a foot in both worlds are very very critical. The other thing about the Raven in Charlie's carving is I see this issue both from the viewpoint described by Aboriginal participants and from the population health science perspective. Those will be the two predominant stories I need to tell. Maybe the Aboriginal story will be more about healing and reconnecting and restoring and renewing local and family cultures and a sense of wellbeing. And maybe the population health view will talk about the same actions and the same vision, from an 'increasing access to the determinants of health' view.

Introduction

The field of population health aims to discover explanations for inequities in health, and develop the knowledge needed to intervene to reduce those inequities (Health Canada, 2000). Figure 3.2 illustrates the components and relationships between knowledge necessary to explain the sources of inequities in health (e.g. explanatory theory), and the knowledge needed to intervene to reduce those inequities by making change at the source of the problem (e.g. change theory) (Glanz, Lewis & Rimer, 1997). This model for the relationship between the knowledge needed to explain and reduce inequities in health pertains directly to the results of this study as laid out in the three papers.

Figure 3.2: *Developing Knowledge to Explain and Reduce Inequities in Health*



Source: Glanz, Lewis & Rimer, 1997

New 'explanatory theory' for the problem of late access and low participation in prenatal care by Aboriginal people was described in paper #1. This manuscript discussed Aboriginal parents' need for care that is oriented to supporting their efforts to turn around the intergenerational impact of residential schools. The change theory, or intervention

design was described in Paper #2. Focusing on the underlying characteristics of safe and responsive care, this paper described community-based stakeholders' perspectives on an intervention approach, and identified indicators and methodologies that could be used for evaluation vis-à-vis the explanatory theory. Thus, in the transdisciplinary tradition of population health science (Smedley & Syme, 2000), the study used the analytic power of critical theory to unmask forms of inequity and oppression (Fontana, 2004; Mill et al., 2002), which then informed use of the knowledge and tools of multiple intervention science (Edwards, Mill & Kothari, 2004).

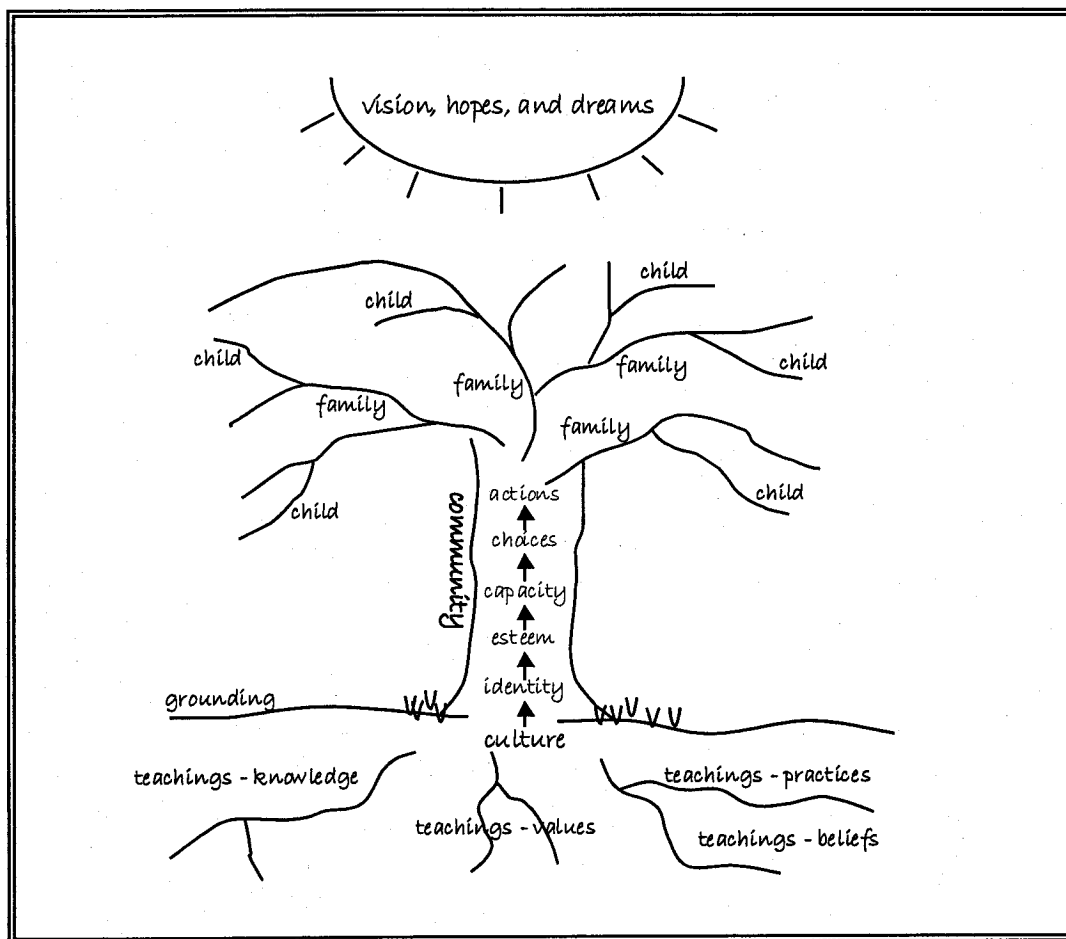
Given the challenges to innovation in the complex jurisdictional, geographical and historical context of health services delivery to Aboriginal populations, the third set of results (presented in paper #3) examined the factors influencing Aboriginal organizations' experiences changing interventions to fit this explanation and approach. These findings identified the importance of participatory forms of governance in successful and innovative models of intervention for early access and participation in care during pregnancy and parenting.

The purpose of Part III is to integrate the results of the study and describe how they contribute to the field of population health. The contributions of the study to a) upstream explanations for the research problem, b) improved intervention design for pregnant and parenting Aboriginal people, and c) insights into the science of intervention design and evaluation are outlined below. This is followed by a summary of insights about doing postcolonial population health research, a description of how the study has contributed to population health science, and a discussion of the study's limitations.

An Upstream Explanation and Vision for Change

Exploring 'upstream' understanding of root causes for inequitable health and social conditions, and identifying interventions to address them is a basic premise of population health (Centre for Children & Families in the Justice System, 2002; Health Canada, 2001). Participants' views of the importance of pregnancy and parenting provided a new perspective and upstream explanation for the inequities in health and social conditions experienced by Aboriginal people. Figure 3.3 is my understanding of participants' views of healthy children, healthy families and healthy communities.

Figure 3.3: *My Understanding of Participants' Views of Healthy Children, Families & Communities*



The metaphor of the tree and resulting diagram evolved during analysis and writing of themes I identified from participants' stories of the IGIRS and vision for a better future. The diagram was shared with participants during face-to-face discussions of preliminary results in April of 2005. The diagram does not incorporate all of the dimensions suggested during participant feedback, such as the seasonal cycle of leaves to show the cycles of renewal and regeneration over time and the interconnectedness of people with the environment. However, the diagram does represent many of the dimensions of participants' views of how pregnancy and parenting are situated in an approach to creating healthy children, families and communities. Cultural teachings are symbolized as the root of strong people, and healthy growth across generations. Strong people are grounded in, and by, their cultural teachings. The values and beliefs are the 'tap root teachings'. The traditional knowledge and practice systems are teachings that grow from the taproot. Children are linked to teachings through their family and community. The tree grows upwards toward the sun, which symbolizes the vision, hopes and dreams for the future. The sap/spirit rises from the nurturing energy that the roots draw from the grounding of the culture in the environment, and is renewed by the energy that the leaves and branches (e.g. the children) draw from the sun.

The tree diagram situates the meaning and importance of pregnancy within a worldview that emphasizes history, culture, identity, connectedness, relationships and spirituality. It also suggests an epistemological standpoint that encompasses metaphysical understandings, and brings particular forms of knowledge (e.g. teachings) into the foreground when making decisions. The tree diagram demonstrates a more holistic approach to improving health, and could stimulate innovation of policy in and beyond

health services. For example, situated within this understanding of goals, roles and purposes for intervention; health organizations and providers become facilitators of community action to reconnect across time, relationships, and with culture.

This 'new' understanding for both the root of problems, and vision to guide action, may "uncover gaps in knowledge and action, and set the ground for new initiatives in both research and policy" (Krieger and Gruskin, 2001, p. 137) on this issue. A critical postcolonial view on participants' perspectives suggests that care based on racialized views of Aboriginal peoples may create additional barriers, and maintain inequities in access to care. These results suggest that health interventions in general, as well as interventions specifically during pregnancy and parenting, must be situated within an understanding of the impact of colonization, and in particular the intergenerational impact of residential schools on Aboriginal People.

Revisiting the A Priori Conceptual Framework

The imagery, language and worldview represented by the tree diagram contrasts sharply with the perspective, language and worldview of the a priori conceptual framework (See Page 39). This contrast underscores a disjuncture between the importance of pregnancy and parenting to Aboriginal people and how to support it as identified in this study, and that of theory and evidence from population health science incorporated into the a priori conceptual framework. Results suggest how several dimensions of the a priori conceptual framework could be improved, but perhaps more importantly, results illustrate the need to bridge the many stakeholder perspectives involved in care for pregnant and parenting Aboriginal people.

Results demonstrate the need to expand several dimensions of the a priori conceptual framework, suggesting a need for stronger representation of the role of time, context, and history into the approach to care during pregnancy and parenting. For example, results described how governance systems influenced the experience of improving care, which is not well represented by the single line for 'context' in the a priori conceptual framework. The idea of identifying principles to guide intervention, rather than prescription of discrete intervention was supported by the results, the emphasis on safety and responsiveness in the forefront of approaches to care was added by the study results. Though the a priori conceptual framework incorporated many ways of knowing, the study results specified *how* different ways of knowledge could be integrated into care. This is a significant contribution of the study, and is a step forward in resolving the conflicts between different ways of knowing or different knowledge traditions. The subject-object relations between stakeholders spelled out in the description of the intervention design, implementation and evaluation process is not well represented by the Venn diagram of stakeholders on the left hand side of the a priori conceptual framework.

The shortcomings of the a priori conceptual model and the contrast with the tree diagram underscore the inadequacies of tinkering with health care models based solely on knowledge and wisdom from western science when designing health care programs for Aboriginal people. The contrast in language, representation and worldview between the a priori conceptual model and the tree diagram signal the need for a more profound level of change. Results also suggest the need for a collaborative approach to improving care that involves multiple stakeholders. Intervention approaches that help to build relationships

and understanding are needed to bridge the disjuncture between scientific thinking in population health intervention; and the worldview, vision and ways of knowing and being of Aboriginal people. Future research and conceptual work are needed to develop the tree diagram as a framework for design of care for pregnant and parenting Aboriginal people. For example, future conceptual work and research could incorporate the fundamental concepts (e.g. connections between children, families and communities; pathway between teachings, culture, identity and capacity for health choices and behavior) in the diagram to explain to provider teams the purpose of interventions, who is involved and how they are used.

This conceptual work to evolve explanatory theory underpinning care for pregnant and parenting Aboriginal people also could draw on emerging concepts in Aboriginal health such as historical or historic trauma. The concept of historical trauma has developed as “a natural consequence of tragic historical events affecting the psyche of Indigenous Peoples” (Information Center on Aboriginal Health, 2005). “Historic trauma is understood as a cluster of traumatic events and as a disease itself. Historic trauma causes deep breakdowns in social functioning that may last for many years, decades and even generations.” (Wesley-Esquimaux & Smolewski, 2004, p. iv). It is a generational grief resulting from a continuous passing on of *unresolved [authors emphasis]* and deep-seated emotions, such as chronic sadness, to successive descendants that occurs when the effects of trauma are not resolved (Aboriginal Healing Foundation, 1999; Wesley-Esquimaux & Smolewski, 2004).

Though not focused on understanding historic trauma in the context of pregnancy and parenting, participants’ spontaneously chose to enter into a detailed and often

emotional description of their experiences of coming to understand their own childhood, parenting and other family roles and relationships in response to the opening question, 'Tell me a little about yourself'. Participants' stories were overwhelmingly imbued with stories of multiple forms of trauma and their journey to heal from many forms of trauma that they traced back to experiences of self and/or family members in residential schools. Thus the centrality of intergenerational impact of residential schools in participants' experiences and efforts to create a better future for their children figured prominently in the study results. These stories and explanations relate closely to the notion of resolving grief and sadness to stop the transmission of historic trauma.

Furthermore, findings suggest that the impact of intergenerational impact of residential schools is magnified by the importance placed on children by Aboriginal people. That is, recognition that one is transmitting 'the hurts' (e.g. the pain, grief and chronic sadness) onto ones' own beloved children may deepen and extend the intergenerational trauma, while masking its source. However, findings also indicate that pregnancy and early parenting are significant periods of opportunity for supporting Aboriginal people to resolve or 'turn around' the intergenerational impact of residential schools.

These findings may be useful to those who are addressing issues of historical trauma, particularly in the context of care for pregnant and parenting families. Further research focusing specifically on the influence of historic trauma on Aboriginal peoples' pregnancy and parenting experiences may yield further insights to inform relevant, supportive and responsive care.

Improved Interventions for Pregnant and Parenting Aboriginal People

An approach to interventions for pregnant and parenting Aboriginal people based on results of the study could be used to improve early access and participation in prenatal care interventions in a number of ways. The results suggest an upstream, solution-focused orientation to care, that potentially could improve the life course of future generations through enhanced fetal and early childhood development (Graham, 2002; Hertzman, 2000). As advocated by the Aboriginal Healing Foundation (2005), the results also suggest that a holistic approach is needed to “help create, reinforce and sustain conditions conducive to healing, reconciliation and self determination, and address the legacy of abuse by building on the strengths and resiliency of Aboriginal people”.

The results pertain to all five dimensions of the *Ottawa Charter for Health Promotion* (World Health Organization, 1986), one of the historical precedents of population health science (Hayes & Dunn, 1998). Results contribute to our ability to increase equity in policy and actions (International Society for Equity in Health, 2005) in each of the five strategies described in the *Ottawa Charter*. First, the study contributes the knowledge needed to *reorient health care services* to be more relevant for pregnant and parenting Aboriginal people. Results describe an approach to health service delivery that is based on facilitating and *supporting community action*, and *building personal capacity* and coping skills of Aboriginal parents and families. The approach to care developed by both Aboriginal organizations emphasizes *creating supportive environments* and relationships, to encourage and stimulate Aboriginal people’s self-determined action. Such an approach is built on respect for and acknowledgement of Aboriginal people’s inherent strengths and capacities, and is in direct contrast to more

paternalistic approaches that position Aboriginal people as passive (less capable) objects of expert (aka superior) knowledge and action. As findings in this study suggest, culturally respectful, comprehensive care starts with listening to the persons' stories, and working to see things through their eyes and thought processes. "There is no judging or categorizing—and the urge to chronicle a history of complaints, or record signs or symptoms, does not occur...The patient must be central to the ceremony; he or she is not a passive recipient of the intervention" (Grandbois, 2005, p. 1009).

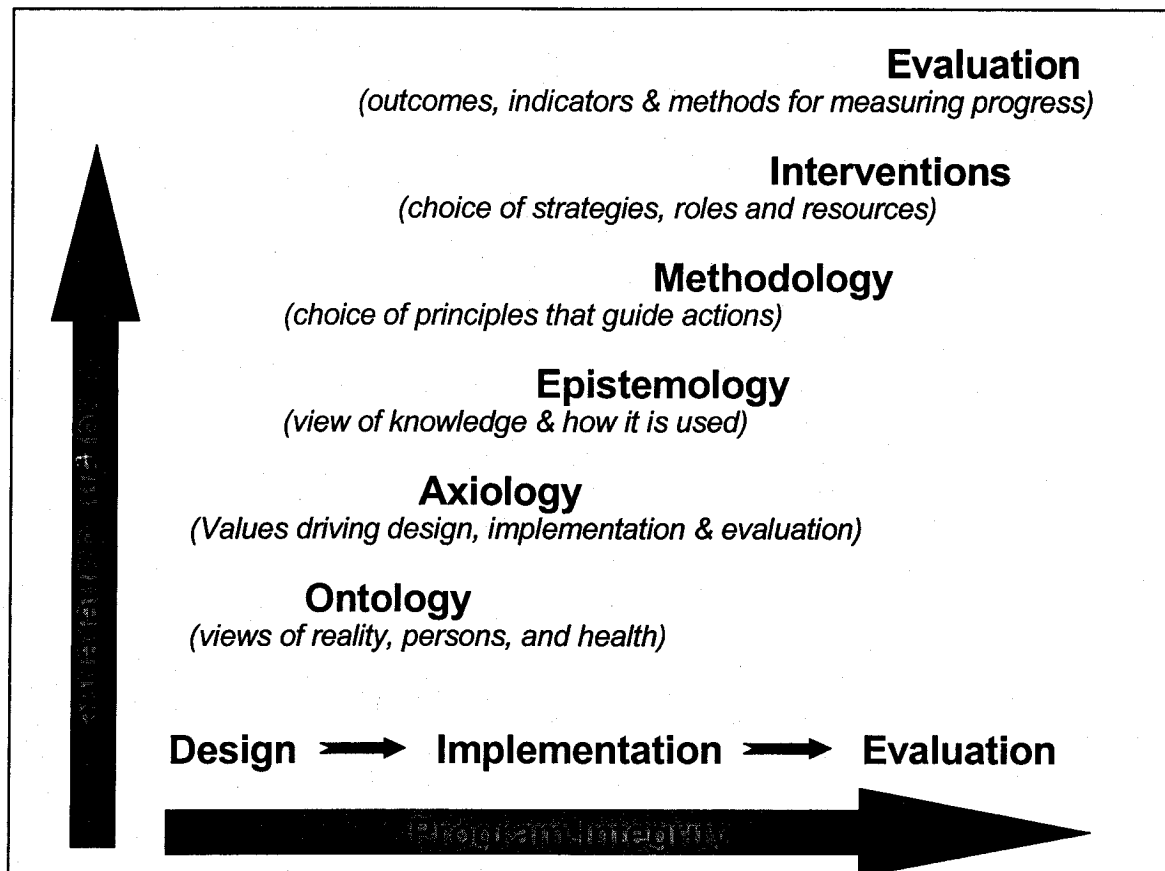
Aboriginal organizations' experience improving care contributes knowledge to inform public policy that will facilitate organizational innovation, and equitable approaches to governance and health system change.

Thus results position Aboriginal people as the principle actors in population health interventions, with health organizations and providers playing supporting roles. In this approach Aboriginal peoples' cultural and experiential knowledge are brought into the forefront of care. Many ways of knowing are made available and put into the service of facilitating action on client and community goals, and building strength and capacity. This flexibility and sensitivity to many ways of knowing demands competencies from practitioners that may not have been emphasized or even introduced in basic undergraduate education programs. The increased emotional and spiritual dimensions of practice will require organizations to facilitate access to emotional support, respite, and continuing education that providers may require to sustain such care. These examples of how results could inform improvements to care for pregnant and parenting Aboriginal people suggest a shift to a deeper level of thinking about the design and evaluation of population health interventions.

Approach to Population Health Intervention Design and Evaluation

Population health intervention design and evaluation are often discussed in terms of logic models – e.g. goals, objectives, resources, intervention strategies and evaluation outcomes (Coote, Allen & Woodhead, 2004; Smedley & Syme, 2000; Winett, 1995; W.K. Kellogg Foundation, 2004). Though population health intervention recognizes interrelationships between people and their environment and aspires to tailor interventions to fit specific populations (Edwards, Mill & Kothari, 2004), approaches to *how* such tailoring might be achieved have not been elucidated. The approach to multiple intervention design and evaluation developed in this study contributes to this gap in the science of population health intervention (See Figure 3.4).

Results suggest that intervention design must be coherent in two dimensions: design and implementation. First, looking at the vertical arrow in Figure 3.4, the worldview, values and orientation to knowledge underpinning interventions must be coherent with those held by the target population. These three lower layers - the underlying worldviews, values and views of knowledge that underpin population health interventions - are often not discussed in the population health intervention literature. This is particularly important when working with minority populations, whose worldviews, values and views of knowledge may diverge from those of the majority. A second aspect of vertical coherence is the fit between the 'steps' of intervention *design*: goals must be coherent with underlying worldviews, values and views of knowledge; strategies must be coherent with goals, and so on. Indicators and methods chosen for evaluation must be coherent with the total intervention design, especially in light of the importance of evaluation measures and results for ongoing funding and resources for interventions.

Figure 3.4: *Approach to Population Health Intervention Design*

The horizontal axis of the approach to population health intervention highlights the importance of coherence between the resources and approach used in *implementation* of the intervention program and its design. The pitfalls of inattention to program implementation in the science of population health intervention have received some attention (Dane & Schneider, 1998; Goodman, 2000; Merzel & D'Afilitti, 2003; Rychetnik, Frommer, Hawe & Shiell, 2002). Examples of resources for program implementation include: financial resources; human resources such as the provider team mix and competencies; infrastructure resources such as health information system management capacity; management resources such as staff supervision and support;

resources for orientation, training and/or continuing education; resources for interagency communication, co-ordination and collaboration; and resources for marketing and promotion (Dane & Schneider, 1998). However, coherence between underlying worldviews, values and views of knowledge and goals, strategies and evaluation of population health intervention has added implications for program implementation. Results suggest that: a) the long term view of both the root of inequities and social conditions and vision for change described in paper #1; b) the intensity and resources required by the intervention and evaluation approach described in paper #2; and c) differences in governing health authorities' orientation to organizational capacity development in the experiences of the two Aboriginal organizations outlined in paper #3, have implications for the resources required to design, implement and sustain such programs. Failure to understand or acknowledge the underlying dimensions or view of meaningful outcomes of the intervention approach described in this study is, at best, naïve on the part of health decision-makers and managers, and discouraging and stressful for Aboriginal organizations and communities trying to implement safe and responsive care for Aboriginal parents within such contexts. Achieving equity in health and social conditions for Aboriginal people will require resources to support coherent implementation of the intervention programs that have the capacity to achieve similar outcomes (Mooney, 2003) to that of the mainstream population.

This approach to population health intervention design is particularly salient to population health's aim of reducing inequities in health, which often focuses on reducing inequities experienced by minority or marginalized populations. Furthermore, imposition of dominant values, beliefs and ideologies as 'the right' way in intervention programs

may extend the experience of oppression in contexts with a history of collective violence such as Canada (See paper #1). This contributes a general principle for population health interventions. That is, intervention design and evaluation must consider the coherence between the worldviews, values and orientation to knowledge of the intervention and the population, if the intervention is to reduce rather than maintain inequities, oppressive practices and relationships. Furthermore, interventions must be based on explanations which incorporate historical and contextual realities and experiences of the populations, as well as an understanding of how such history has shaped social relations in the macro-context that may influence the more micro-level encounters within health care relationships (Browne & Fiske, 2001; Browne, Fiske & Thomas, 2000; Browne & Smye, 2002).

Contribution to Population Health Science

Equity research elucidates the genesis and characteristics of inequity in health for the purpose of identifying factors amenable to policy decisions and programmatic actions to reduce or eliminate inequities (International Society for Equity in Health, 2005).

This study demonstrates how a critical postcolonial lens facilitated an analysis of how population health science may better identify, deconstruct and take action on upstream determinants of inequities in health and social conditions (Reimer-Kirkham & Anderson, 2002). Insights into doing 'postcolonial population health' research and how such research contributes to knowledge and knowledge development in population health are summarized below.

Doing Emancipatory Research in Population Health

Taking an emancipatory standpoint and orientation brought several useful insights to the field of population health research including: bridging roles in Aboriginal health,

implications for rigor in emancipatory research, and facilitating community voice and concrete action.

Finding my place in the postcolonial project: bridging many 'worlds'. At the outset of this study, I was often questioned about my legitimacy as a white person doing research with Aboriginal people. Some of these issues were discussed earlier in this thesis (See page 52). In this section I step back from the personal and political dimensions of the experience, and locate it within the postcolonial project discussed in Part I. During conduct of the study, I found myself moving back and forth between the 'worlds' of Aboriginal parents, leaders and providers in community-based Aboriginal organizations, health policy makers and administrators, and academics. The differences between these 'worlds' are reflected in the language and orientation of each of the papers. The underlying intent of paper #1 was to understand and describe the worldview, values and knowledge of Aboriginal parents. Paper #2 sought to understand and capture the worldview, values and knowledge of Aboriginal parents, providers and leaders involved in the design and delivery of care during pregnancy and parenting. The language and orientation of paper #3 intended to speak to the worldviews, values and knowledge of decision-makers in community-based health service delivery organizations, the intermediate health authorities (e.g. Tribal Council and regional health authorities), and health policy makers in both federal and provincial jurisdictions.

I was struck by the dramatically different geophysical contexts and material circumstances, worldviews, values, priorities, cultural practices and norms, and language among these 'worlds'. I often described this experience as being and bridging 'between two worlds'. As an individual, I found this 'between two worlds' and bridging experience

both exciting and stressful. I found myself struggling to make the shift back and forth from one world to the next. Yet, I was excited by an awareness of how the taken for granted knowledge in one world could fill a much needed intelligence gap in the other world. It was also meaningful to be in the position to spell out the importance of the knowledge, and invite participation in bridging the divide between the worlds. I was, in Battiste's (2000) words, finding my role in an Indigenous renaissance, where Aboriginal and non-Aboriginal people work collaboratively to imagine and create the post-colonial. This recognition of and ability to shift between the language and orientations of these sometimes disparate stakeholder groups is essential to emancipatory research, that seeks to uncover and reduce societal inequities, yet not impose a new orthodoxy in doing so (Sonn, 2004).

Implications for rigor in emancipatory research. This 'between two worlds' experience meant going back to criteria for rigor in emancipatory research rather than relying on taken for granted rules and procedures for doing research. For example, I initially intended to use the criteria and procedures common in qualitative and naturalistic research (Erlandson et al., 1993; Lincoln & Guba, 1985; Yin, 2003). The tensions inherent in ill-considered implementation of these criteria when doing emancipatory research are illustrated in the discussion of auditability. Prior to implementation I had initially summarized how auditability would be used to enhance rigor in the study:

Auditability addresses the extent to which the research process is consistent over time and across researchers and contexts (Erlandson et al., 1993). Auditability is enhanced by: clear research questions and definitions of constructs which are both clearly linked to underlying theory; explicit description of the researchers' role and status; adequate sampling to answer research questions; consistent data collection, management and analysis protocols; and review of methods with participants and research peers (Smith, 2004, p. 48).

At face value this seems reasonable. However, it becomes problematic when the essential research aim is to uncover and understand the meaning of experience from participants' perspectives; and participants' worldviews, values and knowledge orientation are fundamental to what is being sought. Imposing *my* (or at least the academe's) definitions, *my* view of my roles and their accompanying status as deemed important in *my* world, and the rules and procedures for relationships that are right according to *my* norms, was inconsistent with emancipatory aims. Rather, reflexivity of qualitative methods allowed participants and the researcher to engage in a process of dialogical reciprocity to enable multiple truth claims to emerge through the co-construction of meaning (Ungar, 2003). In this emancipatory study, the postcolonial aim of making space for voices of "those who are otherwise silenced in the production of knowledge contribute(d) to a deeper understanding of the localized discourses of resistance ... [Those] who become the audience to the lived experiences of research participants, are forced to consider the truth claims of others through these 're-presentations'. These may differ substantively from representations privileged through popular discourse" (Ungar, 2003, p. 95).

Thus, it was essential in this study that my worldview, values, norms and views of what was important knowledge were *not* imposed on participants. Rather the aim was to discover theirs, and to develop safe dialogues that explored the commonalities and tensions with the perspectives I brought to the subject for the purpose of answering the research questions (as they evolved in response to participants' perspectives). For example, 'clear definitions of constructs' becomes problematic if one is seeking to discover participants' views of first 'what' construct is important, and then to understand

how they understand it from their knowledge, value and ontological orientation. For example, 'prenatal care' was changed to 'care during pregnancy and parenting' in response to participants' orientation and values. Participants did not view pregnancy and parenting through a biomedical lens that bounded their experience within the nine months +/- time frame of biology. 'Explicit description of researcher role and status' becomes untenable when using the concept of hybrid identities that was so essential to establishing authentic person-to-person relationships in the research encounter. My 'role and status' became relative to the individual encounter and person, rather than stable and always relative to my position as doctoral candidate. For example, though my identity as a doctoral candidate from the University of Ottawa and purpose as a researcher was always explicit and transparent, the importance of that part of my identity was relative to who I spoke with, and how we situated our relationship. My identity as a daughter, a sister, a mother of biracial children, and a woman who understood how to live on the land, was more important to the relationship or my "status" as a person. These common experiences were more central to the relationship and thus the quality of the research (Sword, 1999), than my identity as researcher.

Another example is deconstructing the conflicts in the notion of 'adequate sampling' when used in the context of emancipatory research. Maximum variation sampling and juxtaposition of sources were used to make sampling decisions in the study. The criteria often used to determine adequacy of the sample in qualitative research is saturation (Lincoln & Guba, 1985). Saturation assumes that there are a finite number of issues and that it is possible to explicate them. However, given issues such as front of stage/back of stage perspectives, trust in the researcher-participant relationships and the

costs of authentic engagement as a whole person, it seems naïve to assume that all issues will be uncovered. The following field note alludes to these tensions:

I have been thinking about saturated as being filled up, the opposite as being depleted or as being emptied out. I feel more emptied out, which suggests that methodologically I am doing something different than collecting a pile of conceptual information or codes. There is a much stronger emotive engagement and exchange. I feel a commitment to engage with people where they are at: to try to understand, appreciate and respect who they are and what their experience has been, how they have made sense of it, what resources and experiences they have used to come to be at a place where they feel stronger, they feel they can make choices for themselves and their children. To share such discussion, I have to be emotionally and spiritually present and engaged as a person/researcher. I have to be and/or feel very emotionally safe. That is a very different kind of work to engage with people in that way (Researcher field note, August 14, 2004).

The second problem is that the notion of saturation assumes that there are a finite number of variations across individual experiences, which is built on a positivist ontological standpoint (Mill et al., 2003). A more realistic assumption is that the research will produce a 'snapshot' of participants' experience: experience gained by many people, across many contexts, over a long period of time. To assume that the totality of the experience will be captured and that the meaning of the experiences is universal is incongruent with the emancipatory aims and critical realist position adopted in the study.

Facilitating community voice and concrete action. Putting relationships, and respect for participants' perspectives, experiences and values first, means that the interests, viewpoints and values of others are fitted (or not), into the communities' frameworks. This is the essential business of doing emancipatory research from a postcolonial standpoint. In this study efforts to facilitate participants' and communities' voices being heard in the interest of concrete action and change to broader social structures were realized in a number of ways. Examples of facilitating participants' voice

to be heard to support concrete change to care for pregnant and parenting Aboriginal people included:

- During planning and implementation of the study, I spent a lot of time and effort to challenge and resolve conventions of the academe to be congruent with Aboriginal views and values.
- During analysis I took the time required to stay immersed in and honor participants' stories and perspectives. For example, time was spent immersed in each of Aboriginal parents' stories of the intergenerational impact of residential schools, to honor the strength and courage of participants' who shared these personal and traumatic experiences, and also to follow through with their commitment to developing a wider understanding of the impact of this history. Verbatim quotes were used extensively in the manuscript submitted for publication in a special issue on Indigenous health, as well as in other reports of study results.
- Researcher recommendations resulted in an invitation and funding for a community health nurse from an Aboriginal partner organization to speak about their program approach at a national meeting of policy stakeholders to develop design, implementation and evaluation plan for the new FNIHB maternal child health program in March of 2005. An organizational leader was then invited to present development of the program to a subsequent meeting of national stakeholders in June of 2005.
- Results of a workshop with nurses working in First Nations communities that explored approaches to knowledge transfer were submitted for publication in the

journal recommended by workshop participants (Smith & Davies, under review) (See Appendix S).

- Researcher-Aboriginal organizational partners applied for and received a \$50, 000 research grant to investigate use of relational knowledge translation strategies to improve care for pregnant and parenting Aboriginal people based on study results.

These outcomes illustrate how the study resulted in concrete actions to improve care for pregnant and parenting Aboriginal people.

Contribution to Population Health Knowledge and Its Development

The contrasts between the language and orientation to care during pregnancy and parenting illustrate the disparate ‘worlds’ of stakeholders to care for Aboriginal people during pregnancy and parenting. The inequities between use of different kinds and sources of knowledge to develop interventions must be acknowledged and addressed (Lynam, 2005; Sonn, 2004). Aboriginal peoples’ worldviews, values and knowledge must be understood, acknowledged, and used as the framework within which other ways of knowing are integrated in the design, evaluation and governance of care. Rather than modifying western models to better fit Aboriginal people, use of Aboriginal peoples’ worldviews, values and knowledge as the organizing framework for interventions is needed to redress the power imbalances underlying inequities in health and social conditions experienced by Aboriginal people. The results provide a rationale and imperative to stimulate further dialogue and action. Results have formalized the rarely disseminated views of Aboriginal parents and community-based stakeholders such as lay providers, nurses and leaders of Aboriginal organizations, and captured these perspectives in a manner that honors the voice and experience of participants.

As well as *whose* knowledge is used to design population health intervention, results suggest *what* knowledge is important for intervention with pregnant and parenting Aboriginal people, and *how* it must be integrated into programs. Results challenge use of solely rationalist views of knowledge in health intervention design and highlight the importance of feelings or embodied knowledge (Jagger, 1989) to ‘smart decision making’ for clients, providers, and organizations. ‘Smart’ decisions are particular to individual people, organizations or communities. Using multiple ways of knowing, by integrating self-understanding of meaning, history, capacity, goals and priorities with other knowledge such as information about context and research evidence, is integral to making ‘smart’ decisions. This view of decision-making in health and health care highlights the critical role of embodied knowledge and building relationships in interventions to reduce inequities in health, and warrants further development in the field of population health.

Accounting for the Influence of Gendered Relations

The sample composition for this study was predominantly women. This may reflect a study limitation, or be an indicator of gendered relations and roles in the study context. “Gender refers to the culturally and socially determined differences between men and women, the relationships between them, and their roles in the community at large.” (Global Development Research Center [GDRC], 2005a). Despite a common view that gender inequality is a thing of the past, Canadian women continue to experience socially constructed inequities such as higher levels of poverty and lower wages, and more often being the target of domestic violence. These inequities are even more marked for Aboriginal women (Parliamentary Standing Committee on the Status of Women, 2005).

For these reasons, it is important to account for the influence of gender in both the sampling procedures as well as the results, and to suggest how gender inequities as a feature of colonial relations could be unmasked.

The influence of gender in the sampling procedures. The gender composition of the sample was predominantly women. This reflects the gender composition of the policy and health service leaders and provider stakeholder groups that work with pregnant and parenting Aboriginal people. Considerations for why these stakeholder populations may be predominantly female and suggestions for future gender analysis research are discussed in the next section, ‘accounting for the influence of gender in study results’.

The phase II sample of community members and leaders was also predominantly female but the community population was not. The study sought to obtain perspectives of community members who could articulate their experiences with the innovative model of care. Thus sampling began with the champions of the new model (from the provider and health service leaders), and networked out to people who had a variety of roles in the community and were familiar with the innovative approach to care. Thus community members, providers and leaders in Phase II were identified who had diverse experiences or roles, as well as responsibilities for care. In the community member group, participants were first identified who were either receiving care, or had received care through several pregnancies over the lifetime of the innovative program. Both fathers and mothers were identified and sought, though more women than men were identified. This may reflect that closer bonds and trusting relationships had been developed between care providers and pregnant community members because of the greater care needs of women during

pregnancy. Those women in trusting relationships with care providers may have been more willing to undergo a research interview).

Both male and female community members suggested through network sampling resulted in 'no shows'. These 'no shows' may have been due to the short time period available for data collection. However, they may also have reflected other gender-related issues. The interviewer was a woman and it was not possible to offer the alternative of having a male interviewer. Potential male participants may have been less likely to be available during the short time periods the researcher was in the community due to other obligations. However, the short time period for interviews was offered as a reason for non-participation by both men and women in the study communities. Lack of time curtailed overcoming practical barriers to involvement in the study (e.g. potential participants were working, away at preplanned events and vacations), and precluded development of familiarity and trusting relationships with the researcher. Future researchers must take into account the time requirements to develop familiarity and trusting relationships with the community.

Accounting for the influence of gender in the study results. Examining the influence of gender inequities was not a feature in the design and conduct of the study. Therefore, the influence of gender inequities on study results can only be presumed, suggesting an area for future research. The focus of the research questions did not direct sampling and data collection strategies that would develop a data set to support gender-based analysis of the issue. Explicit plans for gender analysis might have included for example, sampling procedures that sought diverse perspectives on the influence of gender. Interview questions or probes could have explored participants' views on how

their experience was shaped by gender relations. Document review could have explored the extent to which interest in pregnancy and parenting roles and occupations in society, such as in the nursing profession, are influenced by gendered notions of social roles. Gender analysis of the composition of community member stakeholder groups in the future studies may explore the extent to which gendered views of family roles and responsibilities related to parenting influence study results.

These and other considerations could form the impetus for future research, incorporating gender analysis within a postcolonial-feminist lens (See Anderson, 2002, 2004; Anderson et al., 2003). Gender analysis “examines the differences in women's and men's lives, including those which lead to social and economic inequity for women, and applies this understanding to policy development and service delivery” (GDRC, 2005b). “It is a tool for understanding social processes and for responding with informed and equitable options” (Status of Women Canada, 1998).

Gender analysis within emancipatory methodologies assumes: “all requisite knowledge for gender analysis exists among the people whose lives are the subject of the analysis; gender analysis does not require the technical expertise of those outside the community being analyzed, except as facilitators; and gender analysis cannot be transformative unless the analysis is done by the people being analyzed” (Parker, R. (1993) cited in GDRC, 2005b). In the context of this study, gender analysis was not included for a number of reasons. First, this was the first study with these community and organizational partners, and explicitly aimed to be de-colonizing in both its methods and outcomes. Therefore the views and analytical lenses used by participants to make sense of their pregnancy and parenting experiences were held in the foreground. As Anderson

(2004) states, “we need to speak of vulnerabilities as contextual, and as transcending population categories .. assumptions about people based on categories has the potential to disenfranchise and disconnect”(p. 245). I chose to try to understand the representation of their experience that participants used. This was an intentional position taken in recognition of the history of research with Aboriginal people, and disenfranchisement of Aboriginal knowledge and perspectives.

Second, gender analysis, in populations and contexts in which social relations have been fraught with violence and oppression needs to be explicit and upfront in negotiating the purpose and desired outcomes of the study. Future emancipatory research projects might include a research question exploring the different experiences of women and men related to pregnancy and parenting. Questions such as, ‘In what ways were these experiences influenced by your gender?’ (Status of Women Canada, 1998) could be added to the interview guideline, and followed through in participatory analyses. Examination of the interlocking systems of oppression on the basis of gender, race and class would contribute to an inclusive approach to examine the “*social relations of domination and oppression*”, and how they operate (Anderson, 2004).

Limitations of the Study

The study had several limitations many of which were described in the papers in Part II, and referred to in the section above. Overall, the time spent in the participating communities and organizations was limited by the financial resources available for the study, and the time and costs of travel to and from the study sites. More time during fieldwork would have enabled development of deeper relationships with the communities as well as individual participants. A prolonged period of fieldwork would have enabled

more frequent feedback loops with participants during analysis, and more iterative loops between interviews, analysis and subsequent interviews. Greater participant involvement in iterative loops between data analysis and data collection would have moved the analytic product further into the domain of participants' perspectives. As is, the results are a product of my view and interpretation of a snapshot of their stories and experiences through a postcolonial lens, from my standpoint as a population health researcher. Being explicit about the boundaries and depth of the study and naming the research accurately is essential to the integrity of the research results, and to the aims of emancipatory research.

Future Research

Figure 3.4 –*An Approach to Population Health Intervention Design* (See Page 197) provides an organizing framework for planning future research to improve population health interventions. Examples of research focused on improving intervention design, implementation and evaluation for Aboriginal and minority populations are outlined in Table 3.1. Future research based on the specific focus of this study could further develop a conceptual model or framework for design of interventions for pregnant and parenting Aboriginal people. For example, further qualitative work could explore with a greater number of Aboriginal organizations and communities; in both urban and rural settings; and between provincial jurisdictions; the underlying purpose and priorities in delivery of care (e.g. based on paper #1 and #2). As patterns are explicated across communities, organizations and settings, a survey instrument could be developed, validated and then administered with large numbers of communities and organizations to explore the extent that findings of this study are relevant across the diverse cultures, histories, and contexts in which Aboriginal live. As Grandbois (2005) advocates theories

linking illness, risk behavior and social pathology (such as interpersonal violence, addictions), with multigenerational historical trauma are needed to guide culturally relevant prevention and treatment.

Table 3.1: *Future Research Planned or Underway*

Project Focus	Study Population	Partner Organizations
Intervention Design		
- Further development of a conceptual model or framework for intervention design for pregnant and parenting Aboriginal people	-Aboriginal & Mainstream Health Service Delivery and Policy Stakeholders	-Friendship Centers -Tribal Councils -Regional and Provincial Health Authorities -FNIHB
-Relational Knowledge Translation Project –to build relationships between Aboriginal and mainstream stakeholders that will facilitate knowledge exchange	-Aboriginal Community Members	
Capacity for Implementing Safe and Responsive Care		
Develop and Test Interventions to Develop Provider Competencies for Safe and Responsive Care	-Nurses -Lay health providers -Interdisciplinary team members -Aboriginal community members	-Friendship Centers -Tribal Councils -New Zealand Council of Nurses -New Zealand health organization and research partners
Identify and Measure Factors Influencing Organizational Capacity to Support Safe and Responsive Provider Practices	-Health service delivery organizations	-Canadian Nurses Association - Canadian Health Service Delivery and Policy Organizations

A second example of research examining factors influencing intervention design for pregnant and parenting Aboriginal people is the relational knowledge translation project outlined in Table 3.1. This project focuses on the differences between values, and explanations for the inequitable health and social conditions experienced by Aboriginal people, held by Aboriginal organizations and mainstream health decision- makers. The

project will identify and test knowledge exchange strategies that build relationships needed to develop mutual understanding and exchange of knowledge to inform coherent intervention designs. Both Aboriginal organizations involved in the thesis research are partners in the relational knowledge translation project.

Particularly germane to capacity for implementation of population health intervention is the issue of provider competencies for safe and responsive care. Intervention research is needed that will a) develop the interventions; b) pilot test them in a range of different settings and with different provider groups (e.g. nurses, lay health workers); and then c) systematically test such things as improvements in competencies, impact on clients' feelings of safety and satisfaction with care, level of participation in care, and outcomes of care. Research to identify and measure factors influencing organizational capacity to support safe and responsive practice is also needed, and could involve greater numbers of Aboriginal and non-Aboriginal stakeholders and health service delivery organizations. Further research could examine in greater depth the similarities and differences in Aboriginal organizations' experiences and capacity to support safe and responsive care for pregnant and parenting Aboriginal people across the range of governance models used in the 10 Canadian provinces.

Conclusion

This dissertation contributed new knowledge to the population health issue of care during pregnancy and parenting for Aboriginal people. Emancipatory research methodology, a postcolonial standpoint, and qualitative methods were used in a two-phase case study design to explore and juxtapose the perspectives of stakeholders to this issue. In particular, the study sought to describe perspectives from Aboriginal parents and

community-based providers and organizations reputed to have developed an innovative approach to care for pregnant and parenting Aboriginal people.

The results explained the importance of pregnancy and parenting to Aboriginal people. Results suggested that explicit recognition and use of community-based stakeholders' views and values related to health care programs' design and evaluation and governance; greater stakeholder involvement in health system change; and participatory governance models are needed to support Aboriginal organizations' efforts to improve care for pregnant and parenting Aboriginal people. Implications for population health intervention and knowledge development were generated, limitations were summarized, and plans for future research were outlined.

Part IV:

STATEMENT OF CONTRIBUTIONS

This section of the dissertation provides a statement of the contributions of collaborators. It was written in accordance with the guidelines of the Faculty of Graduate and Postdoctoral Studies at the University of Ottawa. Contributions of supervisory committee members in the development and implementation of the study and preparation of manuscripts and the final dissertation document, as well as community participants and paid staff are described.

The PhD candidate, Dawn Smith, designed, implemented and led all aspects of the study as part of the fulfillment of the requirements of the degree Doctorate in Philosophy at the University of Ottawa. The PhD candidate made all submissions for ethical review, recruited individual participants and Aboriginal organizations, developed all study materials, collected and analyzed all data, and wrote all documents and manuscripts included in this dissertation.

Dissertation supervisory committee members included Drs. Nancy Edwards as supervisor; and Colleen Varcoe, Barbara Davies and Patricia Martens as committee members. Supervisory committee members provided feedback on early drafts of the study conceptualization and design, and guidance on timelines and requirements for developing research partnerships with Aboriginal communities and organizations. They provided support and consultation during study implementation, data analysis and interpretation, and contributed to the development of the manuscripts reporting study results. Co-authors for manuscripts were identified based on the authorship guidelines of the Ottawa Health Research Institute (2003). Co-authors contributed to interpretation of data through dialogue during committee meetings or one to one discussions; critically reviewed manuscripts; and approved final version of the manuscripts submitted for

publication. Order of co-authorship was designated according to the relative contribution of those participating.

Two people were hired to transcribe audiocassettes of the interviews. Staff was hired to take notes, record and transcribe proceedings of the three workshops in April for discussion of preliminary results. An editor was paid to review the manuscript and check for internal consistency and lay out of the document.

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APPENDICES

Appendix A: Selected Perinatal Health Risk Factors and Indicators

Indicator	Aboriginal People ^a	Canadian Population ^b
Demographics		
% population under 15 years	38	21
% children living in single parent homes	32	13
% children with mothers < 18 years	9	1
% low birth weight	5.4 ^c	5.7
Infant, Child and Youth Health Status		
% children born with FAS/FAE	10% ^d	.033 %
% children up to 2 years ever being breastfed	54	75
% children under 2 breastfed for >6 months	39	24
Children being taken into foster care	4X ^c	1
% parents rating child health as poor/fair	16	2
Infant mortality ^f from injuries/100, 000	63	17
Preschool mortality from injuries/100, 000	83	15
Teenage mortality from injury/100, 000	176	48
Youth Suicide Rates (1991)	37/100,000 ^g	approx 7/100,000
Key/Related Determinants of Health		
% population with adequate housing	54 (on reserve) ^h	80 ⁱ
% never completing high school	64 ^j	31
% below LICO	44 (off reserve) ^k	20
Average annual employment income (\$)	14, 055 (on reserve) ^l	26,474
% population >15 years unemployed (1991)	31 (on reserve) ^m	10
% children 0-6 living in low income families	60 ⁿ	25

^a Assembly of FN (1999) unless otherwise indicated

^b F/T/P Advisory Committee on Population Health (F/T/P ACPH) (1999) unless otherwise indicated

^cStandards used to measure and rate LBW developed using non-naïve populations. "There is some evidence to suggest that FN and Inuit infants may have growth patterns that differ from the majority culture. ...if Aboriginal's have a higher weight for height growth pattern, then a weight of 2500 grams may be set too low for the FN population in capturing infants at increased risk of health problems" (MacMillan et al., 1999).

^d from study of FN reserves in Manitoba (MacKenzie, 1997), cited in Department of Indian Affairs and Northern Development (DIAND) (1999)

^e Assembly of FN (1994)

^f Morbidity rates for injuries were calculated on different time scales in the two studies, and were therefore not comparable.

^g MacMillan et al (1995)

^h DIAND (1999)

ⁱCanadians paying rent living in inadequate housing, cited in F/P/T ACPH (1999). Rates for total nonAboriginal population would be lower when including population living in owned housing.

^j Frideres and Reeves (1993), cited in Dion-Sout and Kipling (1999)

^k Budgell (2001)

^l Statistics Canada-1996 Census: Aboriginal data, cited in Budgell (2001)

^m MacMillan et al (1995)

ⁿ Statistics Canada-1996 Census: Sources of Income, cited in Budgell (2001)

Appendix B: Maternal Child Health Care Search Strategy**Databases** (* Those marked with an asterisk were hand searched)

Cochrane Database of Systematic Reviews*

Evidence Based Medicine*

Database of Reviews of Effectiveness*

Cochrane Clinical Trials Register*

Health Technology Assessment Database of the National Health System in the United Kingdom*

Effective Public Health Practice Project Database of Systematic Reviews*

Medline

EMBASE

Cumulative Index of Nursing and Allied Health Literature (CINAHL)

Sociofile

Keywords

Maternity care.tw

Reproductive health care.tw

Family centered.tw

Maternal child health care.tw

Prenatal care.tw

Postnatal care.tw

Health services, Indigenous

Community health services

Midwifery

Practice guidelines

Aboriginal.tw

Indigenous.tw

Eskimos.tw

Native American

Aborigines

FN.tw

Métis.tw

Inuit.tw

Appendix C: Cultural Safety Search Strategy

Databases

Medline -1996-2002

EMBASE

Cumulative Index of Nursing and Allied Health Literature (CINAHL)

Sociofile

PsychInfo

Keywords

Culturally appropriate services

Cultural competence.tw

Transcultural nursing

Intercultural.tw

Cross cultural health care

Culture care diversity

Cultural materials

Transcultural communication

Cultural awareness

Cultural safety.tw

Cultural security.tw

Cultural sensitivity.tw

Grey Literature

Authors of studies cited in the published literature were contacted and asked to identify any additional sources of research or review evidence related to cultural safety. A PhD dissertation, proceedings of a workshop on cultural safety (CASN, 2003), and beginning discourse on nursing association websites were accessed (e.g. International Council of Nurses; New Zealand Council of Nurses).

Appendix D: Summary Table of Included Literature

	Author	Date	Population	Method	Purpose
1.	Health Canada	2000	general	Policy	Develop and describe national guidelines for family-centered maternity and newborn care
2.	Blythe	1995	Aboriginal	Narrative Review	Identify best practice principles for intervention programs for 0-6 year olds in Aboriginal communities
3.	Brunton & Thomas	2001	general	Systematic review	Effectiveness of public health strategies to reduce or prevent the incidence of low birth weight in infants born to adolescents
4.	Ciliska, Mastrili, Ploeg et al.	1999	general	Systematic review	Assess the evidence for effectiveness of public health nursing interventions when carried out by the strategy of home visiting with clients in the pre and post natal period
5.	Clement, Sikorski, Wilson, Das & Smeeton	1996	general	Systematic review	assess predictors (demographic, obstetric, maternity care, attitudinal variables) of women's satisfaction with traditional and reduced prenatal visit schedules
6.	Dicensio, Guyatt and Wilan	1999	Adolescent-general population	Systematic review	Assess effectiveness of interventions to decrease incidence of low birth weight in pregnant adolescents
7.	Edwards, Sims-Jones & Hotz	1996	general	Comprehensive review	Review effectiveness of interventions to reduce exposure to tobacco (environmental tobacco smoke and maternal smoking) during pre and post natal period
8.	Elkan, Kendrick, Hewitt et al.	2000	general	Systematic review	Review the effectiveness and cost-effectiveness of domiciliary (home) health visiting
9.	Green, Renfrew & Curtis	2000	General (British)	Structured review	Define continuity of care and identify aspects of continuity that matter to women.
10.	Howell et al.	1999	General	Narrative review	Identify what is known about the prevalence of substance abuse in pregnancy, factors that lead to substance abuse and that facilitate or impede treatment success, and the components of

	Author	Date	Population	Method	Purpose
					successful treatment programs.
11.	Mangham	2001	general	Narrative review	Integrated findings from review of the literature and input from front-line service providers to identify guidelines for best practices in promotion, prevention and early support for children and families.
12.	Mueller & Thomas	2001	general	Systematic review	The Effectiveness of Public Health Interventions to Reduce or Prevent Spousal Abuse Toward Women
13.	Rowe et al.	2002	General population	Systematic review	To review trials of effectiveness of interventions aimed at improving communication between health professionals and women in maternity care
14.	Sikorski et al.	2002	general	Systematic review	Assess the effects of breastfeeding support
15.	Villar et al.	2002	general	Systematic review	Patterns of routine antenatal care for low-risk pregnancy
16.	Waldenstrom et al.	1998	General population	Systematic review	To review randomized controlled trials of alternative maternity services characterized by continuity of midwifery care
17.	Wilcock et al.	1997	General population in North America	Comprehensive review	Define and identify factors influencing patient satisfaction with obstetric care
18.	DeCosta & Child	1996	Australian Aboriginal	Retrospective quantitative descriptive study	Compared women's access to antenatal care and pregnancy outcomes
19.	Blais et al. Collin et al. DeKonick et al. Fraser et al. Klein Reinharz et al.	2001 2001 2001 2001 2001 2001	General population in urban and rural Quebec, Canada	Mixed evaluative design	Compare process and outcome indicators of midwives services to physician services 2) identify professional and organizational factors associated with integration of midwives into the health care system 3) compare women's perceptions and outcomes of midwifery versus physician led care in Quebec; and 4) compare cost-effectiveness of services
20.	Dawson et al.	2000	General population in Victoria, Australia	Descriptive Survey	Map the provision of shared obstetric care and describe views of providers about the ways in which current practice could be improved

	Author	Date	Population	Method	Purpose
21.	Glei & Goldman Goldman & Glei	2000 2003	Indigenous and ladino populations in rural Guatemala	Retrospective regression analysis of predictors	Examine the extent to which women combine traditional and biomedical pregnancy care, the frequency with which midwives refer to biomedical providers, the content and quality of care offered by midwives, and the effects of midwife training programs on referral practices and quality of care.
22.	Hiebert	2001	FN women in remote Manitoba, Canada	Quantitative	Identify maternal predictors of participation in prenatal care and factors related to early initiation of prenatal care
23.	Lapham	1997	Urban population of American Indians in southwest US	Quantitative descriptive study	Determine the prevalence of risk factors for adverse pregnancy outcomes among American Indians and compare self-reported information collected under two computer interview conditions: "anonymous" and "confidential".
24.	Makerras	2001	Indigenous Australian population in Northern Territory	Mixed method case study/program evaluation	Determine the extent to which the Strong Women StrongBabies Strong Culture program increased infant birth weights, increased early initiation of prenatal care, and improved maternal weight status.
25.	Marchant et al.	2001	General population in UK	Descriptive survey of maternity care organizations	To explore current policies and practices in maternity units that aim to identify, assess and support women experiencing domestic violence
26.	Martens Martens & Young Martens Martens Martens Martens	1994 1997 1997 2000 2001 2002	FN community in Manitoba, Canada	Longitudinal multi-method program of research	Test a breastfeeding decision-making model and evaluate effectiveness of community-based pre and post-natal interventions to increase intention to breastfeed, and initiation and duration of breastfeeding
27.	McFall et al.	2001	Cherokee Nation patients	Descriptive survey	Assess the relationship between receipt of preventive services and satisfaction in 5 clinics operated by the Cherokee Nation.

	Author	Date	Population	Method	Purpose
28.	Bradley & Martin	1994	Low income in urban US	Retrospective descriptive study	Evaluate the impact of home visiting by public health nurses on enrollment in pregnancy-related services
29.	Olds Kitzman, Olds et al.	2003 2000	Low income mothers in urban and rural US	Longitudinal experimental program of research	Evaluate effectiveness of prenatal and infancy home visiting interventions by public health nurses to improve the early health and development of low-income mothers and children and their future life trajectories
30.	Penney & Pearson	2000	Consultant led maternity units in UK	Criterion based Audit of organizations	Assess organizational uptake and use of clinical guidelines on the management of diabetes in pregnancy
31.	Tay & Emmanuel	2003	Low income populations in Singapore	Survey of organizations	Determine reasons for poor uptake of HIV screening by pregnant women and to propose recommendations for improving uptake of HIV screening.
32.	Waldenstrom & Nillson	1997	Low risk women from the general population in urban area of Sweden		Evaluate the effect of birth center care versus standard care during pregnancy, birth and postpartum
33.	Wiist & McFarlane	1999	Latina population in a US city	Quasi-experimental	Evaluate change in detection rates after introduction of an abuse assessment protocol administered by public health staff during prenatal clinics
34.	Young et al.	2002	FN childhood diabetics in Manitoba, Canada	Case Control study using multiple regression modelling	Identify explanatory factors to which children with diabetes may have been exposed in the intrauterine environment and during early infancy
35.	Mayberry et al. Affonso et al. Affonso et al. Affonso et al. Affonso et al.	1999a 1999b 1996 1995 1992	Indigenous Hawaii, US	Qualitative	Assessment, design, implementation and evaluation of a multiple intervention program that involved local women as partners with public health nurses, and promoted respect for and integration of cultural/ethnic ways of knowing and healing into culturally based, interactive prenatal care.
36.	Benoit et al.	2003	Aboriginal population in	Qualitative case study	Give voice to Aboriginal women by asking them whether

	Author	Date	Population	Method	Purpose
			urban Canada		the appropriate professional services and educational programs they need to address their health care needs were being provided in the inner city.
37.	Baldwin and Stevenson	2001	Native American women in remote Alaska	Program evaluation	Describe program characteristics and outcomes of a culturally sensitive prenatal care program
38.	Buchareski et al.	1999	Aboriginal women in Edmonton Alberta, Canada	Program design and evaluation	Describe development and evaluation of a community development approach to providing culturally appropriate prenatal care for Aboriginal women
39.	Calm-Wind & Terry	1991	FN women in Nishnawbe-Aski Nation, Canada	Qualitative	Interview traditional midwives to describe their practices and define terms for an exemption of traditional Aboriginal midwives to the Health Professions Act in Ontario
40.	Chamberlain et al	1997 2001	Inuit women in remote Northern Canada	Program evaluation	Identify the safety, cost-effectiveness and patient satisfaction of a midwifery operated birthing center for Inuit women in the Canadian north
41.	Falk-Raphael	2001	General population in urban and rural southwestern Ontario, Canada	Exploratory qualitative	Describe the practical meaning of empowerment to public health nurses and their clients
42.	Fisher & Ball	2002	American Indian and Alaska Native Population in urban US	Participatory research	Describe application of the Tribal Participatory Research model to the development, implementation and evaluation of Indian Family Wellness Project, a family-centered prevention intervention for preschoolers
43.	Long & Curry	1998	Native American women in US	Qualitative	Examine the relationship between traditional beliefs and practices and use of prenatal care
44.	Nel & Pashen	2003	Indigenous Australian in remote settings	Descriptive Case Study	Describe health risks, interventions and outcomes of a culturally appropriate antenatal program adopting a primary health care approach including

	Author	Date	Population	Method	Purpose
					community controlled health services, & outreach maternal health clinics.
45.	Sokoloski	1995	urban dwelling FN women	Qualitative	Examine beliefs about pregnancy and participation
46.	Sword	2003 2000 1999	Low income women in suburban Ontario, Canada	Qualitative	Explore influences on use of prenatal care by low income women using a theoretically based socio-ecological explanatory model
47.	Watson et al.	2002 2002	Indigenous Australian Women living in rural and remote settings	Qualitative	Explore issues of concern for Indigenous women from the Northern Territory around their child birthing experiences in an acute care setting.
Cultural Safety					
48.	Anderson	2002	Vietnamese immigrants in Canadian city	Qualitative	Cultural safety
49.	Browne	2003	FN women in rural BC	Qualitative	Cultural safety
50.	Browne	2002	FN women in rural BC	Qualitative	Cultural safety
51.	Jeffs	2001	In New Zealand		Cultural safety
52.	Spence	2001			Cultural safety
Other					
53.	-- deleted ---				
54.	Archibald and Bird	2001	Aboriginal - Canada	Discussion Paper Narrative Review	Review of best practices or innovative approaches to health services design and delivery in First Nations and Inuit communities
55.	Dion-Stout & Kipling	1999	Aboriginal	Description of Roundtable	National Aboriginal roundtable on sexual and reproductive health was convened to identify problems and propose solutions of concern to Aboriginal people in Canada in preparation for the UN conference on population and development in 1999 (Cairo +5)
56.	Potvin et al. Cargo et al. Macaulay et al.	2003 2003 1998	Aboriginal – Kahnawake, QC	Evaluation of participatory governance model/Program	Reports the findings of an evaluation of influences on shared decision-making in a participatory /community

	Author	Date	Population	Method	Purpose
	Montour et al. McComber et al.	1998 1998 1997 1991 1988 1989		of research	governed diabetes prevention project.
57.	Bartlett	1995	Aboriginal- Winnipeg, Canada	Model description	Description of Aboriginal designed model for health promotion with individuals and communities, and comparison with primary health care
58.	Poole	2001	Aboriginal and non Aboriginal Vancouver, BC	Program Evaluation	Program evaluation of a unique outreach project in downtown eastside of Vancouver reports program successes in engaging women in accessing pre- and postnatal care, in making improvements in their housing and nutritional status, and in retaining custody of their children, and makes recommendations for supporting women to reduce substance use during pregnancy and to support the growth, assessment and health of their children.

Appendix E: Culturally Related Concepts

Concept and Definition	Underlying Definition/View of Culture
Cultural Competence means developing an awareness of one's own existence, sensations, thoughts and environment without letting it have undue influence on those from other backgrounds; demonstrating knowledge and understanding of the client's culture; accepting and respecting cultural differences; and adapting care to be congruent to a client's culture. Cultural competence is a conscious process and not necessarily linear." (Purnell and Paulanka, 1998, p. 2). Evolved from or built upon related concepts such as culturally appropriate and culturally sensitive.	A "totality of socially transmitted behavior patterns, arts, beliefs, values, customs, lifeways, and all other products of human work and thought characteristics of a population of people that guide their worldview and decision-making" (Purnell & Paulanka, 1998, P. 2)
Transcultural nursing is "an essential area of study and practice focused on the cultural care beliefs, values, and lifeways of people to help them maintain and/or regain their health, or to face death in meaningful ways; focusses on understanding cultures and their specific care needs and how to provide care that fits their lifeways rather than assuming professional nurses always know what is best for them; (Leininger, 2003, p. 1)	Culture is "patterns of learned behaviors and values which are shared among members of a designated group and are usually transmitted to others of their group through time" (Leininger, 1985, p. 60).
Cultural security is a concept that has recently been coined by Aboriginal scholars in Australia and has been defined as "an ethical commitment that the construct and provision of services offered by the health system will not compromise the legitimate cultural rights, views, values and expectations of Aboriginal people. It is a recognition" (Houston, 2002, p.8).	"Aboriginal people have seen culture as including many facets. It is an inherited strength and obligation, it has a spiritual dimension, it is law and history and tradition, a way for aboriginal people to live together and a framework for interaction with the nonAboriginal world and it is song and dance and other objects of Aboriginal people (Houston, 2002, p. 6).
Cultural safety actions which recognize, respect and nurture the unique cultural identity of [Aboriginal Peoples], and safely meet their needs, expectations and rights" (Woods & Schwass, 1993, p. 5 &6) as perceived or evaluated by intended users; akin to an ethical standard.	A person's culture is as they would define it, as it is situated in the complex network of experience, and related meanings enmeshed within historical, social, economic and political processes (Kirkham & Anderson, 2002).

Appendix F: Definitions for Principles of Prenatal Care

Principle	Description	Supporting Evidence ^a
Multi-dimensional	Ecological programs that use a whole person model of health, and a comprehensive range and combination of strategies. <u>Ecological</u>- multiple levels of intervention, (e.g. individual, family, community, public policy); multiple channels (e.g. 1:1 interaction; support or education groups; social marketing, political action) <u>Whole person</u> model of health (physical, emotional, mental, spiritual....) <u>Comprehensive</u>- a way of designing a combination of levels, channels, and subsystem targets to achieve desired outcomes.	1, 2, 3 4,6, 7 24,26,29 35,36,39 42,43 44,46,47 54,55, 57
Culturally Safe	Actions which recognize, respect and nurture the unique cultural identity of [Aboriginal people], and safely meet their needs, expectations and rights^b; as perceived or evaluated by intended users; akin to an ethical standard; includes provider knowledge, attitudes and behaviors as well as the dynamics of the health care system, and broader socio-political environment; includes culturally relevant model of care being implemented by culturally competent providers, in a critically reflexive, respectful and supportive manner;	36, 43, 48, 49, 50, 51,52,
Trusting Relationship	A consistent, sustained, emotionally safe 1:1 relationship between a pregnant woman and a care provider; most often developed through interactions in the persons home as well as other community spaces; characterized by mutual positive regard, respect and consistent presence over time, events/experiences, and stages of pregnancy; based on culturally safe, holistic and client centered programs and providers.	1,4,5,9 12,13,16, 17,19,21,29, 32,35, 41, 46, 47, 55
Community involved/ Driven	Community members and leaders assume a variety of roles in programs, through the entire 'program lifecycle' - from pre-planning through community assessment, design, implementation, evaluation and program renewal and maintenance. Roles are various from governance, administration, advisory, to program delivery as paid (e.g. professional and lay home visitors) and unpaid positions (e.g. peer support).	26,35,38,42, 44,54,55, 56, 57
Continuity/ Integration	Communication, co-ordination and collaboration between programs, and levels of services (e.g. community, regional or provincial levels) to increase responsiveness and reach of all programs. Also includes integration between traditional and western models of prenatal care to enhance relevance, and cultural safety and appropriateness of services.	1, 9,16, 21,22, 24,28, 35,38, 43

^a Studies are numbered in Appendix D

^b Woods & Schwass, 1993, p.5&6

Appendix G: FNIHB –Pacific Region Letter of Support

First Nations & Inuit Health Branch
Pacific Region
#540 – 757 West Hastings Street
Vancouver, BC V6C 3E6

December 10th, 2003

RE : Dawn Smith RN MN
Population Health PhD Candidate
University of Ottawa

Research Proposal ***Evidence-Based Prenatal Care in First Nations Communities
A Pilot Project to Develop First Nations Partnerships and Methods***

I would like to offer my support and that of the community health nursing staff in British Columbia First Nations communities for Dawn's research project. I believe the process and results will provide for both communities and nursing personnel with a greater appreciation of research and prenatal care issues.

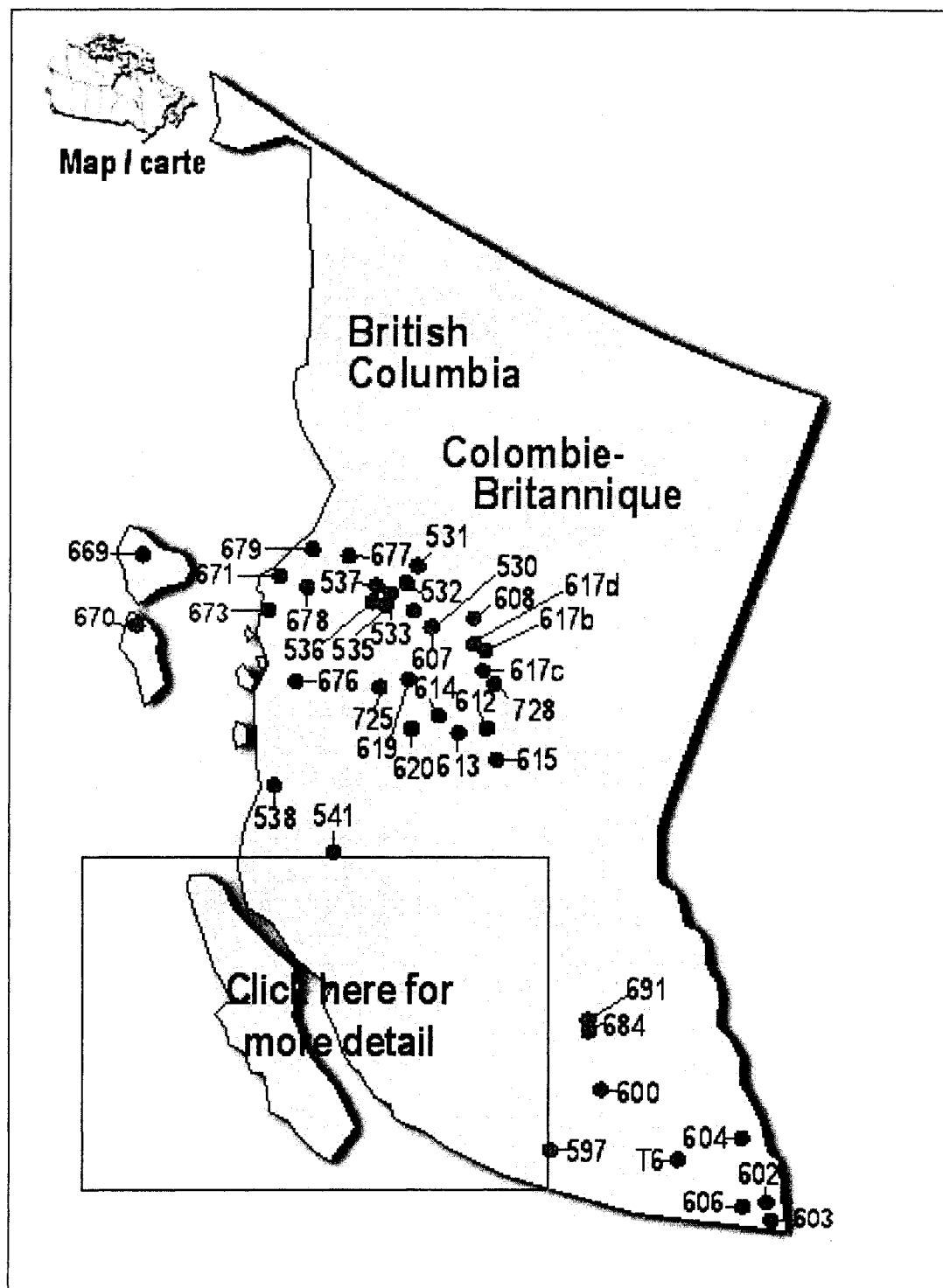
First Nations community members require appropriate community based research that includes their participation. Currently First Nations community research has been based on a medical model with very little in the emphasises placed on prevention or promotion.

Community health nurses in First Nations communities need the opportunity to take part in research that focuses on their specific populations and client needs. The need for an evidence based nursing practice is critical for the First Nations client populations.

Sincerely

Charlotte Thompson RN MSN MA (can)
Regional Nursing Consultant

Appendix H: Geographical Locations of First Nations Communities in BC





Université d'Ottawa • University of Ottawa

Cabinet du vice-recteur
à la recherche

Office of the Vice-Rector,
Research

HEALTH SCIENCES AND SCIENCE RESEARCH ETHICS BOARD

CERTIFICATE OF ETHICAL APPROVAL

This is to certify that the University of Ottawa Health Sciences and Science Research Ethics Board has examined the application for ethical approval for PHASE 1 of the research project entitled **Learning from Success: First Nations Communities' Approaches to Prenatal Care (file H 01-04-04)** submitted by Dawn Smith, of the Faculty of Graduate and Postdoctoral Studies, who is supervised by Nancy Edwards, of the School of Nursing, Faculty of Health Sciences. The Board found that this research project met appropriate ethical standards as outlined in the Tri-Council Policy Statement and in the Procedures of the University of Ottawa Research Ethics Boards, and accordingly gave it a Category 1a (approval). This certification is valid for one year from the date indicated below.

Rita D'Alessandro
Protocol Officer for Ethics in Research
For Dr. Hugh French, Chair of the Health
Sciences and Science REB

January 28, 2004
Date

550, rue Cumberland
Ottawa (Ontario) K1N 6N5 Canada

550 Cumberland Street
Ottawa, Ontario K1N 6N5 Canada

(613) 562-5270 • Téléc./Fax (613) 562-5271

Appendix J: Letter of Introduction to Phase I



Université d'Ottawa • University of Ottawa

Faculté des sciences de la santé
École des sciences infirmières

Faculty of Health Sciences
School of Nursing

(Date)

Key Informant Name, Position

Organization Name

Address

Dear Sir or Madam:

I am a nurse and a doctoral student at the University of Ottawa and am conducting a research study called "*Learning From Success: FN Communities' Approaches to Prenatal Care*". I am contacting you to explore your interest in participating in a telephone interview to share your experiences and thoughts relevant to this study. Below I have described who I am, what the study is about, what your participation would entail, and potential harms and benefits that may arise during the study.

Who is doing the Research?

I am the Principal Investigator of this research study, which is part of the requirements for a doctoral degree in Population Health at the University of Ottawa. My supervisor is Dr. Nancy Edwards, Professor with the School of Nursing and Department of Epidemiology and Community Medicine, University of Ottawa. I have chosen to do my research with communities on Vancouver Island because that is where I have lived and worked with communities as a nurse and nurse educator for several years.

What the Study is About

As you may be aware, the prenatal period is an important time for fetal growth and development. I am interested in learning about approaches to prenatal care that FN communities have designed, implemented and evaluated. I am also interested in understanding how contextual factors have influenced FN communities' efforts to design, implement, evaluate and maintain prenatal care programs. Results of this study may be of interest to other FN communities that are developing prenatal care programs that fit with their unique culture, strengths, and contexts.

Expectations of Participating in the Study

If you agree to participate, I will talk with you on the telephone for about 20 minutes regarding your views regarding prenatal care in FN communities. With your permission, I will tape record our conversation. I will ask for your assistance to identify FN communities that may be interested in participating in a qualitative case study describing their experiences with prenatal care. I will ask you to identify documents describing factors influencing design, implementation, evaluation and maintenance of prenatal care programs by FN communities. I will ask you to verify that I have understood and

represented your views correctly during analysis and write up of the study which will require another 10 minutes of your time at a later date.

Your Rights Related to Participation in the Study

There are no direct benefits to you or your organization for participating in this interview. However, the information provided by you and other key informants will be used to identify important contextual influences on FN communities efforts to design, implement, evaluate and sustain prenatal care programs, and suggest communities that may be interested in participating in this study.

There is no obligation to participate in this study. You may choose to withdraw at any time, or choose not to answer any questions. Participation will require a total of about 30 minutes of your time, but will not affect your work in any other way. You may choose to NOT have our conversation tape-recorded, in which case I would take detailed notes of our conversation.

Your name will not be recorded with any of the information that is collected in this interview. A code will be assigned to all information provided so that it cannot be linked to you. Personal and organizational identifiers will be removed to protect your identity. Community names and identifying information will be removed and/or pseudonyms used in reports of the study. People from your or other organizations will NOT have access to any of the information you provide.

Any tape-recording of conversations will be destroyed within 2 years. Written transcripts or notes of our conversation will be kept in a locked cabinet in the research offices of Dr. Nancy Edwards at the University of Ottawa for a period of 7 years. The only people who will have access to information obtained in these interviews will be members of my thesis supervisory committee.

For Further Information

If you have questions or suggestions regarding this research study, please contact me at (613) 562-5800 extension (to be determined) or email dawnsmith@ca.inter.net , or contact my supervisor, Dr. Nancy Edwards at (613) 562-5800 extension 8395 or email nedwards@uottawa.ca . If you have questions about the rights of research participations, you may contact the protocol officer for Ethics in Research, Office of the Vice-Rector, University of Ottawa at (613) 562-5841 or email: ethics@uottawa.ca .

Thank you for considering this request. Please contact me by telephone or email in the next week or so to explore further your interest in participating in this study.

Sincerely,

Dawn Smith, RN, MN, Population Health PhD candidate, University of Ottawa
Tel: (613) 562-5800 (extension to be determined)
Email: dawnsmith@ca.inter.net

Appendix K: Text of Informed Consent for Phase I Interviews

Hello, my name is Dawn Smith. I am a nurse and a doctoral student at the University of Ottawa on a project called "*Learning From Success: FN Communities' Approaches to Prenatal Care*"

I am the Principal Investigator on this project, which is part of the requirements for a doctoral degree in Population Health at the University of Ottawa. My supervisor is Dr. Nancy Edwards, Professor with the School of Nursing, University of Ottawa.

Background to the Study

As you may be aware, the prenatal period is an important time during fetal growth and development. I am interested in learning about prenatal care programs in on reserve FN communities. I think describing FN communities' experience designing, implementing and sustaining a local approach to prenatal care may help other FN communities to develop prenatal care programs that fit with their unique culture and contexts.

So, to start with I want to discuss what YOU and other key informants know about prenatal care in FN communities in BC, and what you see as important influences on design, implementation and evaluation of locally tailored prenatal care programs. I would also like to identify communities that may be interested in participating in a qualitative research study of their experience designing, implementing and evaluating prenatal care.

I am inviting you to share your experiences and ideas by participating in this telephone interview. *There are no right or wrong answers, and it is important that I gather as many differing perspectives as possible.* The interview will take approximately 20 minutes. During the interview, I will ask you to talk about: a) your views of prenatal care on reserves in BC; b) factors that may have influenced prenatal care; c) communities you feel may be willing to participate in a case study; and d) other people (key informants) I could talk with about this topic. At a later date, I will contact you by email or telephone to ask you to verify that I have understood you correctly, which will require about 10 minute of your time.

There are no direct benefits to your or your organization in completing this interview. However, the information provided by you and other key informants will be used to identify factors influencing on-reserve FN communities efforts to design, implement, evaluate and sustain prenatal care programs, and identify communities who may be interested in participating in this study.

There is a small chance that during our conversation emotions may surface related to changes that have occurred in the delivery of prenatal care programs. You are under no obligation to participate in this interview and, if you choose to participate, you may stop your participation at any time or refuse to answer any questions. There are no consequences to you NOT for participating in this project.

All information collected during this interview will be kept confidential and will not be communicated to anyone outside of the research team. All information will be kept in a locked cabinet in the research offices of Dr. Nancy Edwards at the University of Ottawa for a period of 7 years. The only people who will have access to information obtained in these interviews will be members of my thesis supervisory committee.

Your name will not be recorded with any of the information that is collected in this interview. A code will be assigned to all information provided so that it cannot be linked to you. Personal and organizational identifiers will be removed to protect your identity. Community names and identifying information will be removed and/or pseudonyms used in reports of the study.

If you have any questions about this study, I can be reached at telephone number (613) 562-5800 extension (to be determined) or email dawnsmith@ca.inter.net. Alternatively you may contact my supervisor Dr. Nancy Edwards at the University of Ottawa. Tel: 613-562-5800 ext 8395, e-mail: nedwards@uottawa.ca. If you have any ethical concerns, you may contact the Protocol Officer for Ethics in Research, Office of the Vice-Rector (Research) TEL: 613-562-5841, e-mail: ethics@uottawa.ca.

Thank You !

Appendix L: Key Informant Interview Guide

1. What do you see as the most **common health promotion and prevention issues** women and families experience during pregnancy in on-reserve FN communities?

.....

.....

.....

.....

2. Please describe what has been done to **enhance prenatal care** in on-reserve FN communities in BC over the last 5-10 years (i.e. What was done and why? What was the outcome of the effort? Who was involved?)

.....

.....

.....

.....

3. What are the most important factors influencing prenatal care program design, implementation and evaluation on-reserves in BC? (Probe for any unique factors on Vancouver Island)
 - a.)What do you feel have been **supports or enablers** for improving prenatal care on reserves in BC over the past 5-10 years?

.....

.....

.....

.....

- b) What do you feel have been **challenges or barriers** to improving prenatal care on reserves in BC over the past 5-10 years?

.....

.....

.....

.....

4. I am planning a qualitative case study of prenatal care in on reserve FN communities. Please **suggest communities** that a) have designed, implemented and evaluated their own approach(es) to prenatal care; b) are on Vancouver or adjacent islands; c) have more than 10 births/year; and d) may be willing to participate in this study.

.....

.....

.....

.....

5. I would like to talk with other people in BC who may have insight into design, implementation and evaluation of prenatal care on reserve. Please suggest **other key informants** who may be willing to speak with me, and have experiences and perspectives that will help develop a comprehensive understanding of prenatal care in BC FN communities.

a)

b)

c)

Thank You !

Appendix M: Pamphlet of Introduction

WHO IS DOING THE RESEARCH?

The Nurse-Researcher:

Dawn Smith, RN, MN

PhD candidate

Her Supervisor

Nancy Edwards, RN, PhD

SCHOOL OF NURSING, AND
DEPARTMENT OF EPIDEMIOLOGY AND
COMMUNITY HEALTH, UNIVERSITY OF
OTTAWA

Any Questions?

About the Project, contact:

Dawn Smith, Nurse Researcher

Phone: (250) 732-4327

Email: dawnsmith@ca.inter.net

Or

Dr. Nancy Edwards,

Dawn's Supervisor

Phone: (613) 562-5800 x. 8395

Email: nedwards@uottawa.ca

About the Rights of Research Participants, contact:

Protocol Officer for Ethics in
Research, Office of the Vice-
Rector (Research) TEL: 613-562-
5841, e-mail: ethics@uottawa.ca.

Invitation to Participate

In a

Community Health
Research Project:

Learning From Success: First Nation Communities' Approaches to Prenatal Care

WHAT IS THIS PROJECT ABOUT?

Dawn Smith, RN, MN is a PhD candidate in Population Health at the University of Ottawa.

This research project is being done as part of her PhD thesis.

- The goal of the study is describe First Nations communities' views on their experience developing, implementing and sustaining approaches to prenatal care.
- To do this, Dawn would like to spend time in your community, talk with community leaders, elders, health providers and community members with prenatal care experience.
- She would also like to look at documents describing the prenatal care program in this community.

Would you like to talk to Dawn about this research project?

Please tell _____ if you would like to know more about this research project.

Thank You !

Your participation in this study would mean:

Dawn or a research assistant would talk with you about your views and experiences of prenatal care:

- for about an hour at a time and place that is easy for you.
- Talks can be alone or you can choose one or two people you feel comfortable with to have a small group talk.
- At a later date, Dawn may check with you to see if she has understood your ideas correctly.
- Near the end of the study, she may ask for your feedback on the results of the study and how to use them.

VOLUNTARY PARTICIPATION

- You do not have to participate in this study. Communities can withdraw at anytime, or choose not to participate in any aspect of the study.
- Participation of health providers will not affect their jobs in any way.
- Participation of elders and citizens will not affect their health care in any way.

PROTECTING CONFIDENTIALITY

- Names or identifying information will NOT be used in the study or in any reports or publications.
- People from this or other communities will NOT have access to any of the information provided in this study.
- All information will be kept in a securely locked cabinet in Dawn's supervisor's research office.

Appendix N: Certificate of Ethical Approval for Phase II



Université d'Ottawa • University of Ottawa

Service de subventions de recherche et déontologie

Research Grants and Ethics Services

July 20, 2004

Nancy Edwards
School of Nursing
University of Ottawa
451 Smyth, Room 1118K
INTRA

Dawn Smith

**RE: Learning from Success: First Nations Communities' Approaches to Prenatal Care
(File H06-04-02)**

Dear Dr Edwards and Ms. Smith,

You will find enclosed the Health Sciences and Science REB ethical clearance for the abovementioned research study.

Please note that it is the responsibility of the Researchers to:

- a) Inform the ethics office of any changes in the research project; and
 - b) Fill out an annual status report to be sent to the Protocol Officer for Ethics in Research.
- Such report can be found on the ethics web site at:
http://www.uottawa.ca/services/research/rge/rebs/download/rapport_annuel_projets_anglais.doc

Please inform us if you need for a copy of this approval to be sent to Research Services.

If you have any questions, you may contact me at extension 5387.

Sincerely yours,

Catherine Paquet
For Rita d'Alessandro
Protocol Officer for Ethics in Research

cc. Hugh French, Chair of the Health Sciences and Science REB

550, rue Cumberland
Ottawa (Ontario) K1N 6N5 Canada

550 Cumberland Street
Ottawa, Ontario K1N 6N5 Canada

(613) 562-5841 • Téléc./Fax (613) 562-5338
<http://www.uottawa.ca/services/research/rgc/index.html>



Université d'Ottawa • University of Ottawa

Service de subventions de recherche et déontologie

Research Grants and Ethics Services

HEALTH SCIENCES AND SCIENCE RESEARCH ETHICS BOARD

CERTIFICATE OF ETHICAL APPROVAL

This is to certify that the University of Ottawa Health Sciences and Science Research Ethics Board has examined the application for ethical approval for the research project entitled **Learning from Success: First Nations Communities' Approaches to Prenatal Care (File H06-04-02)** submitted by Dawn Smith who is supervised by Nancy Edwards of the School of Nursing. The Board found that this research project met appropriate ethical standards as outlined in the Tri-Council Policy Statement and in the Procedures of the University of Ottawa Research Ethics Boards, and accordingly gave it a Category 1a (approval). This certification is valid for one year from the date indicated below.

Catherine Paquet *J*
Protocol Officer for Ethics in Research
For Dr. Hugh French, Chair of the
Health Sciences and Science REB

July 20, 2004

Date

550, rue Cumberland
Ottawa (Ontario) K1N 6N5 Canada

550 Cumberland Street
Ottawa, Ontario K1N 6N5 Canada

(613) 562-5841 • Téléc./Fax (613) 562-5338
<http://www.uottawa.ca/services/research/rgc/index.html>

Appendix O: Phase Two Informed Consent Forms



Université d'Ottawa - University of Ottawa

Faculté des sciences de la santé
École des sciences infirmières

Faculty of Health Sciences
School of Nursing

Informed Consent for Individual Interviews (Case A)

About the Researcher

My name is Dawn Smith. I am a nurse and a doctoral student at the University of Ottawa. My research study is called "*Learning From Success: First Nations Communities' Approaches to Prenatal Care*". This study is part of the requirements for a doctoral degree in Population Health. My supervisor is Dr. Nancy Edwards, Professor with the School of Nursing, University of Ottawa.

Purpose

This research study aims to learn how to better support women and families during pregnancy. Pregnancy is an important period of human growth and development. Pregnancy provides an important opportunity to improve the health of women and families. The results of the study may help this and other communities to improve support during pregnancy that fit with the unique culture and contexts of First Nations people.

Procedure:

The discussion will take about one hour. *There are no right or wrong answers, and it is important that I gather as many differing perspectives as possible.*

The following are the steps in the procedure:

1. At the beginning of the project: I will plan a time and convenient place to talk with you about prenatal care in your community or area. With your permission, I will tape record the discussion to make sure I don't miss any of your ideas.
2. I will ask you about pregnancy experiences and support in your community, how it may have changed over time, and how you think it may make a difference in your community. I will also ask you about yourself and the roles, activities and experiences in the community.
3. Should you wish, we can take a break from our discussion at any time.
4. To ensure that you continue to consent to participate in this research, I will check with you regularly regarding your wishes to continue.
5. After the interview, I will write out our conversation. I may need to check back with you to make sure I have understood you correctly.
6. Once I have finished all the interviews and discussions, I will write up a report describing the community's experience with developing support during pregnancy and how it makes a difference to health. There will be no names or identifying information used in this report. I would like to give you a summary of this report to read and get your feedback.

Risks and Benefits:

While there are no direct benefits to you for participating in this interview, some people find it helpful to talk about their pregnancy experiences. Also, the results of the study may help your community or other communities to improve support for First Nations people during pregnancy.

There is no direct risk of harm from doing this interview. However, there is a small chance that during our discussion feelings may surface related to past difficult research, interviewing or pregnancy experiences you may have had. If you are having uncomfortable feelings, you can stop or take a break at any time.

The time taken to participate in interviews (60 minutes or less) and review results (about 30 minutes) is a potential inconvenience. I will cover travel and childcare costs incurred to participate in interviews, and give you a small token of appreciation for your participation.

*It is important for you to know that it is unethical to provide undue compensation or inducements to research participants and, if you agree to be a participant in this study, this form of compensation to you must not be coercive. If you would not otherwise participate if the compensation was not offered, then you should decline.

Confidentiality:

Your name and personal identifiers will not be used with any of the information that is collected in this interview. A code will be assigned to all information provided so that it cannot be linked to you. Names and personal identifiers will be removed so that quotes of our discussion in reports or publications of the study cannot be linked to you. Community names and identifying information will NOT be used in reports or publications of the study.

All information collected during this interview will be kept confidential and will not be communicated to anyone outside of the research team. All data from this study (e.g. tapes, notes and transcripts) will be kept in a locked cabinet in the research office of Dr. Nancy Edwards at the University of Ottawa for a period of 7 years, and then they will be destroyed. The only people who will have access to information obtained in these interviews will be myself, research assistants, and members of my thesis supervisory committee. The [name withheld] Tribal Council will have the opportunity to provide storage of the data if and when they are able to provide secure facilities that guarantee the same protection of individual and community privacy. Other individuals that may be contacted regarding this study include: community members, health providers, leaders and elders in the two study communities.

Use of Information

This research will not lead to a commercial product or service. The data collected from this research will not be used for other purposes. It is anticipated that the results of this study will be shared with others in the following ways: a) presentation and dialogue sessions with local, regional, provincial and national health organizations and at professional conferences; b) publication of articles in newsletters and peer reviewed journals for health professionals and decision-makers; c) to assist in teaching health professionals.

Voluntary Participation:

Joining this study is your choice. If you choose to participate, you may withdraw at any time or refuse to answer any questions. There are no consequences to you for NOT participating in this study.

If you have any questions about this study, I can be reached at telephone number (250) 762-4327 or email dawnsmith@ca.inter.net. Alternatively you may contact my supervisor Dr. Nancy Edwards at the University of Ottawa, at telephone: (613) 562-5800 ext 8395, e-mail: nedwards@uottawa.ca. If you have any ethical concerns, you may contact the Protocol Officer for Ethics in Research, Office of the Vice-Rector (Research) TEL: 613-562-5841, e-mail: ethics@uottawa.ca.

Consent of Participant:

I have read the above information and understand this consent form. I have also had the chance to ask questions and they have been answered to my satisfaction. I agree to take part in this study. *There are two copies of this consent form, one of which is for me to keep.*

Participant Signature _____

Date _____

Researcher _____

Date _____

Consent for Tape Recording

I agree to have my conversation tape recorded during the interview. I may stop the taping at any time. I may change or erase part or all of the tape recording. The tapes and written transcript of the tapes will be kept by the researcher. However, if I wish, the tapes will be returned to me at the completion of the study or destroyed by the researcher.

_____ YES, I would like tapes of our conversation returned to me.

_____ NO, I do NOT wish tapes of our conversation to be returned to me.

I have read and understand the conditions regarding tape recording. I have had the chance to ask questions and they have been answered to my satisfaction.

I agree to have this interview tape recorded.

Participant Signature _____

Date _____

Researcher _____

Date _____

I do NOT agree to have this interview tape recorded but consent to notes being taken during and after the interview by the researcher.

Participant Signature _____

Date _____

Researcher _____

Date _____

I wish to receive a summary of the research findings: _____ Yes _____ No

Mailing address or contact information:



Université d'Ottawa • University of Ottawa

Faculté des sciences de la santé
École des sciences infirmières

Faculty of Health Sciences
School of Nursing

Informed Consent for Kitchen Table Talks (Case A)

About the Researcher

My name is Dawn Smith. I am a nurse and a doctoral student at the University of Ottawa. My research study is called "*Learning From Success: First Nations Communities' Approaches to Prenatal Care*". This study is part of the requirements for a doctoral degree in Population Health. My supervisor is Dr. Nancy Edwards, Professor with the School of Nursing, University of Ottawa.

Purpose

This research study aims to learn how to better support women and families during pregnancy. Pregnancy is an important period of human growth and development. Pregnancy provides an important opportunity to improve the health of women and families. The results of the study may help this and other communities to improve support during pregnancy that fit with the unique culture and contexts of First Nations people.

Procedure:

The discussion will take about one hour. *There are no right or wrong answers, and it is important that I gather as many differing perspectives as possible.*

The following are the steps in the procedure:

1. At the beginning of the project: I will plan a time and convenient place to talk with you and one or two people you feel comfortable with about prenatal care in your community. If all participants agree, I will tape record the discussion to make sure I don't miss any of your ideas. Should any of you wish NOT to tape record the discussion, I will take notes.
2. I will ask you about pregnancy experiences and support in your community, how it may have changed over time, and how you think it may make a difference in your community. I will also ask you about yourself and the roles, activities and experiences in the community.
3. Should any of you wish, we can take a break from our discussion at any time.
4. To ensure that you continue to consent to participate in this research, I will check with you regularly regarding your wishes to continue.
5. After the discussion I will write out your ideas. I may need to check back with you to make sure I have understood you correctly.
6. Once I have finished all the interviews and discussions, I will write up a report describing the community's experience with developing support during pregnancy and how it makes a difference to health. I would like to give you a summary of this report to read and get your feedback. There will be no names or identifying information used in this report.

Risks and Benefits:

While there are no direct benefits to you for participating in this discussion, some people find it helpful to talk about their pregnancy experiences. Also, the results of the study may help your community or other communities to improve support for First Nations people during pregnancy. There is no direct risk of harm from participating in this discussion. However, there is a small chance that during our discussion feelings may surface related to past difficult research, interviewing or pregnancy experiences you may have had. If you are having uncomfortable feelings, you can stop or take a break at any time.

The time taken to participate in interviews (about one hour) and review results (about 30 minutes) is a potential inconvenience. I will cover travel and childcare costs incurred to participate in the discussion, and give you a small token of appreciation for your participation.

*It is important for you to know that it is unethical to provide undue compensation or inducements to research participants and, if you agree to be a participant in this study, this form of compensation to you must not be coercive. If you would not otherwise participate if the compensation was not offered, then you should decline.

Confidentiality and Anonymity:

Anonymity cannot be fully guaranteed, as anonymity is not possible among those participating in this small group discussion. However, your name and personal identifiers will not be used by the researchers with any of the information that is collected in this discussion. A code will be assigned to all information provided so that it cannot be linked to you. Names and personal identifiers will be removed so that quotes of our discussion in reports or publications of the study cannot be linked to you. Community names and identifying information will NOT be used in reports or publications of the study.

All information collected during this discussion will be kept confidential and will not be communicated to anyone outside of the research team. All data from this study (e.g. tapes, notes and transcripts) will be kept in a locked cabinet in the research office of Dr. Nancy Edwards at the University of Ottawa for a period of 7 years, and then they will be destroyed. The only people who will have access to information obtained in these interviews will be myself, research assistants, and members of my thesis supervisory committee. The [name withheld] Tribal Council will have the opportunity to provide storage of the data if and when they are able to provide secure facilities that guarantee the same protection of individual and community privacy. Other individuals that may be contacted regarding this study include: community members, health providers, leaders and elders in the two study communities.

Use of Information

This research will not lead to a commercial product or service. The data collected from this research will not be used for other purposes. It is anticipated that the results of this study will be shared with others in the following ways: a) presentation and dialogue sessions with local, regional, provincial and national health organizations, and at professional conferences; b) publication of articles on newsletters and peer reviewed journals for health professionals and decision-makers; c) to assist in teaching health professionals.

Voluntary Participation:

Joining this study is your choice. If you choose to participate, you may withdraw at any time or refuse to answer any questions. There are no consequences to you for NOT participating in this study.

If you have any questions about this study, I can be reached at telephone number (250) 762-4327 or email dawnsmith@ca.inter.net. Alternatively you may contact my supervisor Dr. Nancy Edwards at the University of Ottawa, at telephone: (613) 562-5800 ext 8395, e-mail: nedwards@uottawa.ca. If you have any ethical concerns, you may contact the Protocol Officer for Ethics in Research, Office of the Vice-Rector (Research) TEL: 613-562-5841, e-mail: ethics@uottawa.ca.

Consent of Participant:

I have read the above information and understand this consent form. I have also had the chance to ask questions and they have been answered to my satisfaction. I agree to take part in this study. *There are two copies of this consent form, one of which is for me to keep.*

Participant Signature _____

Date _____

Researcher _____

Date _____

Consent for Tape Recording

I agree to have my conversation tape recorded during the interview. I may stop the taping at any time. I may change or erase part or all of the tape recording. The tapes and written transcript of the tapes will be kept by the researcher. However, if I wish, the tapes will be returned to me at the completion of the study or destroyed by the researcher.

_____ YES, I would like tapes of our conversation returned to me.

_____ NO, I do NOT wish tapes of our conversation to be returned to me.

I have read and understand the conditions regarding tape recording. I have had the chance to ask questions and they have been answered to my satisfaction.

I agree to have this interview tape recorded.

Participant Signature _____

Date _____

Researcher _____

Date _____

I do NOT agree to have this interview tape recorded but consent to notes being taken during and after the interview by the researcher.

Participant Signature _____

Date _____

Researcher _____

Date _____

I wish to receive a summary of the research findings: _____ Yes _____ No

Mailing address or contact information:



Université d'Ottawa • University of Ottawa

Faulté des sciences de la santé
École des sciences infirmières

Faculty of Health Sciences
School of Nursing

Informed Consent for Individual Interviews (Case B)

About the Researcher

My name is Dawn Smith. I am a nurse and a doctoral student at the University of Ottawa. My research study is called "*Learning From Success: First Nations Communities' Approaches to Prenatal Care*". This study is part of the requirements for a doctoral degree in Population Health. My supervisor is Dr. Nancy Edwards, Professor with the School of Nursing, University of Ottawa.

Purpose

This research study aims to learn how to better support First Nations women and families during pregnancy. Pregnancy is an important period of human growth and development. Pregnancy provides an important opportunity to improve the health of women and families. The results of the study may help this and other communities to improve support during pregnancy that fit with the unique culture and contexts of First Nations people.

Procedure:

The discussion will take about one hour. *There are no right or wrong answers, and it is important that I gather as many differing perspectives as possible.*

The following are the steps in the procedure:

7. At the beginning of the project: I will plan a time and convenient place to talk with you about prenatal care in your community or area. With your permission, I will tape record the discussion to make sure I don't miss any of your ideas.
8. I will ask you about pregnancy experiences and support in your community, how it may have changed over time, and how you think it may make a difference in your community. I will also ask you about yourself and the roles, activities and experiences in the community.
9. Should you wish, we can take a break from our discussion at any time.
10. To ensure that you continue to consent to participate in this research, I will check with you regularly regarding your wishes to continue.
11. After the interview, I will write out our conversation. I may need to check back with you to make sure I have understood you correctly.
12. Once I have finished all the interviews and discussions, I will write up a report describing the community's experience with developing support during pregnancy and how it makes a difference to health. There will be no names or identifying information used in this report. I would like to give you a summary of this report to read and get your feedback.

Risks and Benefits:

While there are no direct benefits to you for participating in this interview, some people find it helpful to talk about their pregnancy experiences. Also, the results of the study may help your community or other communities to improve support for First Nations people during pregnancy.

There is no direct risk of harm from doing this interview. However, there is a small chance that during our discussion feelings may surface related to past difficult research, interviewing or pregnancy experiences you may have had. If you are having uncomfortable feelings, you can stop or take a break at any time.

The time taken to participate in interviews (60 minutes or less) and review results (about 30 minutes) is a potential inconvenience. I will cover travel and childcare costs incurred to participate in interviews, and give you a small token of appreciation for your participation.

*It is important for you to know that it is unethical to provide undue compensation or inducements to research participants and, if you agree to be a participant in this study, this form of compensation to you must not be coercive. If you would not otherwise participate if the compensation was not offered, then you should decline.

Confidentiality:

Your name and personal identifiers will not be used with any of the information that is collected in this interview. A code will be assigned to all information provided so that it cannot be linked to you. Names and personal identifiers will be removed so that quotes of our discussion in reports or publications of the study cannot be linked to you. Community names and identifying information will NOT be used in reports or publications of the study.

All information collected during this interview will be kept confidential and will not be communicated to anyone outside of the research team. All data from this study (e.g. tapes, notes and transcripts) will be kept in a locked cabinet in the research office of Dr. Nancy Edwards at the University of Ottawa for a period of 7 years, and then they will be destroyed. The only people who will have access to information obtained in these interviews will be myself, research assistants, and members of my thesis supervisory committee. Other individuals that may be contacted regarding this study include: community members, health providers, leaders and elders in the two study communities.

Use of Information

This research will not lead to a commercial product or service. The data collected from this research will not be used for other purposes. It is anticipated that the results of this study will be shared with others in the following ways: a) presentation and dialogue sessions with local, regional, provincial and national health organizations and at professional conferences; b) publication of articles on newsletters and peer reviewed journals for health professionals and decision-makers; c) to assist in teaching health professionals.

Voluntary Participation:

Joining this study is your choice. If you choose to participate, you may withdraw at any time or refuse to answer any questions. There are no consequences to you for NOT participating in this study.

If you have any questions about this study, I can be reached at telephone number (250) 762-4327 or email dawnsmith@ca.inter.net. Alternatively you may contact my supervisor Dr. Nancy Edwards at the University of Ottawa, at telephone: (613) 562-5800 ext 8395, e-mail: nedwards@uottawa.ca. If you have any ethical concerns, you may contact the Protocol Officer for Ethics in Research, Office of the Vice-Rector (Research) TEL: 613-562-5841, e-mail: ethics@uottawa.ca.

Consent of Participant:

I have read the above information and understand this consent form. I have also had the chance to ask questions and they have been answered to my satisfaction. I agree to take part in this study. *There are two copies of this consent form, one of which is for me to keep.*

Participant Signature _____

Date _____

Researcher _____

Date _____

Consent for Tape Recording

I agree to have my conversation tape recorded during the interview. I may stop the taping at any time. I may change or erase part or all of the tape recording. The tapes and written transcript of the tapes will be kept by the researcher. However, if I wish, the tapes will be returned to me at the completion of the study or destroyed by the researcher.

_____ YES, I would like tapes of our conversation returned to me.

_____ NO, I do NOT wish tapes of our conversation to be returned to me.

I have read and understand the conditions regarding tape recording. I have had the chance to ask questions and they have been answered to my satisfaction.

I agree to have this interview tape recorded.

Participant Signature _____

Date _____

Researcher _____

Date _____

I do NOT agree to have this interview tape recorded but consent to notes being taken during and after the interview by the researcher.

Participant Signature _____

Date _____

Researcher _____

Date _____

I wish to receive a summary of the research findings: _____ Yes _____ No

Mailing address or contact information:



Université d'Ottawa • University of Ottawa

Faculté des sciences de la santé
École des sciences infirmières

Faculty of Health Sciences
School of Nursing

Informed Consent for Kitchen Table Talks (Case B)

About the Researcher

My name is Dawn Smith. I am a nurse and a doctoral student at the University of Ottawa. My research study is called "*Learning From Success: First Nations Communities' Approaches to Prenatal Care*". This study is part of the requirements for a doctoral degree in Population Health. My supervisor is Dr. Nancy Edwards, Professor with the School of Nursing, University of Ottawa.

Purpose

This research study aims to learn how to better support women and families during pregnancy. Pregnancy is an important period of human growth and development. Pregnancy provides an important opportunity to improve the health of women and families. The results of the study may help this and other communities to improve support during pregnancy that fit with the unique culture and contexts of First Nations people.

Procedure:

The discussion will take about one hour. *There are no right or wrong answers, and it is important that I gather as many differing perspectives as possible.*

The following are the steps in the procedure:

7. At the beginning of the project: I will plan a time and convenient place to talk with you and one or two people you feel comfortable with about prenatal care in your community. If all participants agree, I will tape record the discussion to make sure I don't miss any of your ideas. Should any of you wish NOT to tape record the discussion, I will take notes.
8. I will ask you about pregnancy experiences and support in your community, how it may have changed over time, and how you think it may make a difference in your community. I will also ask you about yourself and the roles, activities and experiences in the community.
9. Should any of you wish, we can take a break from our discussion at any time.
10. After the discussion I will write out your ideas. I may need to check back with you to make sure I have understood you correctly.
11. Once I have finished all the interviews and discussions, I will write up a report describing the community's experience with developing support during pregnancy and how it makes a difference to health. I would like to give you a summary of this report to read and get your feedback. There will be no names or identifying information used in this report.

Risks and Benefits:

While there are no direct benefits to you for participating in this discussion, some people find it helpful to talk about their pregnancy experiences. Also, the results of the study

may help your community or other communities to improve support for First Nations people during pregnancy.

There is no direct risk of harm from participating in this discussion. However, there is a small chance that during our discussion feelings may surface related to past difficult research, interviewing or pregnancy experiences you may have had. If you are having uncomfortable feelings, you can stop or take a break at any time.

The time taken to participate in interviews (about one hour) and review results (about 30 minutes) is a potential inconvenience. I will cover travel and childcare costs incurred to participate in the discussion, and give you a small token of appreciation for your participation.

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Confidentiality and Anonymity:

Anonymity cannot be fully guaranteed, as anonymity is not possible among those participating in this small group discussion. However, your name and personal identifiers will not be used by the researchers with any of the information that is collected in this discussion. A code will be assigned to all information provided so that it cannot be linked to you. Names and personal identifiers will be removed so that quotes of our discussion in reports or publications of the study cannot be linked to you. Community names and identifying information will NOT be used in reports or publications of the study.

All information collected during this discussion will be kept confidential and will not be communicated to anyone outside of the research team. All data from this study (e.g. tapes, notes and transcripts) will be kept in a locked cabinet in the research office of Dr. Nancy Edwards at the University of Ottawa for a period of 7 years, and then they will be destroyed. The only people who will have access to information obtained in these interviews will be myself, research assistants, and members of my thesis supervisory committee.

Use of Information

This research will not lead to a commercial product or service. The data collected from this research will not be used for other purposes. It is anticipated that the results of this study will be shared with others in the following ways: a) presentation and dialogue sessions with local, regional, provincial and national health organizations, and at professional conferences; b) publication of articles on newsletters and peer reviewed journals for health professionals and decision-makers; c) to assist in teaching health professionals.

Voluntary Participation:

Joining this study is your choice. If you choose to participate, you may withdraw at any time or refuse to answer any questions. There are no consequences to you for NOT participating in this study.

If you have any questions about this study, I can be reached at telephone number (250) 762-4327 or email dawnsmith@ca.inter.net. Alternatively you may contact my supervisor Dr. Nancy Edwards at the University of Ottawa, at telephone: (613) 562-5800 ext 8395, e-mail: nedwards@uottawa.ca. If you have any ethical concerns, you may contact the Protocol Officer for Ethics in Research, Office of the Vice-Rector (Research) TEL: 613-562-5841, e-mail: ethics@uottawa.ca.

Consent of Participant:

I have read the above information and understand this consent form. I have also had the chance to ask questions and they have been answered to my satisfaction. I agree to take part in this study. *There are two copies of this consent form, one of which is for me to keep.*

Participant Signature _____

Date _____

Researcher _____

Date _____

Consent for Tape Recording

I agree to have my conversation tape recorded during the interview. I may stop the taping at any time. I may change or erase part or all of the tape recording. The tapes and written transcript of the tapes will be kept by the researcher. However, if I wish, the tapes will be returned to me at the completion of the study or destroyed by the researcher.

_____ YES, I would like tapes of our conversation returned to me.

_____ NO, I do NOT wish tapes of our conversation to be returned to me.

I have read and understand the conditions regarding tape recording. I have had the chance to ask questions and they have been answered to my satisfaction.

I agree to have this interview tape recorded.

Participant Signature _____

Date _____

Researcher _____

Date _____

I do NOT agree to have this interview tape recorded but consent to notes being taken during and after the interview by the researcher.

Participant Signature _____

Date _____

Researcher _____

Date _____

I wish to receive a summary of the research findings: _____ Yes _____ No

Mailing address or contact information:

Appendix P: Phase Two Interview and Small Group Discussion Guide

INTERVIEW AND DISCUSSION QUESTIONS

Pregnancy and prenatal care have often been seen as a fairly narrow medical issue.

I see pregnancy:

- *Holistically;*
- *As presenting both opportunities and challenges;*
- *As experienced by individuals, families and communities.*

Prenatal care would be about supporting women and families through the opportunities and challenges of pregnancy.

I want to learn about all aspects of your views and experiences about pregnancy and support for First Nations women, families, and communities.

ABOUT YOU

1. Please tell me a bit about yourself

YOUR VIEWS AND EXPERIENCES RELATED TO PREGNANCY

2. Tell me about your pregnancy related experiences (of self or of others).
 - important aspects of pregnancy
 - important opportunities and challenges

SUPPORTING WOMEN AND FAMILIES DURING PREGNANCY

3. Tell me about support for women and families during pregnancy in this community.
4. How has this approach to prenatal care made a difference to women, families and the community as a whole?
5. What would you consider to be the strengths and weaknesses of support available to pregnant women and families in this community?

ADDITIONAL COMMENTS OR STORIES?

6. Please share any additional comments or stories you feel are important.

QUESTIONS FOR HEALTH PROVIDERS AND LEADERS

MAKING THE CHANGE

7. What did prenatal care used to be like in this community?
8. What would you say are important differences between prenatal care now and how it used to be?
9. What was involved in changing prenatal care to the current approach.
10. What are influences on **developing** prenatal care that works for First Nations women and families in this community?
11. What are influences on **maintaining** prenatal care that works for First Nations women and families in this community?
12. What would you recommend to make it easier for others to develop prenatal care that works for First Nations people?

Appendix Q: Early Result

Learning from Success: Aboriginal Communities' Approaches to Supporting Pregnant and Parenting Women and Families

Summary of Early Results



The mother hummingbird with a baby riding on her back symbolizes the flow between the past and the future. The eagle symbolizes direction, courage and strength. The raven within the hummingbird is the trickster. (used with permission - Charlie George, Heiltsuk Nation, Bella Bella).

Dawn Smith, RN, PhD candidate
University of Ottawa
March 23, 2005

Introduction and Acknowledgements

This is the early stage of writing up results of my doctoral research project. I spent a very short period of time meeting you, talking with you, spending time in your communities and spaces. Really, I feel like I have had only a very quick snapshot of your lifetimes of experience. So it is very important that opportunities are created for you to see how I described what I understood from this brief 'snapshot'. To see how I make sense of your stories to answer the research questions, and write up results that can make a difference.

This document is a rough draft and a work in progress. I wanted to make it a quick and easy read, but at the same time I had a hard time separating out 'the wheat from the chaff'. It will help me to discuss it with you. Our discussion will deepen my understanding and improve the results. From your perspective, it may be very clear what is 'wheat' (e.g. important), what is 'chaff' (e.g. less important). Please have a look, choose the parts that are of most interest to you and come to our workshop discussion with your ideas and suggestions. This is the purpose of sharing these 'early results' with you.

I would like to recognize and thank all of you for supporting this work. It has truly been an amazing learning, healing and growing experience for me, both personally and as a researcher. You have been gentle and generous with your experience, your understanding and your time. I believe this is important work, and want to do my best to honor your stories, and make a difference.

I welcome your suggestions, and look forward to a lively discussion with you.

Dawn

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ABOUT THE STUDY

This paper describes the early results of the research project entitled 'Learning from Success'. The purpose of the project was to describe:

1. Aboriginal People's views of the importance of pregnancy and parenting;
2. Community-based stakeholders' views on support during pregnancy and parenting and how it makes a difference; and
3. Aboriginal organization's experience improving support for pregnant and parenting Aboriginal people

The project was conducted with two Aboriginal health care delivery organizations and communities in a mainly rural region of a Canadian province. Initially 16 key informants were interviewed, and data regarding issues and contextual influences on Aboriginal people's experience of pregnancy was collected. Then a case study design was used to investigate two Aboriginal organizations' experiences in developing safe and responsive support for pregnant and parenting Aboriginal women and families. Data was collected by one-to-one exploratory interviews, small group discussions, and by review of documents, administrative records and utilization statistics. Interview and discussion participants were selected to obtain a variety of perspectives on the research questions (i.e. clients, family members, providers, managers and administrators, policy decision makers, and community leaders). Table One shows the sample for the second part of the study.

Table One: Community Participants

	Case A	Case B
Leaders	8	9
Providers	10	15
Community Members*	11	4
Aboriginal Identity	21	15
Female	25	26
Total	29	28

EARLY RESULTS

Early results are summarized in two sections.

1. The first section sets the context for the importance of pregnancy and parenting for Aboriginal People. The experience of pregnancy and parenting create natural and powerful turning points and opportunities in people's lives to reverse the destructive cycle resulting from the intergenerational impact of residential schools. *Turning it Around*, and its four sub-themes describe the importance of pregnancy and parenting in the context of Aboriginal Peoples' past, their present circumstances, and their vision and hopes for the future: The themes include:
 - *Turning it Around: Vision and Pathway to a Better Future*
 - *Understanding and Acknowledging the Intergenerational Impact of Residential Schools*
 - *Healing*
 - *Building Strength and Capacity*

→ *Pregnancy and Parenting: Turning Point/opportunity for Turning It Around*

2. The second section describes the successful approach and strategies developed by Aboriginal health care organizations and providers to support the opportunity provided by pregnancy and parenting. As the theme title suggests, successful approaches understand and acknowledge Aboriginal people's past experiences, acknowledge the pain and gifts that have come from it, and align themselves to support the vision and pathway to a better future.

→ *Facilitating Transformation: Safe and responsive support for Aboriginal parents*

The final component of the results is 'under construction'. This part of the research project aims to describe the experience of Aboriginal health care organizations developing and maintaining safe and responsive support for Aboriginal parents. More details from this part of the results will be shared and discussed in the workshop.

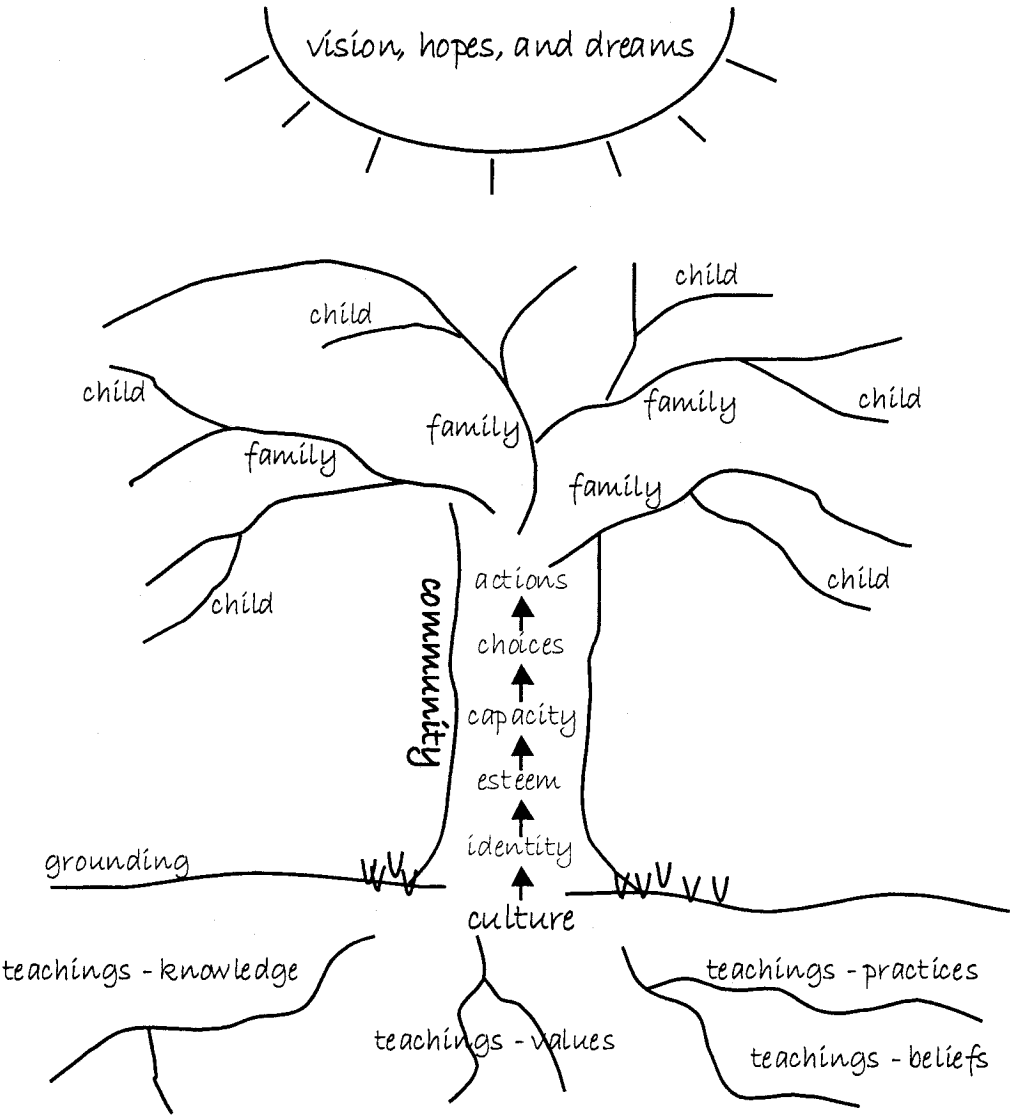
The Importance of Pregnancy and Parenting to Aboriginal People

The 'Growing Healthy People' diagram on the next page illustrates my understanding of participants views of the importance of pregnancy and parenting. It is a metaphor for the context, connections between and pathways to 'growing' strong and healthy people: individuals, families, communities and cultures.

The tree represents participants' views of the importance of understanding, acknowledging, and respecting Aboriginal people's efforts to turn around the intergenerational impact of residential schools. Cultural teachings are symbolized as the root of strong people, and healthy growth across generations. Strong people are grounded in/by their cultural teachings. The values and beliefs are the 'tap root teachings'. The traditional knowledge and practice systems are teachings that grow from the taproot. Children are linked to teachings through their family and community. The tree grows upwards toward the sun which symbolizes the vision, hopes and dreams for the future. The sap/spirit rises from the nurturing energy that the roots draw from the grounding of the culture in the environment, and is renewed by the energy that the leaves and branches (e.g. the children) draw from the sun.

Successful support for pregnant and parenting Aboriginal people from health care organizations and providers must be based on an understanding of the context, connections and pathways. These are represented by the tree. *Pregnancy and parenting* is a *turning point* and an opportunity to *turn around* the destructive cycle resulting from the *intergenerational impact of residential schools*. These three themes are summarized below.

Figure One: Growing Healthy People



Turning it Around: Vision and Pathway to a Better Future

The theme *Turning it Around* focuses on Aboriginal Peoples determined efforts to reverse the destructive, degenerative spiraling effect of residential schools. *Turning it Around* describes participants' views of solutions for regenerating strong and healthy children, families, communities. *Reconnecting* at many levels and *reclaiming cultural teachings* will reestablish strong roots to ground present *healing and growth* toward hopes and dreams for a better future. As one participant said,

We are turning it around We are going to be better parents for our children because we are healing. And our children won't experience the legacy. I mean that is my hope, that my children won't experience the pain and things like that. That they will have an understanding and what they will acquire is the gift of the resiliency and the gift of survival, but not the pain of the abuse and everything else. (parent, provider, leader).

Turning it Around involves: a) *understanding and acknowledging the intergenerational impact of residential schools*; b) *healing*; and c) *building strength and capacity* to continue the upward/positive momentum for future generations. *Reconnecting and rebuilding* healthy relationships with self, others and the environment is the central task of both healing and capacity building. Spirituality is understood as the relationships we have with self, others and the environment around us. Spiritual, emotional and social health and well being were most affected by the intergenerational impact of residential schools. Therefore much of the healing work is spiritual and emotional in nature, which must be recognized in approaches to support. In this work, feelings or emotional energy is like the sap that runs through the tree, connecting and nourishing all of the parts of the tree, making it a living, growing, thriving whole. Appendix A shows the themes and relationships of *Turning it Around*. The emotional nature of the work to turn it around is shown in the arrows. The arrows show the **downward** spiraling of the intergenerational impact of residential schools, as well as the **upward** spiraling dynamic of *Turning it Around*.

Understanding and Acknowledging the Intergenerational Impact of Residential Schools

Two thirds of that last generation to attend residential schools has not survived. It is no coincidence that so many fell victim to violence, accidents, addictions and suicide. Today the children and grandchildren of those who went to residential schools also live with the same legacy of broken families, broken culture and broken spirit¹

Turning it Around starts with and depends on *understanding and acknowledging the intergenerational impact of residential schools*. The tree metaphor clarifies the importance of *understanding and acknowledging the intergenerational impact of residential schools* to pregnant and parenting Aboriginal parents. The tree suggests the devastation that occurs when people are disconnected from their culture (or the roots are destroyed), when children are disconnected from families, and from themselves, and when families are disconnected from each other, their communities and culture. This has

been the experience in the families of many of the participants, as a result of the *intergenerational impact of residential schools*. One participant said:

It's so intergenerational. You have generations of people who have been affected by the trauma. ...I have talked to people who have got 5 generations of trauma coming down. So you have 4 or 5 generations of people who haven't been able to connect, who haven't had a sense of spirituality, who haven't been able to make firm attachments with their caregivers. It is a direct result of residential school violence (provider).

Aboriginal children learned to despise the traditions and accomplishments of their people, to reject the values and spirituality that had always given meaning to their lives, to distrust the knowledge and lifeways of their families and kin. By the time they were free to return to their villages, many had learned to despise themselves”ⁱⁱ

The tree diagram shows teachings as the values, beliefs, knowledge and practices that make up a person's culture. Participants described teachings as what we learn as children and use to make sense of the world and our place in it. Because teachings are programmed into identity and ways of being in relationship, as residential school survivors become parents they pass on the residential school 'teachings' they grew up onto their own children. The cycle continues as their children take up residential school 'teachings' and then they pass them on to their children.

To be really perfectly honest.... for years we weren't even considered citizens... or people for that matter. ... there were certain things that... stereotyping... we were this and we were that. So that attitude, I went through that and I think in a sense I passed that on to my kids....you know without me really saying it so much.. and ah... anyway I think that is where it comes from. It's hard to see. Sometimes I don't notice it until I start talking about it. Sometimes we have to forgive ourselves for what we did to our kids. For what we passed onto them (Elder, parent)

... they all went to residential schools, except the youngest. And again that's when we are starting to work on the child's confidence and esteem too. Them being told... the older kids in residential school are told, 'you are good for nothing, you are just an Indian. You will never amount to anything'... (parent, provider)

Participants talked about being caught in a downward *spiral of addiction, violence and poverty*. Residential schools programmed domination, control and abuse as ways of being in relationship with self and others. Trauma during childhood often results in withdrawal and dissociation, cutting people off from their feelings. Modeling unhealthy relationships learned in residential schools, and dissociation from feelings blocks the children and youth from opportunities to develop the skills for healthy relationships. Alcohol and drugs was modeled as a way of escaping from the spiritual and emotional pain, loneliness and isolation. This widens and deepens the downward spiral of addictions, violence and poverty. The understanding of root causes for the behavior and the feelings of helplessness becomes even further removed.

The intergenerational impact of residential schools is seen as underlying a lot of the substance abuse issues, the sexual abuse and the physical abuse. So to get the

root of the problem, there was more attention put on the experience of residential school(provider).

The theme *Understanding and Acknowledging the Intergenerational Impact of Residential Schools* describes the devastation that has resulted from *disconnection and alienation from self, family, community and culture*. These disconnections have resulted in a downward *spiral of addiction, violence and poverty*. The spiritual, emotional and social devastation has been transmitted across generations, and become embedded in communities. The end result is *decreasing capacity and access to resources* needed for a healthy and meaningful life, reinforcing the downward spiral. As participants suggest, it is crucial to understand and acknowledge the reality and intergenerational impact of residential schools, and to recognize the implications this has for bringing the next generation into this world.

Healing

The second major challenge of *Turning it Around* is *healing* from the trauma brought on by the intergenerational impact of residential schools. Participants explained that if things are to be different for their children and grandchildren, if the cycle is to be broken, then they have to face and heal their own trauma. Healing is a self-determined process, for individuals, families and communities. It is a gradual, back and forth process of facing up to and forgiving yourself and others for the hurts, changing beliefs about yourself and others, and accepting responsibility for yourself and your choices. Healing requires courage, determination, persistence, and support.

As one participant explained:

People need to do their own work. You know, they get to do their own healing work: develop the skills, the life skills, the decision-making skills, the comfort with themselves. And that's one part. But then another part is the relationships thing... the relationship with self, the relationship with family, relationship with community. And I think number one is that you really have to get your relationship with yourself sorted out (grandmother).

Forgiving self and others for past hurts, and acknowledging strengths is an important part of healing.

I am afraid to admit when I am wrong. I am afraid, but I have the ability to forgive (parent).

I accept your apology. There has been a lot of pain and suffering since I was 11 years old. I didn't have any respect for myself. ... My daughter was the one who opened my eyes (parent, leader).

Participants expressed that *respect* for all living things is fundamental, and that part of healing is to change core beliefs we have about ourselves.

It doesn't matter what you look like, what kind of clothes you wear... what matters is that you are there, you are human, you are alive, it's that you have feelings (youth).

We don't need to be powerful; we just need to be equal- to respect each other. Letting it all go to hate, that is not good for your inside. You gotta think about your own body... deal with it, heal it and not fill it with hate. Turn things around-Let's do it with love and respect for each other as women and in turn feed it to our children (parent, community member).

Reconnecting is part of healing all the disconnections imposed by intergenerational impact of residential schools, rebuilding for the healthy growth of future generations of children.

We have changed things, because we have learned together. Me and my parents are growing up together. Because their childhood was taken away from them when they were 5 until they were 15 to 18 years old. All my aunts and uncles (parent, leader).

Building Strength and Capacity

Building strength and capacity was described as a significant priority for individuals, families and communities. At all these levels participants described their efforts to develop the knowledge, skills, confidence, networks of support required to begin and sustain work toward their vision for strong health people, families and communities. Developing goals according to ones own priorities, beliefs and vision for the future is a necessary and significant part of capacity building.

It brought the community together to talk about the problems... to talk about the issues... to talk about what we wanted. And really, what they did in the development of treaty negotiations, ...is they said, 'this is what we want in economic development... this is what we want in education... this is what we want in social development'... they went through everything, and what they did without realizing it is that they just did their long term goals... and then once they realized what they wanted, then of course, they started doing things about it (leader).

Many of the capacity building efforts are directed toward developing the infrastructure and social environment that will support children to have and make better choices.

I said, and I will always stand for making this community safe for women and children. And I need the support of everyone here. I can't do it myself- I can't be everywhere. When you see something, you have to speak up about it. I am always telling people that we all have responsibility for making this a safe healthy community. Like, if you see someone molesting a child over there, it is your responsibility to speak up (community leader, parent).

Developing parenting capacity and skills is a focus that cuts across many programs and sectors.

I think the other programs, with the parenting courses and the parenting support work that they are doing... I think there's more linkage there now..., they (have) a lot of parenting initiatives that they did at a school level, which would get the kids before they were pregnant actually, and then they (have) a lot of parenting support for young parents, or teen parents themselves. And they (have) a lot of

professional workers who had been given training in developing parenting programs and parenting support programs and stuff. So I think that the issues that relate to residential schools that affect a person's ability to parent in a healthy way were probably addressed in those programs. In addition, there was a program that is called the (residential schools) survivor program (provider).

Role models, mentors and support people were emphasized as important to building capacity. Many participants described the importance of having even one person who believed in you and showed you that it was possible to build toward your goals and dreams. For many participants even a single person – a sister, an aunt, a grandparent-believing in them, witnessing their struggles and achievements – played a significant part in turning childhood adversity and trauma into resilience, positive coping and life skills.

There is a lot that happens in our communities and I think its one of the big challenges for me was getting past that whole idea that there was no way I could be successful and be a mother. And I think that one of the things that greatly helped me was the fact that my mom was a teen mom. She was sixteen when I was born... 15 when she got pregnant. And everyone said that she should either have an abortion or give me up for adoption, and you know...when I was born her doctor said to her that "There's no way that you are going to provide her with a good life. And you are going to be condemning this little girl to a horrible life and she will never amount to anything". And my mom did not stop working her butt off to make sure that I had a really good life and I did. And so I guess from seeing her I knew that all hope was not lost. I knew that if I just worked really, really hard, that I could get there. Unfortunately I think that not everybody grows up being able to see that.(mother.).

Bringing back the culture is a strong theme in all aspects of turning it around because it is a healing, reconnecting activity in itself, and because it is the root of strong people, families and communities. As in the tree diagram, bringing back the culture reconnects people with their culture and the roots of a strong positive identity.

How do you change society? But that's where the cultural pride comes in. To have a strong cultural teachings and strong pride in who you are. to really giving children a sense of pride in who they are. (mother, provider).

Celebrating birth, starting the connection between the new child and the community, the family and the culture...it is the root of their identity. (Elder, parent).

Reconnecting with culture and nourishing a strong, positive cultural identity builds capacity for people to reconnect with themselves. The process of bringing back the culture also reconnects families, as people reach out to learn, discuss and make decisions about how to practice traditional ways and teachings. The multiple impacts of residential schools means that people must work through multiple tasks simultaneously. They must: reconnect relationships, learn **how** to engage with each other in a healthy way, identify lost cultural teachings and work out how they will be practiced today, and do the personal and family reframe their cultural identities and beliefs.

When I look in our community there's a lot of disjoining in our communities... we talk about how we have these strong family bonds, we have these strong cultural bonds, but quite honestly, I don't believe they are there, altogether. For instance, if we were to sit down and talk about a practice such as a coming of age ceremony, truly people would like say... "You're doing it wrong, and you're doing it wrong". There is no appreciation for the real differences between people. We are really, really focused on making sure that everybody does it right... our way. And for me, I look at them and think that that's what's killing our culture.....And so I think that there is a real disjoin in this family... there's a huge cultural loss and a huge problem of identity, both culturally and family (parent, leader).

Bringing back the culture often is challenging as people debate how to manage, grow with, and live traditional cultural teachings in contemporary life contexts.

it depends if you're in more of an urban area maybe you will draw on say the Cree cultures and a mix of cultures, Métis cultures. ... Whereas, you know, from like say [large First Nation] who's really strong and their feeling comfortable, they draw maybe more from one culture. But if you go outside of the [large First Nation] tribe group, to say a Friendship Centre, it's quite different how they might approach it... so I think that diversity exists: how they do their teachings and how they involve the family and the mother, all that stuff, you know(leader).

Pregnancy and Parenting: Turning Point/Window of Opportunity

Pregnancy and early parenting are a window of **opportunity**, a **turning point**, in people's lives – where there is openness to change – to move out of the downward spiral resulting from the past, and begin the spiral upward toward hopes for better future for themselves and their children. Participants described a whole collection of critical shifts that are brought on by pregnancy and parenting. Participants described: a) reexamining their past and questioning values and beliefs; b) having reasons and motivation to seek help and change behavior; and c) moving into new social and family roles, with a new set of expectations, responsibilities and privileges. There was also d) the importance their families, communities and culture placed on children, and e) the hope invested in children as to the pathway to a better future. Participants comments related to these opportunities and values include:

a. Re-examining their past and questioning values and beliefs:

Pregnancy is an opportunity... pregnancy is when you become a parent.... [and] you reflect on your experience of childhood, and being parented (Elder, parent).

I've found you know having children really makes you question the spiritual, your spirituality. .. So if you're ambiguous before, you weren't sure what you believed you know, it's pretty hard to talk about that with your kids. Yeah to really think well what do I believe. So yes I think questioning as you become a parent is a normal part of becoming a parent but there probably are a lot more conflicting issues I think if you have the residential school issues. Even if you weren't there yourself, but a child of someone who went to residential school because it's passed down for sure. But they

were never taught how to be a parent. They were never parented (spouse, parent, provider).

- b. having reason and motivation to seek help and change behavior;
*During pregnancy is the time that I see women most likely to make a change. Sort of as an observation... if someone is having a lot of alcohol or drugs involved with their life or is not really very healthy, I find that when they find out they're pregnant, it tends to **turn them around** and they tend to work very hard to do the best they can for that pregnancy. So, as a result, I find that is probably most important time, as a health professional, to get in there and support them and give them good information and help them along, so that they are on the **right path** and they are well supported and well taken care of. And often I'll see that it lingers on. You know, that change of the nine months will have been so great, that after the baby's born they are able to continue on a healthier way. So, I think it's a really **great opportunity** (provider).*

- c. moving into a new social and family roles, with a new set of expectations, responsibilities and privileges:
When First Nations women are pregnant, and they get pregnant young... it is almost a rite of passage that they are moving into adulthood and that then there is a whole different expectation placed upon them... 'That's enough fooling around, that's enough of the teenage years, you've got a partner, you've made your choice, you're pregnant, you've got your baby, change your ways' (grandmother, leader).

I was involved at the birth- I was the first person to hold and talk to the babies-I have a very strong bond with my kids that started right from the beginning. -I am involved in all parts of my kids lives: the cooking, feeding, spending time, taking to school events, taking them to all of these things. ...[starting when they were babies] I let them handle my carvings at every stage-I would put the carvings down on the floor so they could handle them. They see and handle the carvings at every stage from the beginning to the finished product. They have an eye for carving now (father).

So your responsibilities are different, your whole viewpoint is different and your expectations... people expect different things. (For example) a young mom in the community, who's 16, had a new baby, her partner is young and there was complaints about how the baby was being taken care of, and the house and everything, and so now, the baby is two months old and the house is spotless and the baby is nice and fat and chubby and breastfeeding well and everybody is happy. But there was that real push I could feel it, from all the grandparents and all the relatives to say, 'get it together, that's enough, you've got to quit fooling around' (grandmother, leader).

- d. The importance families, communities and culture placed on children.
The real cultural belief is that all children are a gift from god. That is the one belief across the board every child is a gift from god. So no matter what the circumstances... if the woman is drinking, if she's doing drugs... it doesn't matter, that child is a gift. And that has an enormous influence on the women (provider).

In terms of pregnancy, I think that the community in general really embraces women who are pregnant, in a general blanket sense. There's an excitement about it and I think that, absolutely, everyone wants the best for the kids (parent, provider).

Once they realized that they were pregnant, whether they were First Nations or not ...they felt that that was somehow making something positive, in a life that was not very positive. when they found that out [they were pregnant] they worked hard at getting into some of the community programs that... their life turned around (provider).

e. The hope invested in children as to the pathway to a better future.

I was abused. I was neglected, I was physically abused by my parents, by my friends. This is something I don't want to happen to the next generation of children. I want things to be different for my kids. I want them to succeed- I can see they are going to succeed. They are doing well in school and they are going to have a chance (father).

Today, I tell my grandchildren, do not follow the steps of your grandmother. I got pregnant at 18, delivered at 19. And my hopes and dreams of my grandchildren are not to follow in my steps. .. I would hope for them that they would pursue their education and wait until they jump into a relationship (grandmother).

In the context of the intergenerational impact of residential schools, and Aboriginal Peoples determination to *Turn it Around*, the critical shifts of pregnancy and parenting collectively represent a huge opportunity for change. Successful health intervention programs must recognize, understand and incorporate the experience and opportunities that are represented by this collection of critical shifts. Successful programs are built on understanding and acknowledging the past, recognizing, respecting, and supporting people's efforts to work through their present life circumstances towards their hopes for a better future.

Facilitating Transformation: Safe and responsive support for Aboriginal parents

'Successful' programs understand the windows of opportunity that happen during pregnancy and parenting, but also recognize the added significance these have for Aboriginal people. Support is designed to *respond* to these opportunities in the context of Aboriginal Peoples' history, individual and families' unique experiences and circumstances, and as well as their hopes for the future. *Safe people, relationships and places* are at the center of successful programs. Through the relationships in which people feel safe, acknowledged and respected, secondary needs can be addressed.

Safe Places, Safe People and Safe Relationships

Safe places are important from multiple perspectives, because it has been *unsafe* to be an Aboriginal person. In participant's views, many mainstream health care environments have been demeaning, disrespectful or dismissive of their experience, and/or of them as people, creating emotionally unsafe spaces and interactions. Their home and community environments may not have been safe, and other public spaces such as schools may also

have not been safe. For example, of mainstream health care environments participants described:

Lots of the time they don't feel comfortable (at the health unit). It's not a culturally acceptable place. They are the only First Nations based there. The rules are very rigid. You have to come at a certain time. They don't understand the difficulty of getting rides, they don't understand the + laws, they don't understand how appointments can be missed... So, there's cultural stuff...and also they feel they're being judged on the way the baby looks, or how they talk or ... health nurses assume they're stupid or they're slow and they can't read, or, you know, these sorts of things. And it's not all, but these stories start and then another mom tells another mom that I went up to a health nurse and that nurse didn't treat me well... and then they just spread like wild fire and before you know it you have a lot of people who (won't go for care). So, they're more inclined to come to our program... They are more inclined to come to programs that are close to them geographically, where they'll see people that they feel comfortable with (grandmother, leader, provider).

Participants described the risks associated with care seeking that make safe places and safe people so critical:

It took a long time for trust to be established. That this was a safe place and that it had benefits versus the risks of coming into this place. I think we have to acknowledge for people who have been marginalized, the risks need to be weighed out versus those benefits. And you know some of the risks might be that it puts on the table that you are using a substance that could cause harm to the fetus or if you have other children at home and you identify that you are using a drug of some sort, there is a risk that a child's, the other children may be impacted by risk of proclaiming that issue. I mean just coming out of the closet and telling people that you have a problem has it's own risks. And that's where the trust factor comes in. You know if, if the way that that problem solving is handled is respectful, effective and client focused, then that's why people will come. The word of mouth is going to put it out there that it's OK to take that risk. (provider, leader).

You know it's easy for maybe you or I to say well I'll go to that drop in but if I've never been part of a group, if I've had bad experiences in school, if I've not completed my education and I might fear that I have to take notes and I'm illiterate or I might have to read materials and I'm illiterate, again one of my terrible learnings I'm ashamed to say, I worked with one woman for probably 10 weeks before I figured out she couldn't read. And this was in the first year I was working there. And after the woman had her baby she handed me back a whole bag of pamphlets I had given her and she said, here you might want to use this for your next client. And I thought, oh my gosh, they haven't even been opened. Dah! She would, when I'd hand her things, she'd say, oh, I've forgotten my glasses today. And you know it was back in the early years when we hadn't really made a big focus on illiteracy. And so, so that's a risk, someone will find out I can't read. Somebody will find out I can't do numeracy, I can't calculate costs. So I think

there are just as many risks as there are benefits and until that equation pops out that there are more benefits than risks, she's not going to come (leader, provider-TH).

Creating a safe place has added significance for some parents, who have few safe places or people to turn to:

Participant: That's the way the (street) law is.... That's the way the law is in the secret society... it's called a secret. When we say something or we know something about someone we don't say anything, because they'll come after us when they have the opportunity. They'll do something to hurt us. And that's just the way it is in street life. It's a true fact, it's street life. It's harshness.

Interviewer: So you didn't have anywhere to be safe.

Participant: Just the Friendship Centre in (town). Just the old Friendship Centre. It was the only place I would go out... they had coffee all the time, it was warm (parent).

Participants described the characteristics of a safe place, emphasizing the importance of the energy – or feeling of a place along with more concrete things:

Its also the environment, the place; its warm, friendly and caring and we have time for people. There is a different energy in programs built from an Aboriginal perspective. The pace is different, the environment is more relaxed, friendly, casual. It is a comfortable place to be with couches and the coffee room; there is a mix of staff that is similar to the mix of participants (including some) First Nations staff. We dress differently... I don't dress up to see participants ... We are people friendly, not appointment book friendly ... it feels like home here....Its built more around creating a home like atmosphere for participants, and not on an appointment book (providers).

Safe places are also about the nonjudgmental attitude of the whole program and organization:

And we want them to know that parenting isn't easy. Parenting doesn't come naturally for everyone. You are not always going to know how to do it, what to do, why to do it, when to do it. that everybody needs help and support, and if you don't have someone then you have us. Especially for young people that don't have family around or who have a fractured family and can't rely on their family. We let them know right from the beginning that it is okay to be overwhelmed and you don't have to be ashamed to ask for support (provider).

It takes, to begin with, trust... being able to trust....., so part of the program here was setting up a safe environment to have the women come and just be social together and talk about their experiences that they were having... especially for those moms that had just recently given birth. They could talk to the other moms who were expecting (provider, community member).

Safe people and relationships were described as essential to developing support for Aboriginal parents. As one provider said:

That's truly, I believe, what this type of work is... is putting ourselves into people's shoes, being treated the way we want to be treated, and not just using our head, but knowing that our heart is what makes people feeling safe coming to people and speaking from our heart is what makes change happen. It gives us the strength to make change (provider).

Aboriginal parents said that to heal, you have to face up to the pain, to the weaknesses, the problems, which can be very difficult. Therefore, you need supportive relationships with people who will not judge you, but will walk beside you, who will listen and acknowledge your pain, and your strengths along with the mistakes you may have committed as a human being. All actions are based on respect for all people. Respect has to be clear in everything we do and say, whether consciously or unconsciously, and influences people's feelings of emotional safety.

But I think the more First Nation's groups I know, the more I know just to treat everyone like individuals. It truly is. You know, you make these assumptions based on what they should be culturally and then you get challenged and told that's wrong. So, I find it's always best to work on them as individuals and say... and treat them as people, with respect, and then you get amazing results (provider).

The client-provider relationship is an opportunity to build understanding and capacity for healthy relationships. Building capacity for healthy relationships is both the means and the desired end of the work of support organizations and providers. The emphasis is on facilitating healthy reconnection and relationships with self, significant others and family, rather than creating dependencies on providers.

You have to have, I feel, for me to even connect with them and to be open and honest so that we can work with that, is to say, "What has life shown you". "What's your biggest issue, what's your biggest concern?". And when it's coming from them, then probably 95% of the time, people come out and say what their issue is... whether it's to try to quit pot smoking or trying to quit cigarette smoking or working on their partner to do that, or having a healthy relationship... because I've had that too. That was their concern, they wanted a healthy relationship and they wanted to treat each other respectfully so that their children could come into a world where they were treated respectfully (provider).

Safe relationships mean being open, and seeking to understand and acknowledge, rather than to judge. Along with acknowledging the pain, and the struggles, is helping to recognize the gifts and the assets that people have developed through their struggles.

That's all people want, is that acknowledgement. I think we all want that as people, trust that I can make my own decision and trust that I will do the best that I can with skill set that I have. And when you give me that credit... then I'm going to aspire for more (provider).

Connecting with people at a 'heart' or 'spirit' level through developing safe, trusting relationships was described as the most important difference from conventional care. This

became increasingly clear as the community based interviews progressed, so the question was posed, “What happens if you DON’T connect with people at a heart level?” One participant put it like this:

Interviewer: So I’m a First Nations woman, I’m pregnant, I’ve got a whole bunch of stuff that I’m carrying on my back, I’m coming in to meet you in your facilities... because I’m motivated because I know I’m pregnant and I meet you and that heart thing doesn’t happen... then what is the consequence of that?

Participant: If it (connecting at heart/spirit level) isn’t there, they’re not there. That’s what happens. People just don’t feel comfortable... and I can’t say that they’re not going to come back, but that would be my take... is that they’re not going to come back, because that’s the feedback that I have got from people who ... when they feel respected and when they feel accepted, when they feel that you care and they’ll test you out... and they know... they’ve been doing this for centuries, they’ve been through an experience for so long that they know from their teachings and also from their experience and all the kind of painful things that have happened what works and what doesn’t (leader, community member).

Many providers, leaders and community members were emphatic in their response to the importance of connecting with people at a heart level rather than just through a head or intellectual interaction. Their responses to the question posed above ranged from “You might as well pack your bags and head home” to “nothing. Absolutely nothing happens”.

Engaging in safe, mutually respectful, emotionally connected co-creating relationships, with a back-and-forth of knowledge, wisdom, humor, pain, acknowledgement, and caring, is very empowering, enriching yet demanding for both clients and providers.

Responsiveness

Responsiveness encompasses being holistic, being client-directed, and integrating ways of knowing into relationships and care in a way that is consistent with *Turning it Around*. Secondary needs are considered simultaneously, but not at the expense of creating safe supportive relationships for facilitating healing and capacity building. Secondary needs include what is often described as the determinants of health (e.g. adequate housing, income security, food security, success in school, safe physical environments, and REAL access to health services). Safe, trusting relationships are needed to develop an understanding individual circumstances and needs for things such as housing, food, advocacy with mainstream health and social systems, support to start and sustain further education. Individual access is then improved through one to one and family support, education and advocacy. Wider community or regional level patterns of poor access to the determinants of health can then be identified and more systemic or community wide interventions and programs developed in response to patterns of need.

Holistic health means many things. Participants in this study described holistic as:

She talked about everything being holistic... and I was right onboard with her there...that the spiritual, mental, emotional, physical aspects of life all need to be considered and in balance for us to really be able to participate fully in who we are and in our families and in our communities. And that’s a juggling act.

Anybody who has tried to become balanced knows that. But, so we need all kinds of support to do that... we need understanding, we need encouragement... you know there's just a... but that's the thing that (she) espoused in her belief system and sees herself sort of 'guided' by the ancestors in what she does. There is that kind of spiritual dimension in everything that takes place (leader, community member).

Client-directed is different than client-centered in that the client sets the agenda, makes the decisions and takes responsibility or lives with the consequences. For example,

Most of it, I truly believe, if I look back over the years, it's about 50-60% emotional support. I might have an agenda that I'd like to talk about breast feeding today, but that might be the last thing on their agenda, so if we can't do what's on their mind and their focus, then how can we really reach what we need to do (provider).

I think acting as a professional, keeping boundaries, confidentiality. I think there are a lot more factors to it than just trust. They do make the decisions for themselves. Whatever the decision is, it's not up to me to put a judgment on what type of a choice it is. It's ultimately their choice and they have to deal... and I've said to one of the women recently. 'You're the one who is having to make the choices, because you have to put up with the consequences of the choices you make'. So you know, that to me is both our boundaries at the same time (provider).

From client's perspective, boundaries are also important:

If I were a mother again, I would want to be comfortable asking the nurses for stuff. I would want to feel comfortable to go in there and say, "Okay, can you weigh my baby?" and not be oh my god... I don't want to go see her because she might ask too many questions. She might ask too many personal questions and all the other nurses and all the other employees will know about my life because it's not kept confidential. That's the biggest problem (parent).

Responsiveness means that many ways of knowing are respected and integrated into care. Ways of knowing can include, traditional knowledge, experiential knowledge, 'heart knowledge', clinical knowledge, and/or scientific knowledge. Participants agreed that ways of knowing were complementary and could be used effectively to support better understanding of why. For example:

And prenatally as well, we incorporate the Elders' teachings about the importance of keeping active. We would say that its important to be active so that you don't have a lazy baby that will make a hard delivery. If you think about it, today people who are in the field of fitness would call it inactivity. The Elders call it laziness and explain why it is important to the baby in a different way/different reason, but the end result is still the same- it's important to be active during pregnancy. And if I said "Dr. Paul Steinhauer said this", they are going to go 'who's that guy'. If I say 'our Elder Sara said this' they are going to go, 'oh yeah okay'-it has more meaning to them. But I also tell them that what the Elders say is

also supported by what the western scientists have found (leader, provider, parent).

A parent explains her struggle to fit into the dominant ways of knowing and being in mainstream society:

Participant: It was like two collision- this world with that world. And it took many years to realize how do I fit into this society? How do I adjust to this society? How do I meet up to their standards, their education, their lifestyle, their raising of their children was so different from the way we raised - we were raised as children. And ah, it was hard. It took me many years to adjust.

Interviewer: Did you find a way of adjusting that honored where you came from?

Participant: I went back to my traditional spirituality, my teachings- the holistic approach of the drums and the medicines, the sages. We never used sages, but we used cedar. Cedar- my doctor was both worlds and we used the medicines. We used the potpourri things they had here to put it in- the potpourri instead of the flowers and the whatnot (parent).

There consistently was an emphasis on bringing traditional knowledge in the foreground of care. Participants explain why:

We're trying to work with women to invite them to explore some of the traditional practices. Like before they give birth and try to incorporate it into a birth plan. And even through the pregnancy, to try to use some of those belief systems and have that guidance instead of you know white society telling you what you should and shouldn't do, you know (provider).

An emphasis on personal and cultural knowledge reverses the pattern of care from imposing and shaming based on mainstream knowledge and practices into a pattern of connecting and affirming cultural knowledge and identity:

Well I think that to be strong on the culture is such a good tool to try to turn it around because, you know I talked to a lot of women and there's a lot of anger, there's a lot of being made to feel ashamed of yourself. That sort of results in sex and abuse issues. And I think going back to the traditional ways of giving pride and food can help to undo some of that. I see that as the answer. And I think it will come. It's going to be slow. But I think that's the answer, going back to the traditional teachings and beliefs. I've been trying to get Elders to come in to, but my numbers aren't large enough to do a prenatal class as such but you know I used to do a lot of one-on-one. Trying to get Elders to come in and sit and talk about you know what it means to be a parent and do little crafts. Something traditional. To me that so valuable (provider).

Self-knowledge based on lived experience, values and priorities, 'heart knowledge' or feelings, and traditional or cultural knowledge, are also in the foreground. As one provider explains it is a deep level and very complex kind of work:

It's fascinating. You're dealing with people, you're dealing with human beings, you're dealing with human life, and it's not just a pregnant woman that you are

dealing with. You are dealing with a family situation, you are dealing with an anger that is all around that, with the emotion that is all around that... and it's very challenging... In some senses it's very disappointing, you know... part of the nursing is. But you know, you can't live in that mood either. And it's only when we talk about it at this level, at a deep level, that I understand that the work is a deep level work. It's not surface, it's not someone coming into your office and it's all nicey, nicey... it's not about that. It's not about that at all. It's at a much more complex... I guess the word is complex. It's much more complex (provider).

Providers, leaders and community members were clear that up to date scientific or expert clinical knowledge is important and expected. However it is in the background and integrated as it is needed. Providers described that deciding how and when to use different ways of knowing comes from reflective engagement with their own emotional wisdom, as well as being emotionally tuned into the people you are working with, and respecting where they are at.

Strategies

Safe and responsive support to facilitate *turning it around* for Aboriginal parents involves a collection of innovative support strategies. Examples include: reaching out-being visible, education, advocacy, including fathers and families, and an emphasis on the role of food.

Reaching Out/Being Visible

Reaching out to people, and taking the initiative to go to them when you know something has happened, or even if you haven't seen them as regularly was often mentioned as important. Reaching out acknowledges the barriers that the history of unsafe environments, people and relationships may have on care seeking. For example:

There is, I think, very positive support with (the community health nurse), who is able to get out into the homes and do a one-on-one, and that's what really works. There is a very big weakness, in a sense that people and their safety and their issues to walk into the health clinic, that is not working. They don't feel safe. They don't feel that they can trust the staff that work there. They don't feel trust in, not just the people, but in the whole entire government structure. Even sisters and brothers and things like that-fear is a big thing. Fear to talk to somebody about sex and sexual education, for example (community member, leader).

Reaching out was also seen as an indication of being with people because you cared about them, You were reaching out not just because it was your job and you were doing your duty. Reaching out is an example of following the local cultural codes, rather than imposing or limiting care to the cultural codes or norms of mainstream society. Reaching out was the '*way we do things around here –it's our way*'. The following comment describes impact that reaching out has on a provider's relationship with the community, as well as starting prenatal support, education and teaching as early as possible:

I've seen them from right after they were conceived, because we found out about it right away, and right through the process. And I know for myself and the community, it's really been incredible to get to know the community health nurse,

because I really think that the women in this community are fortunate that they get a lot of really good one-on-one support from somebody who actually goes out into the community to seek them out (provider).

Participants described how it felt for them when someone reached out:

We used to have people from (a partner organization) come down- drug and alcohol counselors- and I knew her to see her. And one day she came over here and she says to me, "(My name)", she says and I could feel my feathers getting ruffled. And she was telling me I was a dry drunk and there was no way I could believe her. I said, "No, I'm not." And she said, "You are. So start reaching out". So, after she left I started thinking about it. She just gave me some stuff to think about. So, I started believing her and that was my initial first step to going for help and going for treatments (community member).

Providers talked about the importance of reaching outside of the immediate community to deal with sensitive issues:

There was also times, where we had to report and sometimes when we reported here. That's where it ended- because people in the higher-ups didn't want to create problems in the community. So what I started to do was I had a connection in (a nearby centre) with one of the counselors, and I started reporting to them. And they'd report it (through the proper channels) and you know and there'd be an investigation. I even had to report (a family member) one time. It was hard, but it was part of my job (community member).

Being visible went hand in hand with reaching out:

To me, one of the most important things is being visible. That's the biggest thing. I found that being visible in the community, consistently. I found that the women come much earlier. And as they've gotten to know me I've found that some of the women have actually come within the first five weeks (provider).

Being visible involved "being there almost every week. Making a point of being there and that's what it's all about. Providers talked about creating a number of ways that people could connect with them, such as:

Well, I go into the one community one day a week. So I'll see Elders, I'll work with the mothers, I'll go to the school, I'll do baby shots... a lot of stuff, where people come in and they're looking for something or they want some screening done, and then I'll talk to them about that- about anything (provider).

As well as a sign of respect for local ways, and important to relationship building with individuals and the community as a whole, reaching out and being visible are credited with positive outcomes:

That's why our organization rates are even as high as they are because we are allowed to give a woman an hour and a half and some of our women get that hour and a half if they need it... and a lot of them need it. That's the difference, and that's what's making the difference If we didn't do that outreach work, our

immunization rates would be 40% as well. And we do the pregnancy outreach...that's why our women stop drinking (provider).

Education

Consistent with the understanding of the root problem (e.g. lack of teachings due to the intergenerational impact of residential schools, the vision for turning it around (e.g. building strength and capacity), education is a strong component of support programs. However, rather than just straight information giving, the goal and process of teaching/learning is empowerment. Providers described a one-to-one responsive style of teaching and learning that was noticeably different than simply providing people with verbal or written information. They described an ongoing dialogue with clients, which integrates client's knowledge of themselves, their goals and constraints, with provider's knowledge of such things as bodily functioning, the health care system, and client's rights. For example, while doing fieldwork, a young woman stopped me to ask if the nurse was free because she was thinking about getting pregnant. I shared my conversation with the nurse:

Interviewer: She explained to me that she had stopped smoking pot and she clearly understood the cycle, the menstrual cycle and all of that. She clearly knew when she was supposed to have sex.

Participant: Oh yes, now they're thinking about it. They know that if they want to get pregnant they want to be healthy. They want to have healthy babies. I teach them (about their menstrual cycle). That's one of the things. Every time my ovulation things up there (models and charts)- pretty much all those women know when they are ovulating now. And we all should. I tell them, don't feel bad if you don't know, 80% of the population doesn't. I mean, it's the truth. So, they all know. To me, that's empowering them. They are empowering themselves with that awareness of when they need to not have sex when, you know, if they are going out for the weekend, there is more planning involved than I have ever seen before.

Another provider explained the empowering intention of education, particularly as it relates to advocating for appropriate care in mainstream health care settings:

So the lack of knowledge creates disempowerment for people and the more knowledge that this woman has with this pregnancy going into the hospital to have her baby, the more knowledge she has, whether she uses the knowledge or not, the more empowered she's going to be to actually make choices in the hospital when she's in her labour she'll be able to make choices that are better for her. And it's just natural what her choices are. But as she makes those choices and they are informed choices. And that's what I'm really looking at with the women and the pregnancies because if they have knowledge, knowledge is power. That makes them more powerful, so they are less likely to put up with that type of treatment. So you know, we've all had situations where we've been in the medical system. I mean, I went through it myself. You go into a doctor and the doctor says this, this and this to you, and you just go, 'Hello, I'm not taking that. I'm not accepting this'. And you don't accept it for whatever reasons, whether it's instinct or what. But these people don't know that. And they're not able to verbalize it if

they don't agree with it and that's difficult because they don't have the knowledge to back it up (provider).

Providers work from an understanding the intergenerational impact of residential schools, and a respect for each individual's and families' unique experience. Expectations are based on understanding of where each person is starting from, what their goals and priorities may be, and how the current challenges and tasks of pregnancy may fit into their lives:

Participant: *They can come to me, and I can teach them about, you know, the early stages of pregnancy and conception and what it means and the development and how important it is to be sober, and that's I think the knowledge that the women are gaining. In the next pregnancy, it makes it difficult for them whether to keep the baby or not, or go through the pregnancy, because they already now know they have prior knowledge, but actually this is the development stage. And if this baby... if I'm drinking heavily at this stage then my baby could be born with FAS, so they... that knowledge puts the guilt into the guilt stage.*

Interviewer: *So it might not have a big influence on their (current) pregnancy but it would maybe change their behavior with subsequent pregnancies.*

Participant: *And that's the point (provider).*

Using tools to make pregnancy real, such as a pregnancy test and fetal heart monitor were used effectively within the context of a trusting relationship. As one provider described:

I had one mom who came monthly just to hear the heart beat, so that she could keep focused. It's powerful. I had one mom who didn't want to acknowledge that she was pregnant and didn't want the pregnancy and didn't feel like she was pregnant, and I said, well let's just really see, let's really see if you are, because maybe your not. Maybe it was a false positive. I knew she was but she was uncertain. I said, you are supposed to be about 12 weeks, lets just see. We found the heartbeat right away and she cried and cried and said... it just validated to her that she's pregnant and the heartbeat made her realize that yeah, she wanted to have this baby. And it's not like she couldn't go outside to a doctor to hear it, but she wasn't there. She did not want the pregnancy. And so, but she couldn't terminate it either (provider).

Including Fathers and Family

A relationship-centered approach creates opportunities and encourages families to develop stronger connections and building healthy relationships. For example:

I think it would be really useful as part of any prenatal support that they did try to encourage people to access the family resources. I guess that's something that I feel is lacking and say it's part of the prenatal. Before I went to that or when I was in that... they didn't really talk about anything like accessing anybody outside of the health system. It was just physically, this is what your labour will be like and it was useful. But about how to try to access additional support, like maybe mapping out who your support systems are and who do you feel that you can access? Because often they'll say, well you should access your grandmother, well what if you come from a family where that is not a good person to access.

For me, I had my aunt and my mom and my grandma. For another person, maybe it's a really good friend that they know who's had children. Who is it that you trust enough to get information from? But really, I guess supporting that whole process by actually bringing it up (parent, leader).

Parents described the immediacy of the support from family members:

I was just like, 'oh my goodness, I don't know if I can do this.' And at that point, I still thought 'I can't do this.' Certainly if there hadn't been anyone there to say, "Try it, you're going to try it right now..." I don't know if I would have. I might have just let them say, "Here, let's give her a bottle". So, I'm very, very happy that I had my family all around. They are all very pro-nursing (parent, leader).

The following comment from a new mother highlights that opportunities that new babies offer for families to connect, as well as decode any messages that associate shame with healthy ways of connecting with baby:

I think one of the other things that my aunt did to me when I was actually in the hospital, too, is she just said, "Let your naked baby lay on you". Let your naked baby lay next to your naked skin and don't feel ashamed about having that kind of connection. There's nothing wrong with it (parent).

Fathers were involved directly into the care relationship and activities as they were available, with positive results. For example:

It seems so natural here for when the dads are available. Most of them work in the woods and sometimes they have to shut down in the woods due to fire or accidents or you know, funerals, things like that. So, you know, on those particular days if they're in the village when (the nurse) is doing the prenatal, she welcomes them. She just, you know, enjoys having them both here. And she likes finding out how the men feel. How are you feeling about this thing? You know, have you felt the baby kick? And you know to hear them talk you know, they're beaming, you know. I don't think I've seen a dad come through here that wasn't just beaming when he left after the prenatal session. And yeah and it's a good, a good sign, I think that even that early involvement and that early education about what's happening with the wife's body is an important step for, for men to have, for all people to have. And its teamwork, it's not just all mom's job because the baby's in mom... you need that support and you need to know that Dad isn't going to go out drinking every weekend and leave poor pregnant mom home, you know, to deal with maybe other children, maybe morning sickness or nighttime sickness (provider).

Food- Feeding the body, mind, and soul

Food is both an urgent food security issue, and a positive, culturally based way of connecting, communication and teaching. Food was repeatedly mentioned as a positive, culturally based method of connecting, building relationships and passing on knowledge.

Culturally our way is to, when you feed someone, what, what you're feeding them is you're feeding them information once you're feeding them nutritionally also. You know, what I mean, is you're feeding their mind. You're feeding their body

and you're feeding their soul when you're giving them the respect. And you're giving them the honor that they deserve. Everybody needs to be well-respected when they walk in that door regardless of who they are. That's the way I envision it. Feed the mind. Feed the body. Feed the soul (provider).

Food is a way of nurturing, and creating positive emotional connections with other people and traditional culture:

(An Elder) came in and did some cooking sessions, and she would talk about love, putting love into the food and one batch of bannock turned out really beautiful. And she said, oh you must put a lot of love into that. And so I mean there is such a tradition of when you put love into food, it's just going to come out so much better and you're nurturing through your process that family or those guests (provider, leader).

Participants talked about food as a traditional way of imparting knowledge:

We talked about food and that you know getting together with people around a table is a way of, a really important way of connecting. Actually traditionally that's the way of imparting knowledge. My husband tells me this that when he was a boy if his parents, they didn't really scold him ever or tell him off. They'd sit him down at the table and while he was eating, they'd tell him the right way and the theory is that the knowledge goes down with the food and you retain it better (provider).

Food security, or getting enough of the right food, was also described as one of the most urgent concerns for pregnant and parenting families. Food insecurity is a multifaceted issue. For example, getting enough good quality food is an issue because of low or unsteady income:

The food budgeting is really good because it is encouraging healthy eating. And also they go through with you through their previous day about what you ate and makes you more aware of what you're eating. And, and also they ask you to draw the thing for them (parent).

Food insecurity is also the result of gap in skills, another consequence of the intergenerational impact of residential schools:

We also have to recognize that the parents of today's pregnant women may have been in residential schools. And so they didn't learn how to cook. Therefore, they didn't do what you're doing with your family. They didn't make from scratch or teach their children what is a balanced meal. So we've got some illiteracy (leader, provider).

Participant's described weaving together these two themes- food as a need and as a solution in their programs:

One of the things that we do a lot of at (our organization) is to have gatherings and, culturally when people have gatherings, they eat. So that happens an awful lot, so that people have the opportunity to come together in community ...to come

together and eat in a social kind of a way that I think provides a lot of good nourishment... besides food, it nourishes the soul and just provides people with just those kinds of things that maybe they don't have access to in their every day life. ...Things like community a sense of community... enough food. You know, we have women coming in there sometimes, that haven't eaten for three days because they've been feeding their kids... it's just... And then we have the cooking classes and things like that that (leader, community member).

Promoting breastfeeding is another example of a strategy that combines the need for adequate amounts of healthy food, and promoting healing, self-esteem and pride and strengthening mother-baby attachment:

Another tangent is the breast-feeding promotion. And that's the start of food security is we begin with breast-feeding and that sets up a whole dynamic of healthful eating and food security. And I'm just so proud that (our program) created a policy of support for breast-feeding. And they took some very tough steps around formula and said that they wouldn't be providing it because according to the new code, if you provide some, you must provide a year's supply. And so they took some really tough steps under (the coordinator's) leadership to create a breast-feeding policy (leader, provider).

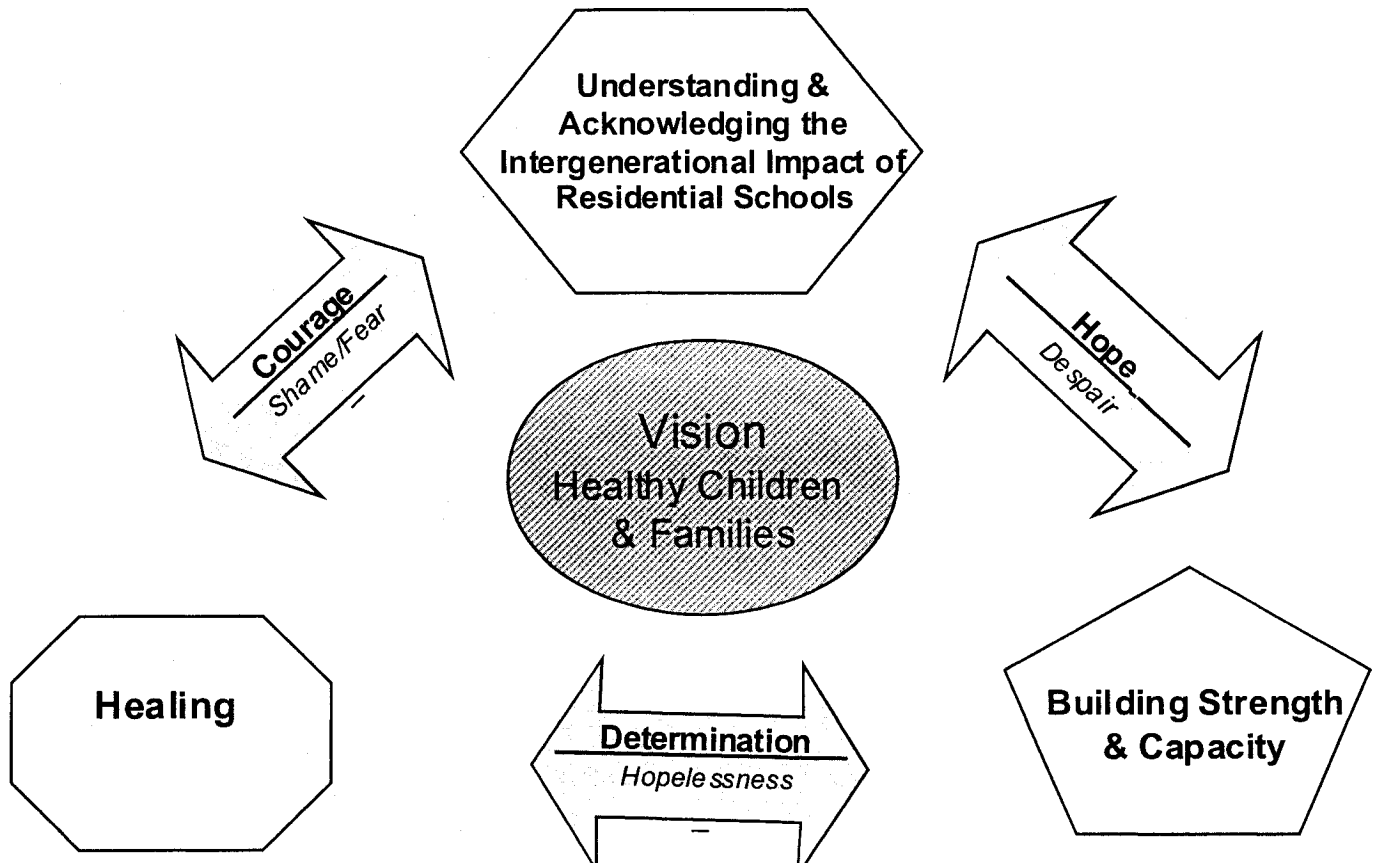
Advocacy

- *It seems I find more ways to play devil's advocate or I'm like one against 10 but I say you know everybody has to be out at eight, or nobody can go outside to smoke and I say no why not, this isn't a prison, you know. Just think how would I feel or how would they feel. Well you're not in prison. You are there to be healed of something or to be treated for something or to give birth to a baby. It should be a pleasant thing and not you know, I mean if, I will follow rules if there are there for the right reasons. Like who are the rules for, but to make it more convenient for the staff. (provider).*
- *When they do live off reserve, they're not able to ask for support from someone here, to say, "Can you come and talk to us?" Social Services for instance. We've done that for others. Like, a social worker telling them what to do. So, if someone goes from the community with them, it's a different story. Like someone like myself or (the support worker) or whoever. I've gone with them for visits to the doctor's office. This is true what they say (provider).*
- *I write notes for doctors in point form and I leave space for them to write answers so that they'll write the answers down and then I'll translate it back to them. I've done that numerous times. A client will say, "I want to ask my doctor these questions" We'll sit for about a half hour interview and I'll say, 'What questions do you want to ask your doctor what do you need to know what are your concerns?' and then I'll write it in a language that the doctor understands. And I'll leave a space for the answer and then I'll write the next question. So, it's all the client's questions and then I'll seal it up in a little envelope and I'll say, 'Take this to your doctor'. The doctor unseals the envelope, reads the questions, jots down the answers and then I translate it to them when they bring it back to me (provider).*

- *if there is an apprehension (child apprehension by provincial government). If we know anything about it before hand , we provide as much information as we can about the mom's participation in the program and home situation. The moms usually come right to us after an apprehension and hook up with one of our family support workers who can support them. They know the whole process inside out and backwards, and will go to court with them and support them throughout the process (provider).*
- *I went up and I sat down with her in the waiting room and I just looked at her and I said, 'Do you want me to go in with you?' And she said yes. So I went in with her and her husband into the doctor's office. She was vomiting, she was coughing excessively, plus the hours journey on a boat. So the doctor was a locum and she explained her situation- she'd already been three days before that to see him and they'd sent her home. Then her husband explained the situation to the doctor. The husband asked the doctor, could he admit her for even a day to see what could be done for her. And the doctor said, "No. I'm going to give you PR Gravol". So I sat there and I sat there and he was writing out the prescription and the husband asked again. That she told him- these people tend not to express themselves when they're very sick. So the woman will say, 'I'm not feeling well. I'm vomiting and I'm coughing.' That's how she would say it. If it was me that went into the doctor, I would probably burst into tears and say, 'I just can't stand this anymore. I'm at my wits...' So he was writing the prescription out and I just looked at him and I said (very forcefully) 'Doctor, you have to admit this woman. She needs to be admitted, so if you could possibly admit her for 24 hours, I would be more than grateful'. So after a few minutes of thinking about it he consented to admit her. She was in the hospital for 6 days on IV fluids and this was in the first three months of her pregnancy. So that's the level to which you have to advocate for people. And I wouldn't have believed it that the doctor didn't actually listen to her. This is again where the system doesn't understand (provider).*

Appendix A: Diagram of Turning it Around

Turning it Around: Vision and Pathway to a Better Future



References

ⁱ Chief councillor Charlie Cootes, Uchucklesaht First Nation, Port Alberni, BC May 1992 (RCAP, p.22).

ⁱⁱ Royal Commission on Aboriginal People, 1996, p.57

Appendix R:

Invitation to a Workshop and Luncheon

INVITATION TO A WORKSHOP AND LUNCHEON

March 15, 2005

Hello everyone,

What: *You are invited to a workshop to discuss the draft results of the 'Learning for Success' prenatal care research project. My main purpose is to share these early results with you and get your ideas and suggestions for preparing the final draft.*

When: *Monday April 4th from 9 to 12 followed by a catered luncheon.*

Where: *[Location not disclosed in published documents to protect anonymity]*

Who: *Staff and community members who did interviews last summer for Dawn's 'Learning for Success' research project on prenatal care*

Details: *An agenda and summary document will be emailed to you and/or available at the Health Center one week before this workshop. Please read and reflect on how the results are put together. I need your help to identify gaps and suggest improvements.*

RSVP: *Please contact [name withheld] at the administration office or email me at dawnsmith@ca.inter.net to let us know if you can come, by Monday March 28th (so we can make arrangements for food).*

I look forward to seeing you, sharing some good food together and learning more from your experience.

- ♥ *If you cannot come to the workshop, I would dearly love to get your feedback and ideas anyways, either in person, by email, or you can leave something for me to pick up at the Health Center.*

Appendix S: Submitted Manuscript on Participatory Knowledge Exchange

Creating a new dynamic in Aboriginal health care:
Community Health Nurses' Views of Knowledge Exchange

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Dawn Smith is a doctoral candidate in Population Health at the University of Ottawa.

Barbara Davies is an Associate Professor University of Ottawa. She is one of the Principals of the Ontario Training Centre for Health Services and Policy Research.

Abstract

We describe the development and evaluation of a workshop entitled '*Evidence-based Prenatal Care with First Nations Communities: A Dialogue between Nurses*'. The workshop was an opportunity for knowledge exchange between a researcher and community health nurses from across British Columbia towards the improvement of prenatal care in First Nations communities. Community health nurses emphasized the importance of a participatory model of knowledge transfer which included building trusting relationships between nurses, centering care around clients and encouraging dialogue with community stakeholders .

Introduction

Inequities in health between Aboriginal and mainstream Canadian populations have been well documented.¹ The capacity of community health nurses working in First Nations communities to facilitate and support change to their practice is growing in a number of ways. There are growing numbers of community health nurses with baccalaureate and graduate level education, who understand the tensions between dominant models of health care and First Nations ways of being. These nurses are positioned to play a pivotal role in facilitating a self-determining and capacity building approach in order to transfer knowledge to health policy with First Nations communities. However, the knowledge from community health nurse-First Nations community partnerships is virtually absent from the published research evidence that is used to inform health policy. Rather than innovative solutions, the literature is more often describing research documenting the problems faced by Aboriginal^a communities². This disconnect between the capacity of nurses to create solutions in partnership with Aboriginal communities, and the invisibility of such knowledge in the published literature raises questions about evidence based nursing such as: a) what knowledge is to be transferred, and where to and from (e.g. the fit of evidence for transfer into Aboriginal communities and contexts); and b) how and by whom will knowledge be transferred?

An opportunity arose to discuss these issues with community health nurses working with First Nations communities in BC in a workshop on evidence-based prenatal care. In this paper we briefly summarize the content and discussion generated by the

^a *The term Aboriginal Peoples "refers to organic political and cultural entities that stem historically from the original Peoples in North America, rather than collections of individuals united by so-called 'racial' characteristics" (Royal Commission on Aboriginal Peoples, 1996). These include the First Nations, Inuit, and Métis Peoples.*

workshop. The state of research evidence, and knowledge transfer concepts as they relate to maternal child health care for Aboriginal populations are reviewed. Feedback from workshop participants regarding use of research evidence and their experiential knowledge to improve prenatal care with First Nations communities is presented. Community health nurses supported a participatory model of knowledge exchange to improve prenatal care, and identified important issues about the knowledge exchange aspects of their work.

Knowledge Exchange and Community Health Nursing

The knowledge transfer movement as a means to improve health care has grown rapidly over the last decade. Terms such as ‘evidence-based practice’, knowledge translation, knowledge brokering, are increasingly being used, though the meanings for and relationships between the terms vary widely. Knowledge transfer is defined simply as the “process by which knowledge or research findings are applied”³. There has been a proliferation of resources to improve nurse’s access to and use of research evidence in their practice, such as best practice guidelines. For example, the Registered Nurses Association of Ontario has developed 28 guidelines, a “Toolkit” for implementing guidelines and an educator’s resource kit for integrating guidelines in educational curriculum and staff development⁴. Recommendations are targeted to nurses’ scope of practice such as assessment, symptom management, medication monitoring, education, referral, and community resources. A new Canadian text entitled ‘*Evidence-based Nursing, A guide to Clinical Practice*’ describes the importance of identifying and considering patient/client preferences and clinical expertise of the nurse as central to evidence-based nursing care. For example, unique characteristics of the health care

setting (e.g. band controlled health center), circumstances (e.g. geographically isolated communities) and available resources (e.g. skills and knowledge of community and health care team members) must be considered in evidence-based decision-making⁵.

Community health nurses must consider use of knowledge transfer concepts and resources in the best interest of the goals of our profession: facilitating people's capacity to control the things that affect their opportunities for health and life choices. We note that vulnerable populations are largely absent from the evidence that 'evidence based practice' is based upon. Second, mainstream health systems have been designed to address the needs and priorities of the general population, and may have not considered responsiveness to the priorities and issues of minority groups. For these reasons, approaches to knowledge transfer to improve health care require attention to how equity of access and responsiveness to minority populations are being considered. The idea of knowledge exchange offers a way to address these issues. Knowledge exchange is defined as "bringing communities together in a variety of ways in order that they a) understand each others' goals and professional cultures, (b) influence each others' work, and c) forge new partnerships⁶.

A Case Example: Maternal Child Health Care in Aboriginal Communities

In Canada, provincial governments are responsible for providing health services to Aboriginal People living off reserves. The federal government is responsible for providing health services for First Nations and Inuit People living on reserves through the First Nations and Inuit Health Branch (FNIHB) of Health Canada. Services are provided mainly by nurses to about 410, 000 First Nations people⁷ living in 602 communities south of the 60th parallel. Health services are focused on primary care and delivered in

community health centres and northern nursing stations. Approximately 1,200 registered nurses are employed by FNIHB or directly by the bands that manage their own health services with funds provided through contribution agreements with FNIHB⁸.

Federal level maternal child health programs. According to FNIHB's Community Health Program Manuals^b, maternal child health care is comprised of prenatal care, evacuation for birth to provincial tertiary care facilities, and postnatal care. In addition to the pre- and post-natal programs delivered primarily by nurses in partnership with community health representatives, there are a number of related programs. Related programs include the Canada Prenatal Nutrition Program, Fetal Alcohol Syndrome/Fetal Alcohol Effects Prevention Program, the Aboriginal Head Start on Reserve, Better Beginnings/Brighter Futures, and Canada's Action Plan for Children programs. Responsibility for these programs is shared by Human Development Resources Canada, Indian and Northern Affairs Canada, local Aboriginal governments, and Health Canada. The result is a collection of programs with independent administrative, governance and implementation systems, rather than a coherent integrated system of support. Further, continuity and depth of support and services over the childbearing continuum are disrupted by evacuation for birth, high rates of nursing staff turnover, and difficulty integrating the various programs offered on reserve.

Summary of the Literature on Maternal child health with Aboriginal Populations

A systematic search and summary of the literature was undertaken to identify best or promising practices for prenatal care. The problem of late or no access and poor use of care by Aboriginal women was well documented^{9,10,11}. The need for more culturally

^b The most recent edition of Community Health Program Manuals from Pacific Region (1998), Saskatchewan Region (1996), Manitoba Region (1995), and Quebec Region (1987) were reviewed.

appropriate care that is relevant to the needs and strengths of Aboriginal women and families was also identified across several studies^{12,13,14,15}.

Though many studies document this problem, few have tackled solutions in a comprehensive manner. In a search and review for evidence to inform prenatal care interventions with Aboriginal populations, and in rural and remote settings, the evidence base was weak. For example, there were NO systematic reviews of intervention studies with Aboriginal People or in isolated settings. The two programs of research with Aboriginal populations were close to urban centers^{16,17}. The quantitative studies with Aboriginal populations and in isolated settings were single studies, in single communities investigating a wide variety of interventions (e.g. targeting gestational diabetes, smoking or abuse during pregnancy) and populations (e.g. low risk, low income, adolescent mothers, First Nations women). Research evidence from program evaluations and qualitative studies also has identified themes and issues to be addressed in prenatal care programs and policies for Aboriginal people, though the majority was conducted in settings close to large urban centers. This example of the scarcity of evidence for basing program and policy decisions illustrates the conundrum of ‘evidence-based practice’ with Aboriginal communities.

The Workshop: A Dialogue with Community Health Nurses

A workshop was held with community health nurses working in First Nations communities in BC. This two hour session was part of a three day conference focused on improving maternal child health programs and practice. Participants rotated through concurrent sessions in groups of 25-30 participants, with each session being repeated three times. The purpose of the ‘evidence-based’ prenatal care workshop was to begin a dialogue regarding the use of evidence to improve prenatal care in First Nations communities. The workshop used a variety of strategies to encourage participants to

share their perspectives, and critically analyze how evidence *is* and *ought to be* used to improve prenatal care in their practice settings.

Workshop content and format. After briefly introducing the issue of knowledge transfer to prenatal care in First Nations communities, multiple ways of knowing were explored, such as personal, empirical, professional or ethical ways of knowing. An initial discussion was stimulated by reflection on and sharing of personal preferences for care based on experiences. Though research evidence from studies of prenatal care were shared, the focus of the discussion was to understand priorities for care based on the experiences of the expert community health nurses. The focus of the workshop then moved to knowledge transfer to improve prenatal care, and the example of the Registered Nurses of Ontario's Best Practice Guidelines was shared. Finally, participants discussed a participatory knowledge transfer approach to improve prenatal care with First Nations communities. Stakeholders to a participatory model of knowledge transfer to improve prenatal care in their practice environments were briefly considered. Some time was allotted at the end of the workshop to complete a feedback questionnaire.

Analysis of feedback. Responses on feedback forms were entered into a database using MS Excel. Data entry was checked by two people. Analysis of frequencies of possible responses was calculated for questions using a likert scale. Participant comments were inductively analyzed for each question, and grouped according to common themes emerging from the data¹⁸. The number of responses for each question was recorded.

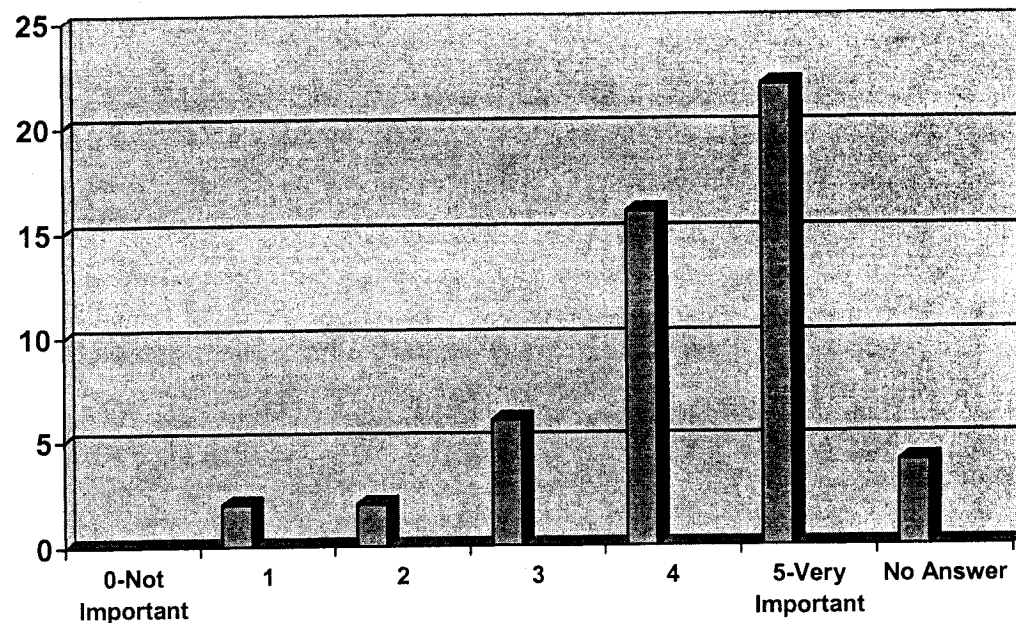
Participant Feedback on Knowledge Transfer with First Nations Communities

Eighty one nurses working in First Nations communities in BC participated in the conference. Fifty two of the 81 conference participants completed a feedback questionnaire at the end of the dialogue on knowledge transfer workshop. The majority of

participants worked as community health nurses (73%), but combined home care /community health roles (9.6%), manager/administrator (11.5%), and nurse educator/consultant (5.8%) were also represented. Participants worked across diverse geographical settings (e.g. urban, rural, isolated) and health care jurisdictions (e.g. FNIHB managed, Band managed or Tribal council managed services).

Model of knowledge transfer. Participants responses to the question, ‘In your view, how important is use of a participatory model of knowledge transfer to improve prenatal care in First Nations communities?’ are shown in Figure Three. The majority of community health nurses reported that a participatory model of knowledge transfer was important or very important when working with First Nations communities. Participants comments included: *“this is the only way to work in First Nations communities”*; *“critical to success and capacity building”*; *“without participation, nothing will change”*; *“it is key to improved care. Not only prenatal but all types of care”*.

Figure Three: *Frequency of Participants' Rating
Importance of a Participatory Model of Knowledge Transfer*



Further, participants comments emphasized the importance of *“building trusting relationships”, “building capacity”, “developing mutual understanding”, “centering care around clients”,* and developing practice to be *“inclusive of elders, aunties, other moms, dads, etc”*.

Stakeholder analysis. Stakeholder analysis identifies priority target audiences for knowledge transfer strategies to increase community support to improve prenatal care, or to improve early access and use of prenatal care. The workshop was planned to include small group work to identify stakeholders, and develop some initial ideas regarding their support and influence for a knowledge transfer strategy to improve prenatal care. Participants were asked to identify people in their practice setting who have influence over how changes are made to improve prenatal care. Participants identified 34

stakeholders groups that were then summarized in the eight categories shown in Table Four. Workshop participants' ratings of stakeholder influence were coded as either high influence or medium/low influence.

Table Four: *Stakeholder Groups, Influence and Support*

Stakeholder Group	Influence	
	High	Medium or Low
Band Leadership and Administrators ⁱ	18	1
Family/Friends & client's support network	15	1
Community Health Nurses	14	-
Community Health Representatives	13	3
Health Leadership and Administrators ⁱⁱ	8	4
Health Staff	8	1
Physicians	7	1
Elders	7	-
Local prenatal programs	4	-
Other local/regional health agencies	4	2
Community	5	2
Clients	7	3

i. Band leaders, Elders, Chief and council, Band manager

ii. Board of Directors, Health Director/Administrator

The first four groups: band leadership/administration, family/friends or clients 'proximal' support network, community health nurses, and community health representatives, were

the most frequently identified as having high influence. The community health nurses rating of influence of these first four groups clearly identify them as priority target audiences. Developing a better understanding of their views, values and priorities related to prenatal care, and creating informal dialogue on the issue between these groups is one way to engage in participatory knowledge transfer.

Community health nurses in the first workshop raised an additional question:

‘Who is responsible for knowledge transfer? As community health nurses I can’t see us adding this to our workload as it is an enormous amount of work’. This question sparked a dialogue that reinforced participant’s emphasis on the importance of stakeholder participation, ownership and control over knowledge transfer to improve practice. However, it also underscores the costs of community health nurse’s knowledge transfer work, and identifies the need of nursing leaders to recognize and acknowledge this work.

Implications of Participants’ Feedback on Knowledge Transfer

What are the implications of this analysis and feedback from community health nurses working in First Nations communities regarding knowledge transfer to Aboriginal health policy? Knowledge transfer opens up opportunities for changing the way that Aboriginal health policy has historically been developed. This beginning dialogue needs to be deepened, extended to other stakeholders in BC and across the different regions of Canada, and taken up between stakeholders at a community level. Further efforts to engage community health nurses and other community stakeholders, who will ultimately be responsible for knowledge transfer work to improve Aboriginal health programs and policy are needed. Research to systematically examine and explicate all stakeholders

perspectives on viable, sustainable models of knowledge transfer that will facilitate Aboriginal communities' capacity for self-determination is warranted.

Ideally, discussions can be linked and dialogue encouraged between and among stakeholder groups and levels using a combination of face-to-face and electronic media. Information technology offers a medium through which stakeholders in geographically dispersed communities can participate in informed dialogue. For example, the portal being launched for nurses working in First Nations communities could be used to continue the dialogue with community health nurses working in remote geographical locations. Organizational support for community health nurses to participate in continuing education may increase their comfort with using this communication medium.

A better understanding of the perspectives of the stakeholder groups identified by community health nurses must be developed. For example, initial focus groups could be organized through their professional or administrative organizations, such as with the community health representatives (National Indian and Inuit Community Health Representative Organization), the Health Directors Committee organized through the Assembly of First Nations, or Chiefs organizations such as the BC Chiefs Health Committee.

Limitations

Though a beginning, this dialogue on knowledge transfer was brief and limited to a small number of community health nurses working in one province. Not enough time was provided for community health nurses to complete the feedback forms. The agenda of the workshop did not allow enough time to discuss each issue. Feedback from participants included comments such as "*do you mean transferring knowledge from*

community to nurse, or from research to nurse to community? (this was) unclear in your presentation". However, such comments may also signal support for inclusive dialogue to develop knowledge transfer approaches that fit with First Nations' communities ways of knowing, being and doing, build capacity in process, and respect their fundamental wish for self-determination.

Conclusion

There is a growing imperative for change to self-determining, health and capacity building policy for Aboriginal people. Emerging concepts such as evidence-based nursing, knowledge transfer and exchange create opportunities to raise issues such as what knowledge, for what purpose will be used by whom to improve care with Aboriginal and other minority populations. Results of a dialogue with community health nurses working with First Nations communities strongly supported a participatory model of knowledge transfer. Community health nurses are geographically, systemically, relationally and professionally located to play a critical role in transfer of knowledge between stakeholders to improve programs and policy for Aboriginal People. Greater recognition and support for this complex and deeply engaging area of nursing practice is needed.

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