A COMMUNITY-BASED PARTICIPATORY APPROACH TO PLANNING CHILD AND YOUTH HEALTH SERVICES IN NORTH WEST BRITISH COLUMBIA: FINDING COMMON GROUND

by

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Abstract

A growing recognition of the need for participatory health services research requires multiple stakeholder collaboration between researchers, clinical service providers, managerial and policy decision-makers, and the public. Recent Canadian provincial and federal reports support the need for participatory inquiry, yet little is being done in practice. This thesis explores a community-based participatory research process for planning child and youth health services and proposes methods to close the gap between research and practice.

The study took place in the North West Health Service Delivery Area of British Columbia. This large geographic region represents over one-quarter of the provincial land mass, yet is home to <90,000 people. Approximately 30% are children and youth 19 years of age and under. Approximately 22% of the residents are Aboriginal.

A participatory research approach was used with a mixed methods design. The priority component was qualitative. Qualitative data were collected and integrated through a unique sequence of methods, including semi-structured interviews, focus groups, and a search conference. Qualitative data were analyzed using a constructivist grounded theory method. The nested component was quantitative. Quantitative data were accessed from a provincial health services utilization database. Geographic information systems (GIS) software was used as a tool to map selected data, which was incorporated into the search conference.

Three general conceptual categories emerged from the data: perceptivity about, emotivity generated by, and inclusivity in, the health system. Two core conceptual categories emerged: boundaries and boundary objects. Three knowledge boundaries were introduced: syntactic, semantic, and pragmatic, building upon and supporting empirical research on innovation and technology development. This study proposes a fourth knowledge boundary: phronetic. The characteristics of boundary objects occupying this phronetic boundary are fluid, real-time,
participatory, and collaborative in locally-situated, multi-stakeholder, boundary-crossing settings. These boundary objects facilitate the melding of knowledge and action in ways that are relevant to stakeholders in their local realities. A conceptual framework is proposed to guide and unify participatory research and planning processes.

This research is expected to lead to more effective multi-stakeholder, community-based approaches to the planning and development of network models for child and youth health services.
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<td>ADTSPEC</td>
<td>Local/Regional Referral Analysis</td>
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<td>AR</td>
<td>Action Research</td>
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<td>ASUR</td>
<td>Age-Standardized Utilization Rates</td>
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<td>BC</td>
<td>British Columbia</td>
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<td>BCCH</td>
<td>British Columbia Children’s Hospital</td>
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<td>BCMCFD</td>
<td>British Columbia Ministry of Children and Family Development</td>
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<td>BCMOH</td>
<td>British Columbia Ministry of Health</td>
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<td>BCMOHP</td>
<td>British Columbia Ministry of Health Planning</td>
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<td>BCMOHS</td>
<td>British Columbia Ministry of Health Services</td>
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<td>BREB</td>
<td>Behavioural Research Ethics Board [UBC]</td>
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<td>C&amp;W</td>
<td>Children’s &amp; Women’s Health Centre of BC</td>
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<td>CAPHC</td>
<td>Canadian Association of Paediatric Health Centres</td>
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<td>CAS</td>
<td>Complex Adaptive Systems</td>
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<td>CBPR</td>
<td>Community-Based Participatory Research</td>
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<td>CCASUR</td>
<td>Continuing Care Age-Standardized Utilization Rates</td>
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<td>CCCHR</td>
<td>Centre for Community Child Health Research</td>
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<td>CCHSA</td>
<td>Canadian Council on Health Services Accreditation</td>
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<td>CCHSE</td>
<td>Canadian College of Health Service Executives</td>
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<tr>
<td>CEO</td>
<td>Chief Executive Officer</td>
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<td>CFRI</td>
<td>Child and Family Research Institute</td>
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<td>CHNLMFV</td>
<td>Child Health Network of the Lower Mainland and Fraser Valley [of BC]</td>
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<td>CHSPR</td>
<td>Centre for Health Services and Policy Research</td>
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<td>CHSRF</td>
<td>Canadian Health Services Research Foundation</td>
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<td>Acronym</td>
<td>Full Form</td>
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<td>CICH</td>
<td>Canadian Institute of Child Health</td>
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<td>CIHR</td>
<td>Canadian Institutes of Health Research</td>
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<td>CPRN</td>
<td>Canadian Policy Research Networks</td>
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<td>EBDM</td>
<td>Evidence-Based Decision-Making</td>
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<td>EIDM</td>
<td>Evidence-Informed Decision-Making</td>
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<td>ESRI</td>
<td>Environmental Systems Research Institute</td>
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<td>FNIHB</td>
<td>First Nations and Inuit Health Branch [of Health Canada]</td>
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<td>FOIPP</td>
<td>Freedom of Information and Protection of Privacy</td>
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<td>HA</td>
<td>Health Authority</td>
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<td>HOSPCOMP</td>
<td>Hospital Comparative Reports</td>
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<td>HSDA</td>
<td>Health Service Delivery Area</td>
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<td>HSRC</td>
<td>Hospital Services Restructuring Committee</td>
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<tr>
<td>IRPP</td>
<td>Institute for Research on Public Policy</td>
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<tr>
<td>KT</td>
<td>Knowledge Transfer or Translation [in this study the latter is used]</td>
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<td>KTE</td>
<td>Knowledge Transfer and Exchange</td>
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<tr>
<td>LCDDU</td>
<td>local, complex, diverse, dynamic, unpredictable</td>
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<td>LHA</td>
<td>Local Health Area</td>
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<td>LHIN</td>
<td>Local Health Integration Network</td>
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<td>MAUP</td>
<td>Modifiable Areal Unit Problem</td>
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<td>MOE</td>
<td>Ministry of Education</td>
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<td>NW</td>
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<td>PAR</td>
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CHAPTER ONE: Introduction

Journey – “an act of going from one place to another”
(Concise Oxford Dictionary, 1995)

The Problem

Despite growing evidence in the academic and grey literature, including numerous federal and provincial commissions and reports on health reform, a participatory approach to planning health services has seen little uptake. Health system reform and redesign in British Columbia (BC) specifically included goals of community participation and local input into planning and decision-making (BC Ministry of Health Planning [BCMOHP], 2001a, 2002a; BC Ministry of Health Services [BCMOHS], 2005a; BC Royal Commission on Health Care and Costs, 1991). Yet, there is surprisingly little follow-through at the community level.

Similarly, health services planning practices remain at odds with research evidence. As Gray (1997, p. 1) poignantly observes, “[a]t present, many healthcare decisions are based principally on values and resources – opinion-based decision-making; little attention has been given or is paid to evidence derived from research – the scientific factor.” In this vein, the National Forum on Health (1997) warns of the gaps in, and misuse of, evidence. This report notes that means have yet to be developed to assist decision-makers, and highlights the demand by patients for greater involvement in decision-making.

This study addresses the gap between actual practice and the research evidence on how to approach health services planning. It investigates the problem of how to effectively engage stakeholders at the local community, regional, and provincial levels of the health system in order to find practical solutions to improve service delivery to children and youth living in North West BC. The following sections in this chapter introduce and highlight a number of on-going challenges related to this journey, underscoring why this study is timely and relevant.
The Health Services Planning Environment in British Columbia

Patients should be at the centre of the health care system, and the system/services should be organized, coordinated and delivered around the needs of patients. The BC Legislative Assembly Select Standing Committee on Health Report (2001) reinforces this intent in its own words: “patients first”. BCMOHP’s New Era document (2001a) reinforces patient-centred health care, specifically that “[p]atient-centred care means finding a way [emphasis added] for government, unions and health regions to work together to ensure that patient needs come first.” (2001, p. 14). However, the recommendations are silent on how to go about this. The New Era document explicitly states that high quality, patient-centred care is the provincial government’s first long-term health goal. It also acknowledges three general categories of obstacles: (a) a history of inadequate planning and management, (b) the growing gap between what the public wants and what the system can deliver, and (c) a lack of sustainability. The three-year service plans (2002/03 – 2004/05) for both the [then] BCMOHP\(^1\) (2002b) and the BCMOHS (2002b, p. 2) include: meeting public and provider expectations, and ensuring “appropriate and productive stakeholder participation [emphasis added] in the development of planning approaches in a newly configured health structure,” The BCMOHP’s Service Plan calls for “[i]nclusion of patient and public perspectives [emphasis added] in health planning and policy development.” These intentions are extremely important and timely. However, a gap persists in how to go about it and, equally important, who will do it.

Anderson & Boothroyd (1983) explored the differences and significance for planning in public agencies stemming from the lack of distinction between social planning (in communities, societies, and agencies) and corporate planning (how to rationally reach goals). They suggest that tensions will arise if direction is solicited and tools used from the corporate planning world for

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\(^1\) The provincial government dissolved the BCMOHP shortly after it was created and its functions were largely re-incorporated into the BCMOHS.
what are social contexts. This may be the chronic difficulty experienced in BC. The former New Democratic Party attempted to engage in a social planning ethos during their tenure from 1991 – 2001, but barely got past the rhetoric stage in health services and systems planning. On the other hand, the Liberal government, commencing with their rise to power in 2001, has taken a corporate (business) stance and pushed for fast, fiscal bottom-line results in the health system. They risked using a corporate planning context at the expense of a social planning context. This was due to various perceptions that the community involvement approach failed under the previous political era, even though health reform has never been systematically evaluated in BC. Thus, it is important to recognize the difference between social and corporate planning. Either or both approaches may be appropriate, but this is largely dependent on where and what is being planned.

**The Child and Youth Health Services Planning Environment in BC**

Planning health services for children and youth poses even more complex challenges than for adults. Further to meeting the usual health service delivery needs of the general population, several requirements unique to children must be addressed, including: (a) the child/family unit; (b) voice and advocacy; (c) time-sensitive developmental imperatives; (d) issues around service transitions; (e) pediatric generalist, sub-specialty, nursing and other professional human resource availability; and (f) highly technical and centralized tertiary/quaternary care. Balancing competing needs with resource availability (human, technical, physical, and fiscal) presents significant challenges, especially in rural and remote areas of the province, such as the Northern Health Authority (NHA). This, combined with the ripple effect of restructuring, service consolidation, and changing hospital roles, such as local availability of pediatric beds, presents challenges beyond the purview and expertise of any individual perspective, professional discipline, government ministry, or public service sector. Indeed, ripple effects and challenges
did arise during reform, presenting a unique opportunity to understand and develop new insights into addressing these shortfalls.

**The Child and Youth Health Services Planning Environment in North West BC**

The NHA’s *Health Service Redesign and Budget Management Plan 2003-04 to 2005-06* (NHA, 2003) identifies key priorities intended to align with the 2003/04 Performance Agreement with the BCMOHS. These entities are discussed in Chapter Two. A number of core public health programs are to be developed, including “an NHA-wide system of integrated services focusing on...child/youth/family” (NHA, 2003a, p. 3). This is to be accomplished through established “[m]ultidisciplinary community health planning teams for Child Youth Family” (NHA, 2003a, p. 11). Additionally, this plan takes into account current provincial restructuring by the BC Ministry of Children and Family Development (BCMCFD), which could see two regional structures for children’s services – Aboriginal and non-Aboriginal – the boundaries for which are planned to be coterminous with the NHA.

The NHA’s community consultation exercise (NHA, 2004) unsurprisingly reiterated many of the same issues. For example, one of the conclusions about how community groups and other agencies could work together revolved around the need to improve communications within the NHA:

> Many ideas for improving this situation were voiced, the main one being that people are keen to see some sort of mechanism for improved and ongoing communications with Northern Health that would involve community input into decision-making and planning, and the ability, at least at some level, to deal locally with local needs (p. 20).

Where children and youth were mentioned in the consultation report, the key issues facing this population group were not specifically highlighted, other than the crisis around youth mental
health services in the North West, and a need for a greater focus on the health of women and children.

Moving Beyond the Rhetoric

The foregoing examples represent good intentions for patient-centred, collaborative, provincial health system reform. Yet, very little has changed on the ground where this effort was purportedly going to make a difference. Having been in the health services industry for a number of years, I suspected that this observation would hold true from multiple perspectives, including the public, clinical service providers, managers, and policy-makers. This was confirmed by participants during the course of this study. This inertia spans different government ideologies, many years, multiple perspectives, multiple jurisdictions, and speaks to the growing, but largely unheeded calls for action. There is an urgent need to move beyond good intentions – to actually do something tangible and relevant to those who provide, manage, and use health services at ground level. Numerous reports from other provinces and the federal level are outlined in Chapter Two, attesting to these issues in greater detail.

The Aim of this Study

The aim of this study is to explore a community-based participatory process for planning child and youth health services in a rural area of BC, and to close the gap between what the research is saying and what is being practised. This will be accomplished through an emphasis on a multiple stakeholder, community-based participatory research and planning process. The study does not attempt to identify the actual health service needs. These needs will be identified through a sustainable, community-based planning process at the local level resulting from, and contiguous with, this study. While there was no guarantee at the outset, I expected that this research approach would help to empower community stakeholders and facilitate sustained action at the local level once the groundwork created by the study was completed. In this way, I
anticipated that the study would be relevant in three ways. First, as a participatory research approach, it would model how to go about child and youth health services planning at the rural local level in the context of, but not directed or dominated by, the broader health system. Second, this approach would facilitate action to address, be relevant to, and respectful of, the nuances of local communities throughout the North West. Third, this participatory research and planning process could be adopted in other jurisdictions in British Columbia, perhaps even more broadly. If successful, it could also serve as a model for collaborative planning in other population groups, such as the elderly who present comparable health service planning challenges at the other end of the life-cycle.

The Research Questions

In qualitative research, it is not uncommon for the preliminary research question(s) to evolve and become more refined over the course of the study. This is especially true when (a) a participatory research approach is taken, (b) participants are invited to be co-researchers, and (c) there is an expectation of an emergence of ideas over time, as is the expectation here. The preliminary, central, multiple research question was initially posed as: What is the process by which child and youth health service needs can be identified and understood, how can this process guide the development and utilization of health services, and how can this process inform evidence-based practice by decision-makers?

Indeed, the research question did evolve during the course of the study. The question of “what is the process...” was refined to: How does a participatory research process inform planning and guide stakeholders involved in child and youth health services in North West BC? I was made aware early in the data-gathering phase that a participatory approach was desired; less clear was how to effectively conduct it. In that respect, the study itself became a means, a
process, and a real-time journey for conducting research and creating action, together with the participants. This emergent role is discussed in the findings in Chapter Four.

Additionally, there were three preliminary sub-questions:

1. How can a complex, adaptive systems lens assist in reframing multi-stakeholder conceptualization of the health system?

2. How can community be (re)defined, and how does multi-stakeholder involvement contribute to community-based participatory planning processes for child and youth health services?

3. What is the role of health care geography in understanding the spatial characteristics of health services utilization, and how can this be used in participatory planning processes?

These sub-questions essentially stood; however, they were addressed from my perspective as researcher, not from the perspectives of the study participants as I had originally, and perhaps naively, envisioned.

All of these questions were developed prior to determining the method I would ultimately use for data analysis: constructivist grounded theory. It is a characteristic of qualitative research, especially when generating theory from empirical data, to accommodate flexibility and allow decision-making to occur in real-time (Mason, 2002). Similarly, this characteristic is described by Lewis (2003, p. 47) as a “key strength…a continuing process which calls for constant review of decisions and approaches.” A constructivist grounded theory method requires the researcher to discover the main theme, category, or storyline emerging from the data provided by the study’s subjects. As the study proceeded using multiple methods for data gathering, the line of questioning I used during subsequent data gathering stages became more closely aligned with my emergent thinking and that of the participants.
The Significance of this Study

This study is significant in how it approaches the research problem, conducts the research, and links research and practice in order to address the complex health services issues facing children, youth, and families in North West BC. Equally significant is the on-going challenge of incorporating research findings into the “real world of health service delivery” (Saunders & Wanke, 1996, p. 34). As this study is concluding, it is noteworthy that the BC government has just recently publicly recognized, and de facto endorsed, a particular health services research strategy for children and families (BCMCFD, 2005a):

Research confirms that collaborative planning and decision-making, and integrated service delivery for social programs that best reflect and meet the local needs of children and their families, are most likely to serve communities well and maximize positive, effective results from available resources (p. 5).

This Ministerial-level acknowledgement highlights the importance of health services research on the complex issues related to child and youth health. How to use such research to address a number of key factors remains unclear, but such research should: (a) involve multiple stakeholders in the health system to gain a broader perspective, (b) be participatory and collaborative, (c) integrate research and practice, (d) derive and integrate key concepts from multiple disciplines, (e) include both research and action components to effect change (particularly at the local level of relevance), and (f) address the issues across the local community level to the health system level. This study incorporates these components in striving to attain integrated health services for children and youth in North West BC.
Delimitations of the Study

Delimitations are factors that are controlled by the researcher, as opposed to limitations which may affect a study, but are not under the researcher’s control (Roberts, 2004). The main study period extended from Summer, 2003 to Spring, 2006. The study site was confined to nine Local Health Areas (LHAs) comprising the North West Health Service Delivery Area (HSDA), one of three HSDAs in the NHA. See Figure 1.

A limitation (as opposed to delimitation) of the study, was that the Nisga’a Health Authority declined to participate. The reasons for this are outlined in Chapter Three. However, given the broader health system perspective that I believed essential to this study, several participants were identified and invited from other geographical areas, including:

- NHA corporate offices in Prince George
- BC Children’s Hospital (an agency of the Provincial Health Services Authority [PHSA]) in Vancouver;
- First Nations and Inuit Health Branch (FNIHB) of Health Canada in Vancouver
- Ministry of Health Services in Victoria, and

I delimited study participants to four stakeholder groups: (a) general public/service recipients, (b) clinical service providers, (c) managerial decision-makers, and (d) policy decision-makers.
My Philosophical Orientation, Beliefs, and Biases

In using a participatory research approach, it is important to recognize and declare my philosophical orientation, beliefs, and biases in the conduct of this study. These can be understood in three contexts: (a) my professional experience in health service delivery with recent emphasis on child health, (b) my academic preparation during this PhD program, and (c) my epistemological self-awareness.
My Professional Experience

Professionally, I have held a number of senior management positions which, over two decades, has added immensely to my repertoire of skills in the area of health services planning at the local community, regional and provincial levels. During the 1980s, I completed a Master’s degree in Health Services Planning and Administration, Department of Health Care and Epidemiology, University of British Columbia (UBC). During this period, I also coordinated the planning of a major hospital expansion project in Chilliwack, BC, a rural community situated in the Fraser Valley, approximately 110 kilometers east of Vancouver. It was during these graduate studies that I became interested in systems theory. I consciously tried to incorporate a systems thinking approach in my planning and administration roles. Given my simultaneous academic and work roles, I embraced the challenge of bridging research and practice on a day-to-day basis.

Other progressively senior management roles followed, leading up to my recruitment in 1989 as Executive Director, Sunny Hill Health Centre for Children, Vancouver, BC. In this role, I was responsible for overall leadership and management of Sunny Hill, a provincial, tertiary resource providing specialized services to children and youth with developmental disabilities. Sunny Hill provided a large clinical and education outreach program with traveling clinics throughout the province on a regular basis. I became progressively aware of the issues facing rural and remote families, especially those living with special needs, and the complexity of planning and providing services. I believed in and promoted a collaborative approach, one of the key values espoused at Sunny Hill.

Province-wide health reform in the mid-1990s included a government-mandated merger of the BC Children’s Hospital, BC Women’s Hospital & Health Centre, and Sunny Hill Health Centre for Children. In this transitional period, from 1996 to 1997, I was Acting Vice-President, Programs, Planning and Outreach at Children’s & Women’s Health Centre of BC (C&W). I was
also CEO, Sunny Hill Health Centre for Children, responsible for planning, site redevelopment, and provincial outreach, and I continued as CEO, Sunny Hill during the merger process.

I was subsequently appointed Vice-President, Health Promotion, Community and Site Services at C&W, 1997 – 1998, responsible for health promotion/child injury prevention, pediatric partnerships, community outreach, BC Reproductive Care Program, telehealth, site planning & construction, plant operations, environmental services, service delivery planning, and special projects.

Another reorganization lead to my becoming Vice-President, Planning and Network Development, 1998 – 2000. I was responsible for service delivery planning, facilities planning and site redevelopment, network development (including child health network initiative, intra-regional and inter-regional provincial partnerships/outreach activities and alliance-building initiatives), health promotion and injury prevention, and telehealth. I was increasingly involved with child and youth health issues at the provincial level. Through my portfolio, I consistently tried to broaden awareness of the need for enhanced relationships between local communities and access to specialized tertiary/quaternary services uniquely available in the Lower Mainland. I was a senior executive member of the Strategic Planning Committee 1998 – 1999, and Chair of a sub-committee on organizational values and beliefs. Among other roles, this further inculcated my sensitivity to, and promotion of, genuine collaboration at the organizational and inter-organizational levels. Perhaps serendipitously as an early sign of my future research, I was invited in 1999 by the North West region to facilitate planning toward integrated neonatal and pediatric services. As discussed below in the section on Gaining Access to the Research Site, the relationships built and local experience gained in the North West were instrumental to my return to the North West, now as a graduate student in a research capacity.
Yet another C&W reorganization saw my entire portfolio, including my position, eliminated in 2000 which effectively de-centralized planning and related functions for reasons that are still unclear to me. With the support of the Head, Department of Pediatrics, UBC, I negotiated a three-year secondment to the Department of Pediatrics, in conjunction with the Centre for Community Child Health Research, BC Research Institute for Children’s & Women’s Health. During this period, I was involved in health systems planning on a province-wide scale with a focus on child health service delivery.

My progressively complex professional roles, spanning over twenty years, provided many successes. But, I also lived through and learned from a number of failures, an anticipated part of the territory of health services planning and administration. These real-world experiences shaped my thinking, pervaded my decision-making role, and reinforced my predilection for a participatory approach to planning. In my view, if any substantive progress were to be made in health reform, it would be through engaging a participatory approach working directly with stakeholders in their communities. That I accumulated decades of experience prior to embarking upon my PhD studies is significant. I had a working knowledge of the BC health system, first-hand experience at the rural community and complex academic levels of health services, and strong leadership skills with an excellent reputation in the health services field. In short, I was confident that I thoroughly understood the issues, at least from the perspective of managerial and policy decision-makers. Without these valuable life experiences and lessons, I likely would not have embarked upon this particular study, nor would I have necessarily approached the study in the way I did.

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2 In July, 2005, this was renamed The Child and Family Research Institute.
My Academic Preparation

Turning now to an academic perspective, my program of studies has had a profound influence on my thinking and, in many ways, legitimized my previous professional practice. My PhD program in Experimental Medicine and my thesis committee allowed me a great deal of latitude in coursework. In addition to regular courses, I enrolled in a number of Directed Studies in order to explore subject matter aligned to my interests and to fill knowledge gaps in my thesis content area. My participatory bias was again reinforced. Concurrently, I was actively engaged in a number of pertinent related initiatives, which also helped to shape and reinforce my philosophical orientation, beliefs, and biases. As a student affiliate in the Western Regional Training Centre for Health Services Research (WRTC)\(^3\), UBC, I was part of a collaborative training milieu of applied health services research with an emphasis on the research needs of health policy-makers, involving decision-makers in the training program, and addressing the research – decision-making interface. I was a trainee in the Centre for Community Child Health Research (CCCHR)\(^4\) in the CFRI, a partnership between Children’s & Women’s Health Centre of BC and UBC. This enabled me to participate in a number of training opportunities directly related to my research, and created a collaborative, multi-disciplinary training and research environment. I was also a student affiliate in the Human Early Learning Partnership (HELP)\(^5\), UBC. This interdisciplinary research area focuses on early child development, and provided me with an opportunity to be exposed to a wide variety of related research. In 2004, I embarked

\(^3\) WRTC is one of five training centres in Canada funded by the Canadian Health Services Research Foundation (CHSRF) as part of the Capacity for Applied and Developmental Research and Evaluation in Health Services and Nursing (CADRE) program. It is co-sponsored by the Alberta Heritage Foundation for Medical Research (AHFMR) and the Canadian Institutes of Health Research (CIHR). For further information on this collaborative training initiative see http://www.wrtc-hsr.ca

\(^4\) CCCHR has four main areas, including population and community-based research in which I am situated. A major focus is on translating research findings to practice. For further information on the CFRI and CCCHR see http://www.cfri.ca

\(^5\) HELP is a network of faculty, researchers, and graduate students from the four major universities in BC, and works in partnership with the BC Ministry of Children and Family Development, and is partially funded by them. For further information on HELP see http://www.earlylearning.ubc.ca
upon a Fellowship Program in the Canadian College of Health Service Executives (CCHSE) concurrent with my PhD program. This builds upon my certification as a health services executive since 1994.

I have enjoyed a unique combination of lengthy professional experience and academic education and training in a number of environments. From professional and academic perspectives, this has expanded and deepened my self-awareness of how I approach reality and scientific inquiry and my claims about knowledge.

**My Epistemological Self-Awareness**

Finally, I would like to share some personal reflections on what matters to me in epistemological terms, and how I conceive of change in real-world settings. I subscribe to the notion that knowledge emerges mainly by interacting and experimenting with the world, not just by passively observing it (Osberg & Biesta, 2003). Bohm (1996, p. 89) suggests “ultimately the nature of the world is that it is all mutual participation.” This is a critical departure from positivist epistemology in which the observer and the observed exist independently in a purported objective, value-free environment. The scientific method distinguishes between the observer and the observed, and accounts for and controls confounding variables that could impinge upon objectivity. On the other hand, “temporal epistemology”⁶, as suggested by Osberg & Biesta (2003, p. 3), is not concerned with knowing and understanding the world as it is. Rather, it intervenes in the dynamic, ever-changing world to create new and more complex conditions with which to interact in yet more complex ways. Thus, temporal epistemology is about active intervention, an elicitation of emergent knowledge by metaphorically “twisting the

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⁶ Osberg & Biesta (2003, p. 2) distinguish this from “representational epistemology”, that is, to “…know things about the world by making representations of it…”
lion’s tail” 7. These insights are of particular importance in the context of multi-dimensional relationship(s) to reality (or realities), and how realities are represented.

Chambers (1997, p. 32) advances a similar notion through “self-critical epistemological awareness.” In the context of developing countries, he portrays reality as local, complex, diverse, dynamic, and unpredictable (*lcddu*). He critically observes a number of attributes: (a) that professionals, including administrators and social scientists, have vested interests; (b) that they are situated far from local realities; (c) that they exhibit a professionalism replete with erroneous beliefs; (d) that distance (physical, organizational, social, and cognitive) blocks, blurs, and distorts *lcddu* realities; and (e) that power, especially in terms of authority, control, and position, deceives and hinders these professionals. They are not self-aware. Chambers’ insights, while reflecting experience in developing countries, is apropos in terms of how planning is typically conducted for health services. This reinforced my feelings about my own experiences, helped me to reflect on my former practices, and influenced how I approached this research. While I embraced a participatory approach in my professional roles, I became even more committed to using a participatory approach in order to mitigate the kinds of problems and bridge the gaps that I had experienced if not, in some cases, inadvertently created.

**My Conceptualization of Change**

Additionally, I would like to share some personal beliefs—perhaps these too are biases—in my conceptualization of change. This acknowledgement is important because change (action) is so integral to participatory research. Change is a common, yet commonly confused, anxiety-producing, and misunderstood concept that we encounter in our personal lives, work environment, and social settings. Commonly, people fear change as if change was a negative, externally imposed event disturbing their personal comfort zone. But change, to be welcomed

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7 This refers to gaining knowledge by actively intervening, not passively observing (Bacon, 1561 – 1626), as quoted in Hacking, 1983, as cited in Osberg & Biesta (2003).
and positively embraced, must first be conceptualized and contextualized in order to be understood. In the arduous process of health services, systems, and policy reform, the challenge of change persists.

My first belief, borrowing from an ecological or natural systems worldview, is that change is a process, not an event. In support of this, a considerable body of literature is developing around the application of complexity theory and complex, adaptive systems theory to health services and policy (Glouberman, 2001; Miller, Crabtree, McDaniel, & Stange, 1998; Plsek & Greenhalgh, 2001; Veazie et al., 2001; Zimmerman, Lindberg & Plsek, 1998).

Second, I believe that we need to reflect upon how we think about change or, to question the method of questioning. In this vein, Capra (1996, p. 40) suggests that systems thinking “…involves a shift from objective to ‘epistemic science’, to a framework in which epistemology—the ‘method of questioning’—becomes an integral part of scientific theories.”

Third, I believe that if people at the local (community) level are genuinely engaged in the conceptualization and framing of problems or issues that are relevant and important to them, their acceptance of, and active participation in, the change process is not only possible, but positively embraced.

Finally, I believe that the conceptual underpinnings that increase the likelihood of success of collaborative planning at the local level include the basic tenets of participatory research. This includes: (a) addressing the conceptualization and framing of the relevant issues, (b) active and meaningful participation by key community stakeholders, (c) appropriate environments for dialogue and reflection, (d) transformative learning by both the researched and the researcher, and (e) a genuine commitment to action (change).
The Journey and a Road Map for the Dissertation

The Journey

Raising the need for a road map implies that a journey is taking place. A journey is about going from one place to another place, as suggested in the definition of journey at the beginning of this chapter. The concept of place is critically important to this journey—to me as a learner and researcher, to the study participants who are grounded in their local realities, and to you the reader, respecting your journey, perhaps to unfamiliar places. Place holds special significance and meaning and will be more fully developed in context in Chapter Two and further in Chapter Five in the context of boundaries. Paradoxically, this narrated journey belies the real journey in the same way that “the map is not the territory” (source unknown), the very point that I emphasize later in this study. A journey means visiting unfamiliar places, or viewing familiar places through a new lens, and is about discovering new people, new things, and new ways. This is a journey that takes place in four distinct but interrelated domains: (a) intellectual, (b) technical, (c) geographical, and (d) liminal.

Intellectual

In the intellectual domain, I journey into the world of transdisciplinarity in which sense needs to be made of the broad range of disciplines associated with health services research and delivery. I explore five areas to elucidate the useful role that such disciplines have, but have not been incorporated to any significant extent: (a) complex, adaptive systems; (b) community-based participatory research; (c) health care geography; (d) knowledge translation, and (e) boundaries/boundary objects. Initially, this may seem to be a strange concatenation of topics;

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8 Rosenfield (1992) distinguishes the terms multidisciplinary, interdisciplinary, and transdisciplinary. Multidisciplinary refers to working on a common issue from a discipline-specific basis. Interdisciplinary research addresses a common issue from a joint, but discipline-specific basis. Transdisciplinary research draws from specific disciplinary theories and concepts, but uses a shared conceptual framework to address a common issue. The shared contextual framework used in this study is participatory research.
however, as the journey progresses, the concepts generated in these areas will become more visible, relevant, and shared.

**Technical**

In this domain, I explore a number of technical aspects concerning the strategy for, and design of, the journey. These include such things as gaining access to the territory, understanding the local nuances, designing the proposed journey, and gathering and making sense of the pertinent data and information. This also includes ensuring that the journey is authentic and reflects as closely as possible the reality under study. Additional tools, such as administrative data and mapping software are used to create maps to help everyone participating in the journey to become aware of and understand issues pertinent to their local context.

**Geographical**

The geographical journey has a number of related components—physical, human, demographic, and cartographic. In terms of the physical and demographic aspects, I make a concentrated effort in the course of this journey to travel by car, ferry, and airplane to communities in a variety of weather and travel conditions. Otherwise, it is difficult to capture the expanse of the North and the North West and the population distribution. A glimpse of the territory is offered in Chapter Four but, as many study participants explain, one cannot possibly appreciate the geographical distances, weather, transportation, access, and related challenges unless they are physically experienced. The geographical journey also highlights a number of geographical inter-relationships, such as: (a) urban – rural, (b) centre – periphery, (c) South – North, (d) provincial – local, and (e) system – community.

The cartographic (mapping) component is captured in my use and application of geographic information systems (GIS) as a tool to map selected child and youth health services
utilization data from a BCMOHS administrative database. This served as a useful visual aid for dialogue when I gathered data during a participatory planning (search) conference.

**Liminal**

Finally, the liminal domain, which is the most abstract, is also the most intriguing aspect of this journey. Liminality means “occupying a position on, or on both sides of, a boundary,” (Concise Oxford Dictionary, 1995). Boundaries are borders. In a journey, borders are crossed at multiple levels. For example, these can be physical, cultural, ethnic, gender, age, social, economic, and political. These boundaries can also be walls or gaps that separate (in order to keep entities or environments apart), or bridges that connect (in order to allow exchange between entities or environments). A living cell membrane is a useful metaphor to understand this concept. The membrane functions both as an anatomical structure to separate cell contents from its environment and as a physiological process to connect to its environment to allow the flow and exchange of materials critical to the functioning and sustainability of the cell. Similarly, such boundaries in social constructs can be what separates or connects disciplines, sectors, organizations, theory and practice, or research and action. These boundaries can be visible or invisible, tangible or intangible, concrete or fluid, structural or processual. This requires us to recognize and appreciate boundaries in ways we may not have imagined. Even more elusive are boundary objects that traverse such boundaries. Metaphorically, this concept is akin to the plethora of physiological exchanges occurring at and through the cell membrane. They share many of the same properties as boundaries. Boundaries and boundary objects can be classified and have paradoxical properties and characteristics. These classifications and properties will be more fully explored in Chapter Five in keeping with a basic tenet of grounded theory in which exploration of the literature is often deferred to a later point in the study. Thus, the literature on boundaries and boundary objects is deferred to a more appropriate later juncture in this thesis.
In foreign territory we may fail to appreciate the nuances of crossing the local boundaries (borders) given such characteristics as culture, customs, historical issues, political milieu, and perceptions of and attitudes toward outsiders. Often, it requires a great deal of preparation or access is simply denied or costly.

This section has introduced several points of interest in this journey, and these will be more fully explored in Chapter Four. The following section outlines how the dissertation is organized and will serve as a roadmap to guide this journey.

**A Road Map for the Dissertation**

This dissertation consists of six chapters and is organized as follows:

- **Chapter One** introduces (a) the issues under study; (b) the research and why it is relevant; (c) my philosophical orientation, beliefs, and biases; (d) a metaphor of a journey to set the stage for reading the dissertation; and, (e) a road map to stay on the journey’s intended path.

- **Chapter Two** is largely an intellectual journey that reviews the pertinent academic and gray literature, including a number of government, organization, and agency reports, papers, and commissions relevant to the health system and services at the federal and provincial levels. The scholarly literature relevant to four themes is reviewed, including: (a) complex, adaptive systems; (b) participatory research; (c) health care geography; and, (d) knowledge translation. As noted above, literature on boundaries and boundary objects is deferred until Chapter Five and introduced in the context of the findings.

- **Chapter Three** is a technical journey which discusses in detail the research methodology used in this study. It includes a dominant qualitative component and a nested quantitative component. Included in this chapter are: (a) ethics and research review committee
approvals for the conduct of the research; (b) gaining access to the research site; (c) mixed methods (priority qualitative and nested quantitative) design used in this study; (d) sampling process; (e) data gathering methods (semi-structured interviews; focus groups; search conference); (f) quantitative component; (g) data analysis (qualitative and quantitative); (h) grounded theory and constructivist grounded theory approach; (i) transcribing the data; (j) coding processes; memo writing; (k) validity and trustworthiness; (l) qualitative authenticity criteria; (m) quantitative component; and (n) special considerations and issues.

- Chapter Four is both a geographical and liminal journey which takes place largely in the North West, and introduces and discusses the study’s findings. Three major conceptual categories are developed from the initial analysis of early data, including: (a) perceptivity about the health system, (b) emotivity generated by the health system, and (c) inclusivity in the health system. A common thread is developed around numerous dyadic relationships. Using a constructivist grounded theory method, I develop two core conceptual categories which emerged from the data during analysis of the qualitative data. They are used to develop a theoretical framework for linking community-based participatory research (CBPR) and planning.

- Chapter Five is mostly a liminal journey and brings us to the concepts of boundaries and boundary objects, which are developed in the context of a classification of knowledge boundaries and related boundary objects. An existing model is explored to introduce the concepts. I then develop a model in the context of public sector health services planning in the North West based on the concepts generated from the data. This chapter also

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9 The term dyad, for the purposes of this dissertation, refers to a binary relationship in which there are two parts, regarded as one. This is conceptually different from a dualistic relationship in which there are two independent and separable realms (Angeles, 1981).
explores how to apply the findings to planning child and youth health services, bridging theory and practice settings.

- Chapter Six explores several interface dynamics in different contexts and how they might be applied in practical terms. Based on the findings in this study, a theoretical model is introduced that melds research and planning practice. Insights and implications for each of the stakeholder groups engaged in this study (public, clinicians, managers, and policymakers) are offered. A number of key recommendations for future research, building on the findings generated in the study, are suggested.

Finally, in keeping with this journey metaphor, a number of forms, guides, and maps are provided similar to those available at Information Centres along the highway. A number of Appendices are included to which readers are referred should further detail be required on letters, forms, interview guides, and related materials which were used throughout the course of the study. Selected maps generated to demonstrate the utility of geographic information systems as a tool are included only as examples.

**Summary**

This introductory chapter has presented the gap between what the research evidence is saying and how health services planning is actually done, with specific reference to child and youth health services in North West BC. A brief outline of the issues was presented in the context of the reformed (and still reforming) provincial health system, setting the stage for the purpose, importance, and relevance of the current study. The need to move beyond rhetoric to action was emphasized. The preliminary and refined research question and sub-questions were posed. Study delimitations were summarized. As a researcher, I shared my philosophical orientations, beliefs, and biases. Finally, the research journey and dissertation road map were offered to guide the reader through the study.
Chapter Two will now take us on an intellectual journey. It explores areas needed to better understand the complexity of the issues and challenges involved in the planning and delivery of health services for children and youth in North West BC.
CHAPTER TWO: Review of the Literature

Introduction

There is a considerable amount of scholarly and grey literature in health services research and service delivery. These emanate from, for example, provincial and federal government branches, ministries, and departments; non-governmental organizations, associations, and institutes; funding agencies; and, health authorities. From a scholarly perspective, this study incorporates literature from a broad range of academic disciplines relevant to health services research and delivery. From the perspective of the grey literature, a myriad of sources are available, such as reports, discussion papers, position papers, conference proceedings, and commissions. There are significant challenges to effectively framing the breadth and depth of the core and related issues concerning health services research and service delivery, in particular those concerning children and youth. Balancing relevant content across the disparate and burgeoning sources (to achieve breadth across disciplines) with comprehensiveness (to achieve depth within disciplines) is particularly important. I elected to organize this intellectual journey into the literature as follows. There are two sets of literature. First, in this Chapter, I provide an overview of the health system at three levels—federal, provincial (emphasizing BC activities), and regional (incorporating literature relevant to the recently reformed health system in BC). The examples provided are intended to be illustrative of the complexity and number of initiatives underway, not a comprehensive listing. I then explore four fields of studies—(a) complex adaptive systems, to help make sense of the term system in the health system; (b) participatory research; (c) healthcare geography, including concepts of place and locality; and, (d) knowledge translation. Second, in Chapter Six, I explore literature specific to the concepts that emerged as this research progressed—boundaries and boundary objects. Discussion of this latter body of
literature is deliberately delayed in the context of grounded theory and the emergence of the core categories, boundaries and boundary objects.

The Canadian Health System

Canada does not have a national health system, per se, although reference is often made to this misnomer. Rather, the Canadian health system is an assemblage of ten provincial and three territorial health systems. The Canadian health system functions less as an integrated system, and more as a patchwork of loosely connected parts. The federal/provincial/territorial relationships are very complex, dynamic and, historically, unstable. Responsibility for health was largely conferred upon the provinces through the Constitution Act (1867). Exceptions include services to certain groups of people, such as primary care to First Nations and Inuit peoples, Royal Canadian Mounted Police, Correctional Services, Armed Forces, and Veterans (Kirby, 2001). Other exceptions include: health protection; health promotion; disease prevention and education strategies; health research; and, financial support of provincial health care systems (Kirby, 2001).

The Canadian health system is based on five overarching principles of the Canada Health Act (1984): public administration, comprehensiveness, universality, accessibility, and portability. Still, the system has been subject to a number of time-consuming, costly, and largely repetitive reform initiatives at the federal, provincial, and territorial levels. In the following sections, I provide examples at the national and provincial levels, starting in the last decade, to illustrate these unabating and, to a large extent, unresolved issues. Given the number and scope of these reports it is beyond the purview of this thesis to provide more than a summary review. It is anticipated that the source documents cited will be accessed should a more comprehensive analysis be sought.
Federal Initiatives

In 1994, The Right Honourable Jean Chretien, Prime Minister of Canada, set in motion the National Forum on Health whose purpose was to advise the federal government on how to improve the health system and the health of Canadians (National Forum on Health, 1997). It focused on long-term, systemic issues and established action priorities in three areas: (a) preserving the health care system, (b) transforming knowledge into action, and (c) using better evidence for decision-making.

In 2000, a national rural health strategy was announced by the Government of Canada in response to cross-country advice from rural citizens and providers collected at rural summits (Health Canada, 2001). This strategy prioritized the issues, proposed a collaborative approach, and illustrated that national leadership was required in rural health, including the creation of an Office of Rural Health to provide a “rural lens” to federal initiatives. Strategies for rural, remote, and northern health care were also being developed independently by rural communities rather than awaiting direction (Prince George, 2001). From this summit there were clear expectations that: (a) communities take responsibility for change, (b) communities take leadership for action, (c) communities develop partnerships, and (d) governments (federal and provincial) recognize that communities must be empowered to take action.

Other nationally focused agencies, such as the Institute for Research on Public Policy (IRPP), drew attention to why Canadian Medicare was in need of reform and pointed to factors that eroded public faith in the health system (IRPP, n.d.). Of significance is the call for strengthening initiative and commitment at the local level as key to health system renewal. Purportedly, this is best met by the “principle of subsidiarity, i.e., the level of government that is both closest to the people and best able to deliver a given service should be responsible for that service” (IRPP, n.d., p. 13), adding:
To ensure the continued health of Medicare, we must renew our commitment to local initiative and autonomy. We must reallocate to local or regional bodies the responsibility and corresponding authority for managing and operating the healthcare services needed by the people in their communities. (p. 14)

Interestingly, this same principle of subsidiarity is being touted by BC as part of its government's plan to turn over authority to the lowest appropriate level of governance (Cernetig, 2006). This research study attempts to engage the essence of this principle in health services planning, in part, by using a multiple stakeholder approach and engaging people in their own communities and places of relevance.

Rathwell & Persaud (2002) observe that health reform has taken different paths depending on the perspective taken. For example, federal reform has grappled with system-wide policy; whereas, provincial reform has taken on mainly structural issues. Regionalization is typically a large part of reform initiatives. The notion of regionalization does not enjoy a common definition even though this phenomenon has swept across Canada for decades (Lewis & Kouri, 2004). However, they describe the attributes of regionalization as: (a) regions are geographically defined, (b) regions exist and are given authority by virtue of the provincial government, (c) distributed programs are consolidated within a region, and (d) there is responsibility for a broad spectrum of health services within a region. They also point out that regionalization is rarely challenged as a strategy, is still embraced, and is proceeding in the absence of solid evidence that it is producing the desired effect. For regionalization in Canada, "[e]valuative data are hard to come by" (Lewis & Kouri, 2004, p. 30). Even more telling is the paradox in which a number of Canadian provinces embraced regionalization at the same time that England, for example, was toning down such structures (Glouberman & Mintzberg, 2001).
On the recent national scene, two noteworthy commissions—the Kirby Commission and the Romanow Commission—overlapped to a significant extent in both content and timing, although their respective mandates were different. In 1999, the Standing Senate Committee on Social Affairs, Science and Technology was mandated to study the Canadian health system and examine the federal government’s evolving role in health care. In 2001, the Commission, lead by Commissioner Kirby, began its task and produced a number of reports, including: (a) historical background, (b) major future trends, (c) comparisons to other developed countries, (d) federal roles in health and health care, (e) principles and recommendations for reform, (f) an action plan for restructuring that part of the system concerned with hospitals and physicians, and (g) several related thematic areas (Kirby, 2002, Kirby & LeBreton, 2001).

In 2001, a federal Commission was established, led by Commissioner Romanow, with a mandate to “review medicare, engage Canadians in a national dialogue on its future, and make recommendations to enhance the system’s quality and sustainability” (Romanow, 2002, p. xv). This report, unlike others, recognizes the difficulty with using the term “system” to describe a system in which there is unacceptable fragmentation of services and persistent disconnection in all jurisdictions throughout the health system. Forty-seven recommendations were made. Health system reform and renewal was urged in a number of key areas. One of the recommendations included the creation of a Health Council of Canada to help improve the historically dysfunctional relationships between the federal government and the provinces and territories, and to help monitor and report on health system performance. The First Ministers formed this Council in 2003 with a view to advance the Accord on Health Care Renewal, focusing on and accelerating health services improvements (Health Council of Canada, 2005). This Accord is viewed by the First Ministers as a “covenant”, an action plan for renewal of the health system, and a commitment to partnerships between governments, providers, and the public. The extent to which the Accord meets the recommendations of numerous provincial and federal reports will be
the subject of on-going debate. Moreover, the First Ministers have agreed on a 10-year action plan to ensure that access issues are addressed as a national priority (Health Canada, 2004).

Given the simultaneity of these and other federal and provincial reports, a number of observers have offered thematic summaries, comparisons, and contrasts. For example, Fooks & Lewis (2002) report on nine common themes, including: (a) population health, (b) financing, (c) primary care reform, (d) regionalizing service delivery, (e) pharmaceutical policy, (f) human resource planning, (g) quality improvement, (h) governance and accountability, and (i) home care services. For the most part, these themes are supported to various degrees. However, there are discrepancies between federal and provincial perspectives on their relative importance. Others, such as Davis (2002), believe that the federal and provincial reports reflect consensus on the fundamentals of reform, but lack agreement on service levels, cost, and financing. Yeates (2002) comments that these reports provide public reassurance that the fundamentals of the health system are correct; however, focused efforts toward modernization and sustainability are required.

Another federal and provincial priority concerns primary health care reform. This is distinguished from primary care, which entails the “diagnosis, treatment and management of health problems with services delivered largely by physicians” (Fooks, 2004, p. 3). Primary health care reform “promotes an integrated multidisciplinary and client-focused approach to the delivery of health services to ensure that Canadians receive the most appropriate care, by the most appropriate providers, in the most appropriate settings” (Kouri & Winquist, 2004, p. 1). Opportunities, challenges, and implications of different primary health care models are described from a number of perspectives (BCMOHP, 2003; Canadian Health Services Research Foundation [CHSRF], 2003; Romanow, 2002; Fooks, 2004; Millar & Beardall, 2001).
Primary health care renewal is well underway across Canada, thanks to the Health Canada $800-million Primary Health Care Transition Fund established in 2000. Among its many objectives, this is intended to increase continuity of, and access to, care for populations with unique needs, particularly in rural and remote areas, and improve health services integration (Health Canada, 2005). Ringing familiarly is the yet-elusive goal of “[providing] the most appropriate care, from the most appropriate provider, when and where they need it” (p. 4). Just how the provinces will sustain this renewal when federal transition funding ends is uncertain at this point.

Finally, on the national scene, the debate continues on the privatization of Medicare in Canada, recently made real with the Supreme Court of Canada decision (Chaoulli decision, 2005) to allow an individual in Quebec to use private insurance to buy a medically necessary service—hip replacement surgery (CHSRF, 2005a). This decision and its anticipated predominantly negative impacts on Medicare are being played out in many forums. The privatization versus Medicare debate is heating-up and will undoubtedly be at the centre of a firestorm of questions about how to decide on an appropriate balance of public-private services in individual provinces and territories without eroding the basic tenets of the Canada Health Act and public confidence.

After this overview on the national scale, I now briefly outline the experiences in a number of provinces. For the sake of convenience, I will introduce these initiatives starting at the Eastern seaboard and moving West, and discuss selected provincial initiatives. Seemingly, this has occurred without the major fanfare of major commissions and widespread publication of reports.
Selected Provincial Initiatives

New Brunswick undertook an extensive public consultation approach in the early 2000s with the goal to improve health and access to health services in that province. This resulted in a report, “Health Care: A New Brunswick Perspective”, which included some 17 areas of focus and 122 recommendations.

Quebec mandated a Commission to hold public consultations throughout the province on issues faced by its health and social service system and to propose future solutions. This resulted in the Clair Report in 2000, which focused mainly on organizational and financing issues and offered a number of recommendations and proposals.

Ontario, effectively the only province electing to stay out of the regionalization movement until very recently, did spend a number of years on mandated province-wide hospital restructuring. In 1996, the Health Services Restructuring Commission was established by the Ontario Government with a four-year mandate to address three components: (a) province-wide hospital restructuring, (b) advice on required changes to the health system, and (c) recommendations for improving health system integration and coordination (Ontario Government, 2000). However, the focus of reform in Ontario has more recently moved away from hospitals. The creation of 14 Local Health Integration Networks (LHINs) represents that province’s latest attempt at health system reform. These Networks were created “because local health services are best planned at the local level, by people familiar with the needs of a community…to help plan and coordinate the health care services that are right for people in different communities” (Ontario Government Ministry of Health and Long-Term Care, 2005).

Saskatchewan appointed a Commission on Medicare (Fyke Commission) in 2000 which resulted in a report, “Caring for Medicare: Sustaining a Quality System.” This included the
mandate to identify the challenges associated with reforming Medicare; to recommend an action plan for service delivery; and, to examine long-term stewardship.

In Alberta, the Premier’s Advisory Council on Health, developed a framework document in 2000, including a number of key themes and recommendations for reforming that province’s health care system—“A Framework for Reform.” It recognized the complex and diverse nature of the health system, likening it to “an interwoven web where decisions or actions in one part of the system have a profound effect on others” (Alberta Government Premier’s Council on Health, 2001, p. 4).

**British Columbia Initiatives**

In 2001, The Legislative Assembly of British Columbia commissioned the Select Standing Committee on Health “to examine, inquire into and make recommendations with respect to the changes that are necessary to improve the provision of health services in British Columbia, and to ensure that government expenditures on health care services are sustainable” (British Columbia Legislative Assembly, 2001, p. 2). This resulted in a report entitled “Patients First: Renewal and Reform of British Columbia’s Health Care System”. Four overarching principles were identified: (a) equity, (b) patient-centred care, (c) evidence-based care, and (d) accountability. While patients were appropriately recognized to be at the centre with the need for service coordination around them, the system was recognized for what it was—highly fragmented, lacking communication and coordination, with competitive service providers, and lacking incentives for collaboration. The need for a “made-in-B.C. approach” (British Columbia Legislative Assembly, 2001, p. 11) was highlighted in order to address the province’s geographic and demographic nuances and regional disparities which are accentuated in rural and remote areas. These issues will be more fully addressed in a later section.
Of the several reform initiatives that swept the nation during this time, it is noteworthy that the BC report is not readily acknowledged in the literature in terms of health care delivery reform. Conversely, those from Alberta, Saskatchewan, Quebec, and New Brunswick are deemed “key” reports (Canadian College of Health Service Executives, 2002, p. 3). Similarly, Fooks & Lewis (2002), in their review of health reform in Canada, reflect on a number of key provincial reports, including Ontario. Again, the British Columbia effort is conspicuously absent. The reason for this is not evident in either account.

Following this overview of reform activities across the nation, I turn now to a closer look at the BC health system. First, I provide an overview of reform and regionalization at the provincial level, with specific attention to the Northern Health Authority (NHA). Then, I focus on rural and remote health services, drawing upon recently developed provincial access standards and guidelines as a means to illustrate the inter-connectedness and complexity of issues associated with access to services, for example, in the North West region.

**The British Columbia Health System**

In 1999, the BC Ministry of Health and Ministry Responsible for Seniors created a Strategic Directions document building on health goals developed by the provincial health officer. This was intended to complement the health authorities’ Health Service Plans and the Ministry’s more detailed work plan. The document recognizes the need for a “strong planning approach” to accomplish anticipated change (BCMOH, 1999, p. 1). The need for broader community involvement is raised.

Then, beginning in 2001, the British Columbia health system underwent another major restructuring by the then newly elected Liberal government. Ostensibly, this was to correct the complicated, confusing, and expensive array of the extant 52 health boards, councils, and health services societies (BCMOHP, 2001a). This earlier complex structure had been created under the
political party of the day, the New Democratic Party, in order to move decision-making and responsibility “closer to home” (BC Royal Commission on Health Care and Costs, 1991). This initiative was subsequently criticized for a variety of reasons, for example, issues of timely access, long waitlists, and fragmented services (BCMOHP, 2001a). The again-reformed (and still current) structure includes a number of components. The Provincial Health Services Authority (PHSA), a first in Canada, is responsible for planning, coordinating, and providing specialized services and provincial programs, and ensuring equitable access to health services. Five geographic Health Authorities (HAs) are responsible, on a regional basis, for governing, identifying regional needs, planning health services, and funding and management. Fifteen Health Service Delivery Areas (HSDAs) are responsible for managing health service delivery and ensuring that communities have protected local input into health service delivery (BCMOHP, 2001a). At that time, two Health Ministries were created: a Ministry of Health Services to oversee the day-to-day operations; and a Ministry of Health Planning, another first in Canada, to concentrate on policy-related issues and future needs. Additionally, two Ministers of State, yet another first in Canada, were responsible for mental health and home and community care (BCMOHP, 2002a). Other notable features of the reformed provincial health system include performance contracts for health authorities, a rolling three-year funding model, population-based funding, consolidation of acute care services, and access standards and acute care guidelines (BCMOHP, 2002a). However, the BCMOHP was abruptly disbanded shortly thereafter with limited public explanation.

In 2004, The Federal First Ministers agreed to a “Ten Year Plan to Strengthen Health Care”, the top priority of which is to improve access and reduce wait times (BCMOHS, 2005a, p. 12). Thanks to this agreement, BC expects to receive $5.4 billion in new federal funding over the next 10 years, which will be used to address a number of priority areas. This specifically includes addressing access and service issues for youth addiction and the early screening of
children. Consequently, the BCMOHS, in its 2005/06 – 2007/08 Service Plan, includes a number of goals, objectives, strategies, and performance measures to guide its mission. It is illuminating to briefly review how this is envisioned to unfold in order to demonstrate the complexity associated with even one or two objectives from the perspective of government. Take, for example, the goal of “high quality patient care” (p. 21). One objective is concerned with “[t]imely access to appropriate health services by the appropriate provider in the appropriate setting” (p. 21). It is interesting to read that:

The ministry and its partners have been working diligently over the past three years to ensure hospitals, community services and health professionals are used in the most efficient and effective way possible so that people get the right type of care in the right type of setting that will lead to the best possible outcome. (p. 21)

Moreover, the latest Annual Service Plan Report (2004/05) of the BCMOHS, in reference to the past four years of fundamental reforms and structural changes, boasts “improved access to care, integration of services and providers, and outcomes for patients” (BCMOHS, 2005b, p. 5).

Another objective is the “[i]mproved integration of health care providers, processes and systems to allow patients to move seamlessly through the system.” This objective, however, focuses only on mental health and addiction services. Strategies include, for example, “[p]roviding a full continuum of mental health and addiction services within each health authority, which better integrates primary, secondary, community and tertiary care and is integrated within the large care networks” (BCMOHS, 2005b, p. 26). This strategy is silent on children, but specifically addresses youth addictions. While confusing, the reason for this is entangled in the mandate of the BCMCFD.

The BCMCFD (2005b), like the BCMOHS, is self-laudatory about its accomplishments, claiming, for example:
Over the past four years, we have been working toward making programs and services more responsive to the people that we serve, by redesigning our service delivery system to be more community-based. The ministry made progress in 2004/05, bringing services closer to communities and families while protecting health and safety. (p. 5)

Although the BCMOHS and the BCMCFD make such unsubstantiated claims, they do not correspond with the perspectives of multiple stakeholders participating in my study, which was conducted within this same general timeframe. Indeed, the recent BC Children and Youth Review (Hughes, 2006) is highly critical of, and specifically targets, the current Liberal government’s significant budget cuts for creating untenable instability and confusion in the BCMCFD. Examples of this sort of disjuncture are provided in Chapter Five.

Moreover, the BCMCFD (2005a, p. 3), in its 2005/06 – 2007/08 Service Plan, advised that it “is shifting from centralized, provincial delivery of services to a community-based model that supports a sustainable, more integrated system to best meet the needs of vulnerable people....Strong partnerships and collaborative relationships with stakeholders and community partners are also critical to [their] success.” Their mandate includes a number of areas related to the safety and wellbeing of Aboriginal and non-Aboriginal children, youth, and families, in particular, those who are vulnerable. Additionally, the provincial Child and Youth Mental Health Plan for British Columbia (BCMCFD, 2004) is part of its provincial services mandate. More recently, a new independent Crown corporation has been created to deliver services to people with developmental disabilities (BCMCFD, 2005c). This includes joint responsibility for services to children and youth with special needs (Community Living BC, 2005).

Finally, the BCMOHS has just recently taken on the role of being a “steward of the system and less on being a direct service provider.” (BCMOHS, 2005a, p. 7). In this capacity, it
provides leadership and support to, and a corporate management role for, health authorities and other partners in the provincial health system.

Following this overview of reform and regionalization at the provincial level, I now turn to the regional level, specifically the Northern region of BC. The next section provides a summary of this large and predominantly rural and remote region.

**The Northern Health Authority**

Since 2001, the Northern Health Authority (NHA) has been responsible for the delivery of health services in northern BC (NHA, 2006). The NHA’s 2004/05 operating budget is approximately $448 million per annum, and it employs some 6,000 staff (in approximately 4,000 full-time equivalent positions). The NHA’s geographic responsibility covers approximately two-thirds of the province. This very large region is home to approximately 307,000 people (2005), representing 7% of the provincial population (BC Ministry of Labour and Citizens’ Services, 2006). Twenty-nine percent of the population is less than 20 years of age, compared to a BC average of 23%. The number of children and youth is expected to decrease in all health authorities over the next five years. Thirteen percent of the population is Aboriginal, the highest proportion in the province.

The NHA is governed by a 10-member board comprised of individuals appointed from throughout the North. It employs a single Chief Executive Officer under whom is a management structure that includes a Chief Operating Officer in each of three HSDAs (North West, North Interior, North East). A regional Aboriginal health policy and planning program is implemented as part of the NHA’s commitment to improving Aboriginal health (NHA, 2002).

Throughout the province, the HSDAs are responsible “to ensure community participation in health care decision-making and protect local input into the delivery of health services.” (BCMOHP, 2001a, p. 3). In keeping with this, each of the three HSDAs in the NHA has
explicitly stated that their responsibilities include “ensuring public and stakeholder input into health services planning and evaluation in the area.” (NHA, 2002, n.p.). Performance-based management and accountability occurs as follows: The HSDAs are accountable to the HAs; the HAs are responsible for delivery of services within their geographical area; the PHSA works with the HAs to plan and coordinate care (and also operates and manages provincial health services); and, the MOHP and MOHS hold the HAs accountable for fulfilling their responsibilities (BCMOHP, 2001a). Finally, New Era reform includes three-year Service Plans, which address the provincial government’s (and both the BCMOHP’s and BCMOHS’s) strategic context (planning, vision, mission, values, and strategic shifts), goals, strategies, objectives, performance measures, and targets (BCMOHS, 2002b).

Large, remote, rural areas give rise to particular concerns about access to health care. In the next section, I introduce rural and remote health services, raising, for illustrative purposes, specific issues around, and challenges related to, formulating standards for access to health services in BC.

**Rural and Remote Health Services**

The BC Royal Commission on Health Care and Costs (1991) outlined a number of issues related to rural and remote health. Over 10 years ago, the then BC Ministry of Health and Ministry Responsible for Seniors, observed that “[a]ccess to health care in rural areas is a major issue” (BC Ministry of Health and Ministry Responsible for Seniors, 1995a, p. 3), and that “[t]he health system in British Columbia is in a state of dramatic flux (BC Ministry of Health and Ministry Responsible for Seniors, 1995, p. 5). This was in partial reponse to the advice of the BC Royal Commission on Health Care and Costs (1991).

Issues around access to timely and appropriate services have persisted. These issues are very complex, but BC was the first province in Canada to set minimum standards for patient
travel times to services: Standards of Accessibility and Guidelines for Provision of Sustainable Acute Care Services by Health Authorities (BCMOHS, 2002c). It is illustrative to examine these in greater detail. Henceforth, I shall refer to them as the Standards. The Standards are comprised of two major components: access standards and, based on these, acute care guidelines. This is not intended to be a comprehensive analysis. Only the salient points are discussed here in order to outline some of the practical challenges around access to health services in the context of rurality and remoteness. Many of these same points were also raised during my interviews with participants during the course of my research.

The Purpose of the BCMOHS Standards emphasizes the need to rationalize acute care services toward ensuring sustainability and quality of care. This emphasis on rationalization seems at odds with other Ministry documents which implicitly downplay rationalization in favour of long-term health goals, overarching principles, vision, mission, values, and strategic shifts (BC Legislative Assembly, 2001; BCMOHP, 2002a; BCMOHS, 2002a). This is because the Ministry's general approach has been one of regionalization, which “implies an allocation of health services based on geography” (Meade & Earickson, 2000, p. 368). In rural settings (which is most of the province), service coordination includes local access by getting “services to residents” including, outreach, telecare/self-care and telehealth services, and getting “residents to services” (BC Provincial Coordinating Committee for Remote and Rural Health Services, 1999, pp. 16,19). This distinction impacts concepts of access. Virtual technologies and virtual regions are made possible by new communications and information technologies, and these are changing the concept of the geography of service provision (Cutchin, 2002). Approaches to addressing rural and remote issues should be unique, not just an extension of urban concepts and priorities (Ramp, 1999; Watanabe & Casebeer, 2000). Yet, urban approaches are still being applied inappropriately to rural communities (Romanow, 2002).
Good quality acute care services are based, in the Standards, on three principles—accessibility, safety and effectiveness, and sustainability and appropriateness. They are footnoted as stemming from the dimensions of quality described by the Canadian Council on Health Services Accreditation (CCHSA) framework—Achieving Improved Measurement (AIM). However, the latter clearly identifies the dimensions of quality to be: responsiveness; system competency; client/community focus; and, worklife (CCHSA, 2003). The linkages are not readily evident in the document. Of the three principles, accessibility is a focus of concern. The Standards state that accessibility is “one of the five key principles of the Canada Health Act”. This is correct. However, the interpretation in the standards document is not. Accessibility was added as a principle of the Canada Health Act in the 1980s to ban user fees and extra-billing. It concerns financial barriers to access (Romanow, 2002). To claim it as a principle related to the Standards under discussion, particularly issues around distance, is out of context. On the other hand, it is inappropriate to to limit the concept of accessibility to that of distance.

A principle noted earlier is evidence-based care. “Evidence-based standards have been shown to promote consistency in access [emphasis added] and clinical outcomes.” (BC Legislative Assembly, 2001, p. 15). Yet, the evidence-base from which these Standards are largely derived is apparently limited to a single literature source and a single country’s experience. Accessibility in health services is described in many ways in the literature, including concepts of quality, variety of services, referral mechanisms, waiting lists, and physical access (Martin, Wrigley, Barnett, & Roderick, 2002). Access incorporates a number of important dimensions, which are discussed more fully in the section of Access and Utilization later in this chapter. Accessibility also includes barriers such as gender, culture, ethnicity, and sexual orientation (Cromley & McLafferty, 2002). Age should also be acknowledged. Meade & Earickson (2000) identify a number of additional variables associated with access: availability of services, means of access, provider attitudes, and the failure of the ill to adequately cope with
their own sicknesses. Finally, access can be differentiated in terms of geography (a function of
time and physical distance) and socio-organizational access that help or hinder efforts to seek
care (Ricketts, Savitz, Gesler, & Osborne, 1994). In contrast to these multiple perspectives on
access, the standards in the document capture only two dimensions—time and distance. These
are important, but limited in scope and intent.

The Determining Factors stated in the Standards are factors that impact the quality of
acute care health services. Two are illustrative—Population / Demographics and Distance /
Geography. The Commission on the Future of Health Care in Canada (Romanow, 2002)
reinforces the difficulties that are associated with concepts of access in rural settings. This raises
an important reality—the dominant provincial rural geography, and the very uneven population
distribution. In the context of rurality and rural patient needs, it is inappropriate to develop
standards for access without first considering the evidence (which is multidimensional in this
case) concerning potential impact on the places most affected by the standards, or without
applying more sophisticated and rigorous geographic analyses that are now widely available. Just
what kind of evidence is important to access and take into account is a topic that will be
discussed later in this chapter in the section on knowledge translation.

Distance / Geography perhaps represent the most important factor since it forms the basis
of the Standards. The Provincial Standards of Accessibility section sets out the minimal
requirements of accessibility for acute care health services, based on straight-line, aerial
(crowfly) distance. Simple and convenient, this method lacks the sophistication required for
BC’s challenging geography and population distribution. Martin, Wrigley, Barnett, & Roderick
(2002, p. 12) conclude in their study of access measurement in rural health care in England that
“relationships observed for…crowfly distance do not hold when the more complex measures are
used.” A more sophisticated and accurate technology is geographic information systems (GIS),
which also lends itself to complex modeling (Cromley & McLafferty, 2002; Higgs & White, 1997). Distance, in addition to geographical and time considerations, includes other equally important concepts such as mobility, cognitive distance, economic distance, organizational distance, and social distance (Chambers, 1997; Gatrell, 2002; Meade & Earickson, 2000). Remarkably, the Standards merely suggest that “[t]he geography of the province…must also be considered.” To the contrary, it must be given a higher level of attention.

In summary, the process for developing the Standards could have used a participatory approach with local expertise and could have been informed by different sources of evidence on a scale much broader than the apparent two sources. It could have acknowledged the findings and lessons learned in other jurisdictions. As they stand, the Standards invite critique in both process and content particularly from the perspective of those living in rural and remote communities who face health services access problems on a daily basis. In the context of my research in the North West, I experienced some of the issues firsthand and gathered data from local participants that belie the practicality of implementation of, and full compliance with, the Standards, in rural and, especially, remote settings. Some of these data are shared in Chapter Four and will serve to illustrate many practical challenges facing citizens in the North West, with or without the Standards.

Similar laments are familiar in numerous discussion papers and reports at the federal and provincial levels. Yet, little action is evident at the local, rural level of the health system. The only recommendations specific to child and youth programs suggest the need for greater advocacy and greater prominence of community Child and Youth Committees in leadership and information sharing. This suggestion was within the reformed health system of the mid-1990s, which was again restructured. It is interesting, however, to note the recommendation within the context of substance abuse. Reference is made to a “system of care” model, which recognizes
holism, and the need for case-managed, client-centred coordination, and cooperation between ministries, agencies, providers, and community organizations (BC Ministry of Health and Ministry Responsible for Seniors, 1995a, p. 73). The recommendation calls for testing such a model, for example, in the program area of children and youth.

Health services for children and youth are not specifically recognized. The root of the problem was recognized and articulated during the last decade (Provincial Coordinating Committee for Remote and Rural Health, 1999):

Many of the problems associated with the provision of health services are local in nature. Those involved in their solutions need to have extensive local knowledge and influence. This does not trivialize the contribution that is required from national and provincial organizations, but it suggests that the leadership required, and the responsibility for solution of problems, should reside locally with the Health Authorities (p. 10).

The 2002 update on the 1999 recommendations for enhancing health services in rural BC outlines progress; however, there are still no specific points around services for children and youth (BCMOHP, 2002c). On the other hand, there have been a number of efforts at the national and provincial levels with respect to planning and policy-making. Examples are introduced in the next section, starting with initiatives at the national level.

**Planning and Policy Efforts for Children and Youth**

**National**

Despite recent high-profile political attention at the national level, backed by research evidence on the importance of paying attention to growth and development of children, it is noteworthy that none of the federal or provincial reports thematically focused on children's issues. For example, the National Children's Agenda has recognized since its inception in 1997
that the needs of children span many sectors and levels of participation (Government of Canada, 1997). Similarly, the Canadian Institute of Child Health (CICH) has outlined a number of guiding principles for ensuring the health of children and youth, including the critical role of health sector interventions (CICH, 2000). The Canadian Association of Paediatric Health Centres (CAPHC) is a national organization providing important clinical, education, and research linkages between its members, and aiming to establish evidence-based guidelines for national health delivery for children and youth. Dozens of national organizations exist, too numerous to outline here\(^\text{10}\), who support children, youth, and their families. CAPHC is a national organization (not-for-profit) comprised of members who provide services for children, youth, and families in a broad variety of facilities and centres. Included in its goals is the facilitation of collaborative partnerships in order to help professionals transect traditional boundaries (CAPHC, 2003, 2005).

In this context, a number of national organizations have recently formed the National Child and Youth Health Coalition, to develop a framework toward knowledge development, dissemination, and application, and to strengthen advocacy toward improved child and youth health care and health. This coalition is comprised of the following organizations: (a) CAPHC, (b) Canadian Child Health Clinician Scientist Program, (c) Canadian Pediatric Society, (d) Council of Canadian Child Health Research, and (e) Paediatric Chairs of Canada (CAPHC, 2004). Many provincial issues have national reach and significance, and many provincial initiatives around child and youth health services research and delivery should ideally be connected within and among provinces and territories.

Since 2001, concerted efforts have been made by the Child and Youth Health Networks of Canada (CYHNC). This is a “network of networks” comprising child and youth health service delivery networks across the country, which have developed in different ways for different

\(^{10}\) For examples, refer to the CAPHC website: [http://www.caphc.org](http://www.caphc.org)
reasons. In some cases they arose because of government mandates; in other cases, they arose voluntarily to address issues around interdisciplinary and intersectoral integration. Some are largely urban-based; others span large urban and rural regions. Given the dearth of evaluative research in the planning, development, and effectiveness of such networks, the CYHNC is embarking on a multi-site evaluation strategy in an attempt to answer such concerns (CYHNC, 2005). Ultimately, this strategy should lead to advances in planning, practice, and policy. This is a key organizational form and will be discussed further in Chapter Six in the context of implications for the future.

Other population groups were identified in some reports; for example, Aboriginal peoples, rural populations, and women. Kent (2002), while lauding the similarity of Romanow and Kirby in policy proposals, specifically criticizes the lack of emphasis on children as a priority toward a strategy for population health. This, he observes, would work best through a framework of primary care managed at the local level, effectively shifting the emphasis to community health policy. This lack is particularly disturbing given, for example, the previously well-documented lack of recognition of emerging priorities for First Nations and Inuit children and youth, and the pressing need for a culturally-based action framework (Stout & Kipling, 1999). The 2003 Accord on Health Care Renewal does include the challenge of closing the health status gap between Aboriginals and non-Aboriginals through better service integration. However, it does not address the unique needs of children as outlined above.

**British Columbia**

Child health service utilization was being questioned decades ago, then in the context of BC’s Children’s Hospital and its anticipated role and capacity. Some eight years prior, it “was born into [an] environment of unplanned and uncoordinated pediatric services” (BC Ministry of Health//BC Children’s Hospital, 1990, p. 7). Of interest is that a first strategy was to improve
utilization by “providing more services locally” (p. 4). Indeed, the second strategy involved “improving standards, coordination and planning” (p. 4). The third was “to get players to see themselves as part of a system” (p. 4). Equally envisaged then was the warning against inaction—“disjointed...wasteful...services...major gaps...shortage of tertiary care resources” (p. 5). Over 15 years later, these same recommendations and warnings remain largely unheeded.

The BC Royal Commission on Health Care and Costs (1991) had broad terms of reference to examine the province’s health system, again over 15 years ago. Following 18 months of province-wide consultation, a number of recommendations were made. Among them were a number of guidelines. Of these, it is noteworthy that one recommended putting the interest of the public first and recognized the importance of community involvement: “Decisions should be made as close to the community level as possible; local people must be allowed to shape the local system of health care delivery.” (British Columbia Royal Commission on Health Care and Costs, Summary Report, 1991, p. 6). In the report, reference is made, apologetically, to only one chapter on the needs of children and youth.

The mid-1990s also saw the tragic death of a child due to a widespread failure in the BC child protection system. This led to an inquiry by Justice Gove (BC Ministry of Social Services, 1995), which concluded “the child and youth serving system in BC needs fundamental change to build a new continuum of services and programs designed to ensure the safety and well-being of children and youth” (Morton, 1996, p. 1). Immediately following the Gove Inquiry, a Transition Commission for Child and Youth Services was established, led by Cynthia Morton, Transition Commissioner. She reported on recommendations for change in BC’s systems serving children, youth and families. Among the recommendations was one to “transfer all child, youth and family services to a new ministry” (p. 2), including a mandate for “the integration of service delivery in communities, processes to include communities in planning and system re-design” (p. 2). A
number of similar tragedies concerning children in care have occurred since then, leading to the most recent review by Hughes (2006) as noted earlier in this chapter.

The BC Ministry of Health and Ministry Responsible for Seniors (1995b), in response to the BC Royal Commission on Health Care and Costs (1991), developed policy frameworks for designated populations, including children and youth, to guide the then Regional Health Boards and Community Health Councils. “The ultimate goal of such efforts is to facilitate equitable access to the health care system for all residents of British Columbia” (BC Ministry of Health and Ministry Responsible for Seniors, 1995b). A number of systemic issues specific to children and youth were identified, including: (a) service fragmentation, (b) changing service needs during transitional periods, (c) the need for the health system to partner with the educational system, and (d) the need for community investment in social planning and public policy. To address these and other issues, a number of goals and strategies were suggested. It is useful to reflect on at least a couple of the stated goals so eloquently stated 10 years ago: “Coordinate and integrate program planning and delivery across all systems providing services to children, youth and their families at provincial, regional and local levels”; and, “[p]rovide opportunities for children, youth, their families and their communities to participate in planning, delivering and evaluating the health care approach and their own health services.” (Ministry of Health and Ministry Responsible for Seniors, 1995c, pp. 10, 12). Moreover, as part of the foregoing policy framework, An Action Paper was developed in order to assist in the translation of knowledge into the day-to-day work of people working with children and youth. An action research approach was suggested at that time, noting that “[t]his kind of action research crosses mandates, Ministry responsibilities, public and private sectors, and local, regional, and provincial jurisdictions” (Ministry of Health and Ministry Responsible for Seniors, 1995d, p. 22).
During this same mid-1990s timeframe, planning for the decentralization of early childhood intervention to regional health boards proceeded in the context of a province-wide community consultation process, which included child development and rehabilitation. This report even reminds itself that its recommendations ring familiar: “In summary, like other reports before it, this report calls for an integrated, partnership model of service delivery with all stakeholders at the table…There is a clear call for change, and action” (BC Ministry of Health and Ministry Responsible for Seniors, 1996, p. 25). Unfortunately, what is clear is that 10 years has elapsed without substantial progress being made in integration and partnership between stakeholders, not only in early childhood in which some progress has been made, but also more generally in terms of health services for children, youth, and families.

Similarly, the BC Provincial Health Officer’s Annual Report (1997) which contained a feature report on British Columbia’s children, addressed services for children in the context of “appropriate care”, including four dimensions: “the right service, at the right time, by the right provider, in the right place” (BC Provincial Health Officer, 1998, p. 82). This report highlights the persistent, although narrowing, gap between the health of Aboriginal children and non-Aboriginal children. Of particular note is the observation that “individuals and communities are healthier when they are empowered and have a sense of control over their lives and their destinies” (BC Provincial Health Officer, 1998, p. 109).

The provincial perspective in rural and remote health services delivery for children and youth is also important, necessarily complementing the local and regional perspectives. For example, BC Children’s Hospital (BCCH), including Sunny Hill Health Centre for Children, is an agency of the PHSA, and is the sole tertiary health care provider for children and youth in BC. Their vision is “[b]etter health for children and youth, achieved with partners who work together to ensure access to the best care in the best setting” (BCCH, 2004, p. 9). This reinforces the need
to create and foster the many partnerships and linkages between the local, regional, and provincial components of the provincial health system that address child and youth services.

The recently formed Child Health BC is a provincial health services delivery network that seeks to connect key partners in the area of child and youth health services, including provincial organizations, health authorities, a number of provincial Ministries, advocates, private sector/families, and other agencies and services. Child Health BC (2003) is both a forum and a framework for everyone involved in child health services to work together to create an integrated, accessible system of care that ensures that the right service is provided at the right time, in the right place, by the right provider. (p. 1)

It builds upon principles developed earlier in the provincial pre-reform era by the then Child Health Network of the Lower Mainland and Fraser Valley of BC (CHNLMFV)\(^\text{11}\) which was in existence from 1997-2000. Recommendations at that time foresaw the creation of a provincial children’s health network, a provincial child health care strategy, and a province-wide information system to support these activities (CHNLMFV, 2000).

In parallel to a service delivery network, and as a final example, the Child and Youth Health Research Network is one of eight networks established with funding from the MSFHR\(^\text{12}\). This network constitutes a research infrastructure for coordinating and leading child and youth health research toward evidence-based programs, practices, and policies in BC (MSFHR, 2005). Additionally, opportunities for inter-network, transdisciplinary collaboration are plentiful. For example, collaboration of Child and Youth Health services with Rural and Remote, and with Aboriginal health services, in order to better address the challenges of health services integration in predominantly rural and remote BC.

\(^{11}\) In my earlier capacity as Vice-President, Planning & Network Development at Children’s & Women’s Health Centre of B.C. (C&W), I functioned as Chair, Steering Committee & C&W representative (1998-2000).

\(^{12}\) The other research networks are: Aboriginal, Aging, Disabilities, Environmental & Occupational, Mental Health & Addictions, Rural & Remote, and Women’s.
For the remaining leg of this journey, I draw mainly from the scholarly literature and explore four fields of study, or disciplines. These include: (a) complex adaptive systems (CAS), (b) participatory research (PR), (c) health care geography, and (d) knowledge translation (KT). I am deferring the introduction of boundaries and boundary objects to Chapter Five where these concepts are explored in the context of my research data and findings in the North West.

**Complex Adaptive Systems (CAS)**

**Introduction**

The health system is a complex adaptive system in terms of being a purposeful, organic, and changing network of socially-constructed relationships serving the common purpose of helping to improve the health status of the population. The extent to which these relationships work collectively, as opposed to working as parts separated by structural and functional barriers, determines how system-like the system behaves. Thus, it is important to conceptualize and understand a system, such as our health system, in ways that honour and respect system properties. Otherwise, serious attempts to change the system, its parts, its relationships, and its behaviour are, at best, naïve and will add to the large number of health system changes that clearly have not resulted in a well-functioning system.

Given that the health system is in large part composed of people, it follows that there are significant social and political aspects to the system. These characteristics do not conflict with those of CAS. As Flood (1999, p. 87) notes, “[h]uman systems are adaptive...involv[ing] many people, each with their own interpretations and experiences of social rules and practices that affect them.” CAS helps us to appreciate and understand such unpredictability and the dynamics created, including how people interact with each other and the tensions that arise in these social constructs. Similarly, Stacey (1992) suggests that political interaction plays an important self-organizing role as an expected characteristic of unpredictable complex systems.
Exploring CAS will offer multiple and differing perspectives on the health system and some insights into why our understanding of, and traditional approaches to, planning and policy-making in the health system within the public sector arena have not worked very well. Glouberman (2001), for example, examines the role of CAS in the health policy environment and why it is important to reframe our approach to thinking about health policy development. And, Haynes (2003, p. 28) observes that “[p]ublic services are classic examples of complex adaptive systems.” Hence, my decision to employ this perspective.

**Defining the Terms in CAS**

A system is a set of inter-connected and inter-dependent parts that function together as a whole towards a common purpose (Capra, 1982; Flood, 1999; Kauffman, 1980; Plsek & Greenhalgh, 2001; Reason, 1980; Zimmerman, Lindberg, & Plesk, 1998). A system is an inseparable whole, knowable only as itself, and is irreducible (Wheatley & Kellner-Rogers, 1996). A system can also exist as part of another system (holon). A system can be extremely small (particle fields) or extremely large (solar); closed to the environment (diagnostic equipment) or open (ecosystem); relatively simple (hospital parking card reader) or highly complex (health services delivery).

Complexity science, or complexity theory, is the study of complex systems. It is a relatively new science that focuses on parts, wholes, and relationships; how the parts give rise to the collective behaviours of the system; and, how the system interacts with its environment (Cilliers, 1998; Kauffman, 1980; Kirshbaum, 2001; Zimmerman, Lindberg, & Plsek, 1998). System complexity is measured by the amount of information and level of detail necessary to describe its behaviour (Bar-Yam, 1997). Complexity science is a transdisciplinary field of study that transects traditional scientific disciplines, focusing on parts, wholes, and their many relationships (Bar-Yam, 1997). Complexity science spans all scales from subatomic particles to
the universe, and it encompasses a broad array of disparate settings, such as: bio-molecular and cellular systems, engineering systems, social systems, and population systems (New England Complex Systems Institute, 2001). Complexity theory raises fundamental epistemological questions about “what we observe, how we observe, and what we know as a result of our observations.” (Patton, 2002, p. 123).

**Characteristics of Complexity and CAS**

What is it about complex systems that makes them complex? These characteristics are well-described in the literature, for example, Bar-Yam (1997); Capra (1982, 1996); Cilliers (1998); Murthy (2000); Zimmerman, Lindberg, & Plsek (1998). Of these, the description by Cillers (1998) is particularly apropos to our exploration. He argues that philosophical perspectives can influence how we approach complex systems, and does this in the context of post-modernism\(^{13}\). These characteristics are summarized as followed:

A complex system:

a) is composed of many elements

b) has elements that interact dynamically and change over time

c) has elements that influence, and are influenced by, others

d) has non-linear interactions

e) has interactions that are short-range, but has long-range influences

f) has positive (amplifying) and negative (reducing) feedback loops

g) is usually interactive with the environment (open, as opposed to closed)

\(^{13}\) Cilliers does not attempt to provide a definition of post-modernism because it has accumulated so many meanings. However, he does refer to the position advanced by Lyotard who highlights multiple heterogeneous discourses based on local narratives as opposed to the unification of knowledge through grand narratives. These properties of localness and multiple discourses are important attributes in the context of the other fields of study explored in this and later chapters.
h) operates in a state that is far from equilibrium (which, in the extreme, is death)

i) has a past which is partly accountable for present behaviour

j) has elements that are largely unaware of the functioning of the rest of the system, responding only to locally available information.

McIntyre (1997, p. 1) poses a fundamental question about complexity: Is it “an artifact of the world or of our understanding [underlined in original] of the world?” Further, he contends that “complexity is an ‘epistemological’ matter…. [which] exists not merely as a feature of the world, but as a feature of our attempts to understand the world. Complexity, in short, is inextricably bound up with your point of view.” (McIntyre, p. 4).

Complexity theory and CAS are closely related. Complexity theory is “systems thinking applied to the behavior of natural systems”; and more particularly, “[c]omplexity’s theory of knowledge in living systems is specifically known as complex adaptive systems theory, or CAS theory” (McElroy, 2000, p. 201).

During the last decade, Senge (1990) popularized systems thinking in the context of organizations and organizational learning. Capra (1996) also highlighted the need to shift our thinking from reductionist and analytic thinking to systems and contextual thinking. Systems explanation occurs in terms of relationships or, more accurately, webs of relationships with the system’s environment. Reality, then, is constituted through a network of relationships. He suggests that there are no foundations in such a network; rather, different levels of systems exist with none being more fundamental than any of the others.

In summary, as Waldrop (1992, p. 12) observes: “Complexity, adaptation, upheavals at the edge of chaos—these common themes are so striking that a growing number of scientists are convinced that there is more here than just a nice series of analogies.” In the United States, health care is believed, comparatively speaking, to be the most complex industry, and is adaptive.
in the sense that it adapts to constant change in health services (Kurtin, 2003). This
classification undoubtedly holds true for the health system in national and provincial settings
in Canada and, thus, is relevant to many aspects of health services, for example as a conceptual
lens for planning. This is discussed in the next section.

**Relevance of CAS to Health Services Planning**

Having outlined the main characteristics of CAS, I now turn to the relevance of CAS as a
useful lens to re-conceptualize an approach to planning. There is growing realization at the
global level, for example, in the World Health Organization, that a systems perspective is
necessary in order to overcome fragmentation, competition, specialization, sectorality, and
isolation (Pang, Sadana, Hanney, Bhutta, Hyder, & Simon, 2003). Taking a systems perspective
does not necessarily invoke CAS; however, it is a useful way to make sense of the complex
issues associated with the health system. Scholars in a number of other fields of study have
already done this. Innes & Booher (1999a, 1999b) promote complexity theory to understand and
develop collaboration in the context of social planning and consensus building. In the community
development arena, Gilchrist (2000) suggests that new insights into the properties of social
systems are provided by complexity theory. This is not a new quest, as exemplified by a 1984
symposium on "The Science and Praxis of Complexity". Included was a session led by Canadian
Senator Michael Kirby who lamented that President Kennedy spoke 22 years earlier of the need
for "sophisticated solutions to complex and obstinate problems." Senator Kirby reflected that "it
is essential that a way be found to help the individual citizen understand the complex interactions
of the problems the government is trying to solve...For when the basis of a decision cannot be
understood by the public, a basic condition for the democratic process has not been met." He
posited the question of what the science of complexity can do to help (Kirby, 1984). Seemingly,
little progress has been made in the average person’s appreciation for, and understanding of,
complexity whether they are, for example, public, clinical, managerial, or policy stakeholders. This may be a more fundamental issue than typically acknowledged because of how people typically frame problems for which they seek solutions.

Thus, an interesting paradox arises. A great deal of effort is made to understand a system by the endless analysis of its parts (fragments) when a system can only be understood as its irreducible self. Bohm (1980) emphasizes the problem of fragmentary thinking and how this results in the more serious problem of people seeing—in fact, experiencing—the world as separately existing fragments. Fragmentary thinking leads to even more problems when people take actions that seemingly correspond to this way of thinking, and which, in turn, reinforce their fragmentary world-views. The same is true of how we treat information. Capra proposes a shift from reductionist to contextual thinking. Capra (1996, p. 272) suggests that “[w]e are so used to these abstractions [taking a piece of information out of its context] that we tend to believe that meaning resides in the piece of information rather than in the context from which it has been abstracted.” Bohm’s admonition is that if we take the content of our thought as the de facto description of the world it will lead us to seeing the world in this way; worse, experiencing it as fragments; and, even worse, seeing other people, or even the system, behave in accordance with this perspective. These reificatory processes then convert our abstractions, concepts, models and maps into our sui generis reality and world-view. This process is extremely difficult to countermand; thus, the relevance of CAS theory. In order to overcome this process and pervasive tendency to, develop fragmentary world-views, our thinking about, and approach to, planning needs to be reframed through a lens that respects the complex adaptive characteristics of the health system. The recognition of the value of collaborative approaches as a means to reframe the issues is starting to take hold.

In 2001, a number of national groups collaborated for the first time to produce a report: “Listening for direction: A national consultation on health services and policy issues” (Gagnon
Menard, 2001). The groups included: (a) Advisory Committee on Health Services of the Conference of Federal/Provincial/Territorial Deputy Ministers of Health; (b) Canadian Coordinating Office for Health Technology Assessment; (c) Canadian Health Services Research Foundation; (d) Canadian Institutes for Health Information; and, (e) Institute of Health Services and Policy Research—Canadian Institutes of Health Research. The significance and breadth of this collaborative effort speaks to the genuine desire to use a more coordinated response to address the priorities of policy makers and managers, focusing on key issues from the perspectives both of health services and of policy researchers. This resulted in the identification of 15 research themes of national priority. In 2003, this national consultation was again undertaken and, building on the earlier report, resulted in “Listening for Direction II.” This process identified 10 priority research themes “designed to ensure that the research priorities that emerge are feasible from a research perspective and that they respond to the decision makers’ needs” (Dault, Lomas, & Barer, 2004, p. 7).

This takes us to the role of participatory (action) research and how this approach links with CAS. Over 25 years ago, Reason (1980, p. 35) outlined “new approaches to research” in the context of systems theory and holism, specifically, action research. This type of research is “fundamentally rooted in action” (Reason, 1980, p. 45). Key to this holistic research approach is “an iteration and dialogue between the necessarily partial views of internal and external perspectives (Reason, p. 46). Reason also suggests that this kind of research is guided by the notion of praxis, which, in this context, is characterized in terms of the dynamic interaction between reflection and action. Sohng (1995) describes praxis in terms of interaction between theory and practice. These elements of participation, action, research, and the interfaces between them, will now be discussed in the context of a participatory research approach.
Participatory Research Approach

Participatory research (PR), including concepts of participatory action research (PAR) and action research (AR), is an approach to social research that combines the elements of participation, research, and action (Greenwood & Levin, 1998). This approach is distinguished by differences in degree in, for example, purposes, epistemologies, ideologies, and traditions (Herr & Anderson, 2005). Lewin (1946, p. 34) is generally credited with coining the term “action research” which he describes as “research which will help the practitioner.”

Two traditions are generally acknowledged: the Northern (Lewinian) tradition, arising in the late 1940s to mainly solve practical problems in organizational settings; and, the Southern (Freirian) tradition, arising in the early 1970s, to recognize an emancipatory, democratic and transformational perspective (Wallerstein & Duran, 2003). However, the scholarly literature points to a convergence and blurring of these largely semantic distinctions (Green, et al., 1995). Recent interchangeability of the terms action research and participatory action research demonstrates that their principles and values are merging (Wallerstein & Duran, 2003). Similarly, their basic commitments to balancing the elements of research, action, and participation effectively link these participatory research approaches (Greenwood & Levin, 1998). Stringer (1999) refers to community-based action research as using a collaborative approach to engage stakeholders to systematically resolve problems. Use of the generic term participatory research is being encouraged (Green, 2004; Green & Mercer, 2001; Green et al., 1995). This supports the observation that “[t]hose who first used participatory research and participatory action research [emphases in original] in print consider the two terms to be synonymous” (Green et al, 1995, p. 4). PR emphasizes a bottom-up approach (as opposed to a top-down approach), focusing on locally defined priorities and views, and is set apart from conventional research by the realignment of power to local participants, and the realignment of
the researcher’s role from directing to facilitating during the research process (Cornwall & Jewkes, 1995).

Others are beginning to identify an approach that values participation. Reason & Bradbury (2001, pp. 6, 7) observe that “[t]he emergent worldview has been described as systemic, holistic, relational, feminine, experiential, but its defining characteristic is that it is participatory: our world does not consist of separate things but of relationships.” However, public participation in the context of local decision-making and policy development in the health sector may not be very compatible with the dominant expert model (Thurston, MacKean, Vollman, Casebeer, Weber, Maloff, et al., 2005).

**Community-based participatory research**

Another variation of PR is community-based participatory research (CBPR), one in a family of related participatory approaches to research (as distinguished from methodologies or methods) (Green, et al., 1995; Minkler & Wallerstein, 2003). CBPR and related approaches have gained widespread prominence and use in health (Israel, Schulz, Parker, Becker, Allen, & Guzman, 2003; Minkler & Wallerstein, 2003; O’Fallon, Tyson, & Dearry, 2000; Stewart, 2005; U.S. Department of Health & Social Services, 2003; Viswanathan, et al., 2004; Wallerstein & Duran, 2003; Waterman, Tillen, Dickson, & de Koning, 2001). This is especially apparent in public health (Israel, Schulz, Parker & Becker, 1998; Minkler & Wallerstein, 2003). Proponents of CBPR in public health recognize the sharing of core principles and values (Minkler & Wallerstein, 2003). These scholars typically situate this approach at the Freirian (emancipatory) end of the participatory action research continuum to convey attention to participation, knowledge, power, and praxis (Wallerstein & Duran, 2003). Even so, it is well-recognized that CBPR does not infer a single approach; rather, an approach should be developed uniquely appropriate to the community and situation under study (Israel, Schulz, Parker, & Becker, 1998;
Israel, et al., 2003). For applications in health, for example, when working with disadvantaged communities, compelling reasons for using a CBPR approach include the recognition of local community knowledge, the complexity of interactions, and the gap between research and practice (U.S. Department of Health & Social Services, 2003). Frustration persists with the challenges of applying research findings to community health issues, but CBPR is held out to be an important way to address this problem (Ahmed, Beck, Maurana, & Newton, 2004). A recent systematic review of the literature strongly supports health-related CBPR as a collaborative approach to bridge the gap between knowledge and community practice and its use as a way to rally action in the community (Viswanathan, et al.; 2004).

The notion of relating community and citizen participation in health is particularly important to understand. This comes with a number of challenges, but there are also ways to achieve success. The next section introduces the significance of community and the importance of enhancing the role of the public in CBPR processes. Otherwise, the idea of research being based in the concept of community is hollow. Thus, it is important to relate community and participation.

**Relating Community and Participation**

For the purposes of this study, I adopt the definition of community as “any group of individuals sharing a given interest…cultural, social, political, health and economic issues that may link together individuals who may or may not share a particular geographic association.” (Green, et al., 1995, p. 3). The value of community participation, including the challenges associated with such involvement, has been extensively studied by Zakus & Lysack (1998). In a review article, they describe community participation (also called public, citizen or consumer involvement) in health as a strategy—a complex and fragile process for citizens to develop greater responsibility for their own involvement. However, they also identify several problems
associated with this approach, including: (a) the contextual variability and the need to
disentangle other effects during implementation, (b) a lack of understanding of community
participation and representational conflicts, and (c) a lack of critical analysis and
conceptualization of community (Zakus & Lysack, 1998). Numerous challenges and dilemmas
have also been described (Angeles & Gürstein, 2000; Botes & van Rensburg, 2000). Morgan
(2001) in another review article describes both the “allure and challenge” of community
participation, but also observes that:

Today, facilitators and policymakers are more willing to assume
the responsibility that is entailed by their desire to enhance
participation. This means that they must take greater responsibility
for planning the kind of participation [emphasis added] they want
to encourage. Guidebooks often emphasize that project planners
must begin by having detailed discussions about their own goals
and definitions of participation before taking the concept to the
field. (pp. 222-3)

In this study, as a researcher and facilitator, I fully accept and sincerely attempt to model a
responsibility for planning and encouraging the kind of multi-stakeholder participation upon
which successful child and youth health services can be based. I make a conscious effort to
ensure that I have reflected upon my own goals and conceptualization of participation well
before embarking on fieldwork. This awareness, developed over many years through both
professional experience and academic preparation, was described in Chapter One and is
illustrated in ensuing chapters.

Process has emerged as the sine qua non of participatory research. Community
participation is not just input, but the basis upon which such research operates. Perlstadt, et al.,
(1998, n.p.), in a systematic review of the literature on citizen involvement in health planning,
identify a number of important lessons. These reviewers suggest that successful citizen
involvement in health planning needs to: (a) have an external change agent, (b) address the power differential between people in control and the constituents, (c) collaborate on policy preparation, (d) share the change management process, and (e) institutionalize community. Thomas (1995) warns that government and societal institutions are lagging in their understanding of the importance of public involvement, and that public managers seem puzzled about how to go about it. For example, in keeping with BC’s New Era intentions, this points to the need for enhanced citizen participation; however, the means to achieve this remain elusive in health planning.

On the national scale, Church, Saunders, Wanke, & Pong (1995) conducted an extensive literature review of organizational models in community-based health care in Canada. They observed that one of the objectives of health reform initiatives was to enhance the role of consumers in decision-making. They concluded that, in spite of the growing trend to more actively involve consumers, citizen participation in Canada failed to progress beyond a consultative role (including royal commissions, public forums, and advisory committees). They suggested that the problem stems from power relationships between citizens, administrators, and providers, the root causes of which are unequal interests and disproportionate information. More recently, these observations are substantiated by a number of reports in the grey and scholarly literature. Maioni (2001), in the context of health reform and regionalization across Canada, suggests that decentralization and citizen engagement remain problematic because: (a) the system is very complex, posing interpretability challenges for non-experts; (b) public engagement could create conflict, leading to difficulties in achieving consensus; and, (c) there is a real potential for government to avoid accountability and blame.

Rapidly growing interest in, and attention to, public consultation and involvement in Canada is apparent by virtue of the number of recent publications in both the grey and scholarly
literature, for example: Abelson, Eyles, McLeod, Collins, McMullan, & Forest (2003); Abelson & Forest (2004); Abelson & Gauvin (2004, 2006); Abelson, Forest, Eyles, Smith, Martin, & Gauvin (2003); Abelson, Forest, Eyles, Casebeer, Mackean, & the Effective Public Consultation Project Team (2004); Frankish, Kwan, Ratner, Higgins, & Larsen (2002); Gold & McMullan (2000); Martin, Abelson, & Singer (2002); Turnbull & Aucoin, 2006). In the UK, the National Health Service has vigorously pursued public involvement in health (Florin & Dixon, 2004; UK Department of Health, 2004a). This literature highlights the increasing recognition and importance of public participation, but calls attention to the paucity of research on how to best design and evaluate participatory processes. This is not only limited to public involvement, but extends, for example, to health care priority-setting involving other stakeholder groups such as administrators and clinicians (Martin, Abelson, & Singer, 2002).

How to effectively engage the public in the context of regionalization and local involvement in planning and decision-making processes remains a puzzle, but work is rapidly proceeding on how to best conduct public consultation (Abelson & Forest, 2004). The practical challenges associated with citizen participation in the context of regional authorities is well-recognized, including the need for research on how citizen participation actually leads to better decision-making and an improved health system (Frankish, Kwan, Ratner, Higgins, & Larsen, 2002). The Canadian Policy Research Networks (CPRN) is making a concerted effort to address these issues in health care, including clarifying, enhancing, and assessing the impacts of public participation (Abelson & Gauvin, 2004, 2006), and promoting the development of a strategy to institutionalize public involvement (Turnbull & Aucoin, 2006).

CBPR is particularly well-suited to address the complexity of child and youth health service research and service delivery planning. However, issues of power and control need to be
addressed. Identifying, understanding, and dealing with power relations and control is central to democratic participatory processes. These and related issues are discussed in the next section.

**Power and Control**

The need to recognize and address power relations and control issues in participatory approaches is well documented (Chambers, 1995, 1997, 1998a, 1998b; Cornwall & Jewkes, 1995; Greenwood & Levin, 1998; Martin, 1996; Nelson & Wright, 1995; Rocheleau & Slocum, 1995). Greenwood & Levin (1998, p. 88) underscore that “[Action Research] is about the transformation of power relationships…. [w]ithout an analysis of power relationships, AR is impossible.” To reiterate what was introduced in Chapter One, it is critical that participatory approaches be backed-up by institutional commitment, not just rhetoric (Nelson & Wright, 1995).

In the context and conduct of participatory research, it is important to acknowledge and seek to more fully understand the power relations and centrality of the dynamics between the researcher and stakeholders, and between the stakeholders themselves (Chambers, 1997; Frisby, Reid, Millar, & Hoeber, 2005; Gaventa & Cornwall, 2001; Greenwood & Levin, 1998; Kothari, 2001; Nelson & Wright, 1995; Rocheleau & Slocum, 1995; Smith, 1997; Wallerstein & Duran, 2003). This is particularly relevant in the health system with its entrenched professional hierarchical structures (Martin, 1996; Meyer, 2001).

Huxham & Vangan (2005) point out that while there is a dearth of literature on power in the context of collaborative settings, power issues are nonetheless important in the pursuit of collaboration, especially when participants hold divergent aims. They promote three points on a continuum of power to address this: (a) power over (the relationship and the power this entity has over others), (b) power to (help the relationship and collaborations), and (c) power for
(transferring power to others through collaborations). The approach to power that I take in this study largely revolves around power to and power for.

Another practical way to characterize power is that described by Starhawk (1987): (a) power-over, (b) power-from-within, and (c) power-with. Typically, notions of power imply a power-over relationship in which conscious or sub-conscious control of others, particularly of the oppressed, is at work and which can lead to widespread damage to body, mind, spirit, and environment (Smith, 1997). Power-from-within emerges from connecting to others and our environment, strengthening and renewing self and soul, and helping to sustain us (Smith, 1997). Power-with concerns our relationships with other people, equals, whom we value. This kind of power relationship is fragile, shared, fluid, gradual, and responsive to group interconnectedness. It also includes a harmonious relationship with nature (Smith, 1997). The critical point here is that PR seeks to “shift power-over relations to power-with and power-from-within.” (Smith, 1997, p. 192). Similarly, Nelson & Wright (1995) emphasize the need to shift power in order to allow participants to be active, rather than merely using this shift as a calmative measure to assuage power differentials among people in their organizational structures. Finally, Chambers (1997) specifically decries power as a hindrance to learning, especially among the powerful who may happen to be wrongheaded due, for example, to their position, influence, professional authority, and financial control.

This section has provided an overview of the importance of dealing with issues of power and control on many levels. These concern people and their relationships with each other. I now shift to a discussion of the importance of health care geography, a physical environment over which we typically have little power, authority, or control. However, we can recognize and interact with geographical complexities. This field of study provides valuable insights as to how this can be accomplished in the context of health and health care.
The Geography of Health and Health Care

An Overview of the Evolution of Medical Geography

Medical geography is an integrative discipline which draws on the social, physical, and biological sciences and uses concepts and techniques from the broader discipline of geography to investigate health-related issues (Meade & Earickson, 2000). Its main purpose is to address the spatial distribution, dynamics, and patterns of health and disease-related phenomena and mobility among people (Meade & Earickson, 2000). Medical geography has typically emphasized public health over medicine, and new approaches are being sought to encompass social perspectives (Meade & Earickson, 2000). Historically, medical geography has been recognized as an interdisciplinary, multidimensional body of knowledge continually influenced over time by approaches used in other disciplines (Pyle, 1979; Joseph & Phillips, 1984). Medical geography in the pre-1980s comprised two parallel strands—disease ecology and health care provision. There was little scholarly interaction between them and it has been postulated that this indicates a disconnect between medicine and disease research and service planning (Kearns & Gesler, 1998a).

In the recent past, concerted efforts were made to confront and bridge the duality between disease and health care (Jones & Moon, 1991, 1992, 1993). More recently, Kearns & Gesler (1998a, p. 1) suggest that medical geography is undergoing a paradigm shift to a "geography of health." Parr (2002) reports that a very strong traditional medical geography still exists, but that new research is focusing on health. Medical geography appears to have evolved to geography(ies) of health (Gatrell, 2002) and geography of health care (Meade & Earickson, 2000). The latter is comprised of two major components: (a) the spatial properties of health care resources (where are the providers, [emphasis in original] and why are they there?); and, (b) accessibility, utilization, and planning of health care services (where do consumers [emphasis in
original] seek/receive care, and why there?). For the purposes of this study, I focus on the geography of health care, which is discussed in the next section.

The Geography of Health Care

Access and Utilization

The geography of health care also includes access and utilization of health services. As Meade & Earickson (2000, p. 381) emphasize, however, the most important link is the one between the service user and the provider, and that optimizing resource distribution is possible "only if this relationship is understood." The call to improve access has been common to a litany of recent health system reform initiatives (Ricketts, Savitz, Gesler, & Osborne, 1994).

Accessibility to health care services is a complex subject with a wide spectrum of concepts, characteristics, and behaviours yet to be understood (Martin, Wrigley, Barnett, & Roderick, 2002; Meade & Earickson, 2000; Ricketts, et al., 1994). For example, Penchansky & Thomas (1981, as cited in Cromley & McLafferty, 2002) identify five characteristics of access: (a) availability (the supply of services relative to needs); (b) accessibility (geographical barriers including distance, transportation, time, and cost); (c) accommodation (how services are organized to meet needs); (d) affordability (ability to pay for services); and, (e) acceptability (how users feel about health services, including issues of gender, culture, ethnicity, and sexual orientation).

The problem of understanding and resolving issues of access is further compounded by the distinction between potential accessibility (the geographical distinction between people and services in terms of distance, cost, time, and effort required to reach services) and, revealed accessibility (the actual patterns of utilization premised on individual choices, geographical configurations of services, and effects of referrals and regulations) (Cromley & McLafferty, 2002). In terms of spatial factors, distance (as determined by real, perceived, social, and
economic measures) is surprisingly overlooked (Meade & Earickson, 2000). Distance is a known barrier (Ricketts, Savitz, Gesler, & Osborne, 1994) and is the common factor in both access and utilization. In BC, the importance of distance is accentuated by large bodies of water, mountains, severe winter weather conditions, and related environmental factors. This continues to legitimize the enduring dictum that availability of care varies inversely with the needs of the population served—the “inverse care law” (Hart, 1971). Moreover, “distance-decay” also factors into access: as distance increases between provider and user, utilization decreases (Gatrell, 2002; Meade & Earickson, 2000).

**Locality in Health Services**

Locality is defined as a place where “various social and economic processes come together in combinations which may be specific to the place and may themselves be influenced by the conditions prevailing in the locality.” (Curtis & Jones, 1998, p. 86). For example, Bullen, Moon, & Jones (1996) note that locality is the functional area for planning primary health care. Even more important, they contend that “by basing health care planning on small geographical areas, recognizable and known to the public, there will be greater public involvement in, commitment to and understanding of the disposition of health care resources” (Bullen, Moon, & Jones, p. 801). While it is acknowledged that these observations are based on experience in the UK, the converse is evident in health services planning in BC. Here, such planning is more typically based on the provincial scale, the HA scale, or the HSDA scale. Planning at the level of small geographical areas is a practical necessity, but remains relatively uncommon. There are some exceptions in health (see, for example, Green & Shoveller, 2000; Kearns & Gesler, 1998b). This is particularly disturbing for a number of reasons advanced by Curtis & Jones (p. 107), such as: (a) contextual effects operate at different geographical levels, and can explain health inequalities; (b) individuals may experience benefits unequally when they are generated by an
intervention aimed at the population; and (c) socially disadvantaged people may experience things differently depending on where they live. In the context of social influences, Curtis & Jones query the usefulness of targeting specific health policies toward particular areas, contending that socially disadvantaged individuals may experience their situations differently subject to their geographic setting. Importantly, Curtis & Jones (p. 107) observe that “there is strong evidence that individual characteristics are very important for health difference and that not all individuals in a geographically defined community will be equally able to benefit from an intervention which is targeted only at the collective and not toward the individual.”

These and other contextual effects hold true particularly for children and youth because their needs often require unique interventions that are chronologically, developmentally (cognitive and physical), and environmentally sensitive, as discussed in earlier sections. Additional factors contribute to the healthy development of children and youth and require special attention. These are discussed in the next section.

**Special Considerations around Children and Youth**

It is well recognized that healthy growth and development, especially in early years, is key to health in later years. Many factors are known to contribute to this, including biological, social, economic, physical, and environmental conditions. It is also increasingly evident that the interdependence of space, place, and health is paramount and largely impossible to displace from health policy-making. This was highlighted at the annual convention (2002) of the Union of B.C. Municipalities (UBCM) which observed that the “crisis in the provincial health-care system has drawn attention away from the vital role communities play in health”, especially the role communities should play in helping to develop healthy lifestyles for children (McInnes, 2002, p. B6). This role necessarily extends beyond common conceptions of health services, such as recreation, education, social services, child welfare, and justice.
This also gives rise to the question of how to account for children, and address their participatory role in health services planning, in particular from a health care geographical perspective. Recent literature suggests the need for children to be more actively and legitimately involved. While possible, it is challenging to engage younger children in the participatory approach (although it is possible for youth, as I have demonstrated in this study). Rather, parents/family of children can provide surrogate or direct input. The latter is consistent with, and builds upon, the critical role that families play in the development, health, and care of children and youth as strongly advocated internationally (BC Ministry of Health and Ministry Responsible for Seniors, 1995a, 1995b, 1995c; Canada Government, 1998; National Association of Children’s Hospitals and Related Institutions, 1996; UK Department of Health, 2004b).

In urban settings, Davis & Jones (1996) observe that in the context of the new public health agenda (which emphasizes a commitment to community participation and empowerment) children are still seen largely as objects to be fitted into an adult-constructed world; little attention has been paid to children’s participation or policies that will enable children to make healthier choices. Likewise, Matthews & Limb (1999) in their review of the “geography of children”, stress that research has been fragmented, using only narrow disciplinary perspectives and methodologies. They call for greater children’s involvement in planning.

Generally, there has been little research to date on the concept of place – a social construct entailing where and how people attach meaning to, and experience, their locales (Cresswell, 2004). Despite the key role of health care geography plays concerning access to services, there is only scattered acknowledgement in the grey literature of how place, as a geographical concept, affects health services planning and delivery. Place and how this important concept relates to health and health services for children and youth are highlighted in the next section.
Place and Health

Place is different from space. Kearns & Joseph (1993) acknowledge the inherent ambiguity in this distinction; however, space is considered in terms of being geometric or social. The difference between place and space is more a matter of degrees than absolutes. They suggest a recursive relationship between space and place—space affects the character of place and, conversely, place affects space. Massey (1997, p. 315), even more broadly than health, calls attention to the need to “rethink our sense of place”, and how we relate to place in order to help retain a sense of locality and particularity. Jones & Moon (1993), in their review of the importance of a local context in health planning, draw attention to the shift from space as a container (spatial analysis) to space as a relational phenomenon (reciprocity of space and human activity).

Place is also different from location. A location is a point or area on the earth’s surface. Once named and imbued with meaning, it becomes a place (Gatrell, 2002) and, thereby: shapes people’s health experience through “mystical influences” (Macintyre, Ellaway, & Cummins, 2002, p. 125); is the centre of lived meaning and social position (Kearns & Gesler, 1998a, 1998b); is where one is known and knows others (Eyles & Litva, 1998); has character (Kearns, 1993); and, holds special significance and satisfies the basic human need for roots (Kearns, 1991). Kearns (1993, p. 140) observes the lack of attention to place as an “experienced zone of meaning and familiarity”, asking whether the field of medicine is too detached from the notion of place. He underscores the lack of health services research on a place-centred perspective. The shift from a curative biomedical model to a socio-ecological health model converges on the essence of place. More poignant is the observation by Eyles & Litva (1998, p. 263) that, unfortunately, “[p]lace appears irrelevant to policy because of the usurpation of debate by other discourses that emphasize the patient and the nonplace community.” They reinforce the relevance of place in health care policy and service delivery, specifically boundaries and size.
(size in the sense that smaller units allow more opportunity for participation and accountability). They suggest the idea of formalizing places, and query how “place-based” decentralization and local participation in decision-making could be facilitated. Along this line, Kearns (1991) examines the contribution of health services to the experience of place (as opposed to prior studies on perceptions of place) specifically in the Hokianga district of New Zealand. This study demonstrates the significance of the way provision of health services actively contributes to the vitality of communities, especially in rural areas. Similarly, Warin, Baum, Kalucy, Murray, & Veale (2000) examine the power of place in women’s and community health centres. They observe how positive experiences in community health centres transcend social relationships, health-related experiences, and a sense of community. As Joseph & Phillips (1984) remind us, it is at the local level where action must be taken because this is the place where supply and demand transect, and thus, where detailed planning must reconcile with the broader aims.

Kearns & Gesler (1998b) call for further research on how restructuring is changing both places and the health experience of residents in those places. This challenge is being taken up in various ways. For example, a recent issue of Social Science and Medicine (2003) specifically focuses on re-thinking contemporary health care in terms of place, rather than space. Casey (2003, p. 2247) characterizes this as “the praxis of place”—an “intimate dialectic”—in a “place-world” (p. 2245). As an example, Kelly (2003) suggests a need to reconceptualize our approach to geographic problems in, for example, rural health. She advances the notion of “journeys” as an alternative to “static descriptions of problems faced in rural health” (p. 2281). She suggests that “journeys, like identities, involve new configurations of place, self, other, and power that are negotiated in complex and emergent ways.”

This literature serves to highlight a growing effort, at least in the geography of health care, to shift attention from spatial considerations in health services research, planning, and
delivery to an awareness of place—space with meaning. Despite decades of such awareness-raising efforts, other health services research disciplines have been surprisingly slow to inculcate this in their respective domains. Equally puzzling is the absence of place-awareness by decision and policy-makers in the practice arena.

Throughout my research, I have made a conscious effort to recognize and honour the power of place, made very real to me in my individual interactions with all study participants in their own communities. A few of my interviews were conducted by telephone, but, even then, I had visited their communities during earlier fieldwork. Place, knowledge, and the concepts of boundaries (to be introduced and discussed in Chapter Five in the context of my findings) are closely related.

Place, in the context of geography, knowledge and boundaries, is enjoying recent scholarly attention. For example, a special journal edition (Health & Place, 2004) introduces the idea of the geography of knowledge and devotes several articles to this topic. More particularly, the multiplicity of geographies, various forms of knowledge, and their intersections are raised. As Davies, Day, & Williamson (2004, p. 293) observe, “the geography of knowledge draws attention to how different kinds of knowledge are co-constituted through particular places, embodied practices and technological artifacts.” In their view, this raises the concept of “boundary work” (p. 294) in a number of ways, including: the production of knowledge, the concentration of power and authority, and public participation processes. Boundaries, in terms of knowledge, locales, and participation, is a concept that I will return to, and expand upon, comprehensively in the context of the findings in my study as discussed in Chapter Five.

Such a connection with knowledge, and how it is used in the context of health services and policy research, takes us into the domain of knowledge transfer, linkage, exchange, and translation, as it is variously known. How knowledge flows between, informs, and is used by
multiple stakeholders in the research and decision-making arenas is explored in the next section. This discussion is helpful in terms of explaining the differences in perspective between researchers and decision-makers and how this affects the use of knowledge, particularly the use of evidence to inform managerial and policy decision-making.

**Knowledge Translation**

A large gap persists between researchers (those who develop theoretical and scientific evidence), and decision-makers (those who make clinical, managerial or policy decisions). This has been described in variations of the “two communities” theory which purports that researchers and decision-makers live in separate worlds, differing in terms of relevancy, values, rewards, norms, interests, cultures, and languages (Brazil, MacLeod, & Guest, 2002; Caplan, 1979; Huberman (1991), as cited by Wallerstein, 1999; Lavis, 2003; Lester, 1993; Susman & Evered, 1978; Walshe & Rundall, 2001). Two decades ago, Weiss (1980, p. 381, p. 2) suggested that knowledge was not “utilized” and policy was not “decided”; rather, knowledge “creep[s]” and policy “accretes”. This helps to explain why decisions take shape gradually without a straightforward application of research and analysis. Lomas (1997, p. 1) observes “spluttering progress” in the dissemination and uptake of research. Walshe & Rundall (2001) demonstrate that lack of progress and a conspicuous lack of interest by governments, policy-makers, and managers characterize the research-practice gap in terms of overuse, underuse, and misuse of evidence by decision-makers. Even “factoids”—speculations reported so often that they are considered true (whether or not they, in fact, are)—enter policy-making in the absence of empirical information (Cummins & Macintyre, 2002). The concepts of knowledge utilization and management have been circulating for decades, recently being co-opted by health services research and delivery.
Knowledge management, itself, is evolving with the increasing recognition that earlier technological approaches to managing knowledge as a commodity are flawed. Rather, knowledge “resides in people: not in machines or documents” (Hildreth & Kimble, 2002, p. 1). This is an important distinction. Extending this reasoning to the discourse on knowledge transfer in the health arena, this distinction is not yet appreciated. It is usually the technical evidence (data and information) that is the focus of transfer, exchange, and translation, not the resultant change in stakeholder knowledge.

Knowledge transfer and exchange (KTE) and knowledge transfer, or translation, both known as KT, are terms that, unfortunately, continue to be used interchangeably in current discourse despite connotative differences. KT is defined in several ways. From a relatively narrow and unidirectional perspective, knowledge transfer is “the process [emphasis added] that transfers research results from knowledge producers to knowledge users” (Birdsell, Atkinson-Grosjean, & Landry, 2002, p. 1). CHSRF earlier framed the discourse in terms of evidence-based decision-making (EBDM), highlighting the need for a “linkage and exchange” philosophy between researchers and decision-makers (CHSRF, 1999, 2000). Since 2002, CIHR has promoted a broad definition of knowledge translation that encompasses their entire spectrum of health research (CIHR, 2002):

[Knowledge translation] is the exchange, synthesis and ethically-sound application of knowledge—within a complex system of interactions among researchers and users—to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system. (p. 1)

CIHR is investing heavily in KT and has developed a strategic direction in this key area (CIHR, 2006). This funding body recognizes that partnerships are critical to effective KT, and that ongoing relationships based on trust between knowledge creators and knowledge users strongly
predict success in EBDM. These partners include: researchers, policy makers, administrators, health care providers (formal and informal), the general public and patient groups (including media, voluntary sector, educators, non-governmental organizations), and the private sector.

It is useful to approach KT from the perspective of evidence and EBDM. In the context of health services and policy decision-making, CHSRF, in particular, is re-defining what constitutes evidence and, by extension, KT. Significantly, CHSRF has moved away from EBDM to evidence-informed decision-making (EIDM). This shift recognizes the place of scientific evidence, but also honours other contributions to the decision-making process including, for example, values, stories, anecdotes, and life-experiences. Administrative and policy decision-making, in the face of high uncertainty (situations lacking sufficient information to inform decision-making) is weighted toward a reliance on values rather than information (CHSRF, 2000). More recently, CHSRF engaged in a systematic review of the scholarly and grey literature (Lomas, Culyer, McCutcheon, McAuley, & Law, 2005). Their review explores how those who create and use evidence handle it. They conclude that there are three complementary categories of evidence: (a) context-free scientific evidence (used in medicine), (b) context-sensitive scientific evidence (used in social sciences), and (c) colloquial evidence (stakeholder realities). Thus, how one defines evidence, they purport, depends on context, whether it is context-free or context-sensitive. This underscores the very real challenge of appropriately weighting scientific and colloquial evidence to enable decision-making.

Finally, CHSRF (2006) sponsored a recent conference entitled “Innovation through Collaboration: Working together for an evidence-informed health system.” Continuing ambiguity is acknowledged concerning the term evidence, particularly the on-going debate around the terms evidence-based and evidence-informed. Interestingly, this conference also highlights the growing recognition that the traditional categories of stakeholders in health services research are
beginning to self-identify as “hybrids”. This indicates a trend toward greater cross-linking of the traditional disciplines.

What, then, are the main issues impeding progress in KT, and how might they be addressed? I highlight three here: (a) the epistemological basis of evidence generation; (b) the imperative of local multi-stakeholder involvement; and, (c) difficulties around decision-makers’ use of evidence. Collectively, these inform the methods that could serve to advance KT.

Evidence is “information based on historical or scientific evaluation of a practice” (Tranmer, Squires, Brazil, Gerlach, Johnson, & Muisiner, et al., 1998, p. 21). However, there is a dearth of systematic studies to explain the impact of information on decision-making (Oh, 1997). Values are central to and shape health care decision-making (Upshur, VanDenKerkhof, & Goel, 2001). In addition to values, competing self-interests, beliefs, and emotions often drive the decision-making process, resulting in poor decisions and outcomes (National Forum on Health, 1997). Thus, it is instructive to combine the concepts of evidence and values in evidence generation and determine how this construct might influence approaches to KT.

Upshur, VanDenKerkhoff, & Goel (2001, p. 92) describe such a conceptual model. The model demonstrates the highly interactive nature of evidence generation and acknowledges that it is appropriate to employ a range of research methodologies. They assert “the concept of evidence employed must be robust enough to resonate with practitioners, health-care planners and the wide community of researchers.” This interaction also reinforces the expectation that negotiation occurs before the research is undertaken, pointing to the fundamental importance of establishing trust and commitment between researchers and policy-makers (Davis & Howden-Chapman, 1996).

In keeping with the earlier focus on the concept of place, Anderson, Cosby, Swan, Moore, & Broekhoven (1999) draw attention to the neglected area of research transfer to local
organizations that deliver services to the community. To solve this, they suggest: (a) improved congruence with need and relevance for stakeholders; (b) improved interaction between researchers and users; (c) greater awareness and communication; (d) creation of organizational cultures to inculcate research into decision-making; and, (e) the need for academe to review how researchers work with local agencies. It is also important to humanize the research process, involve all stakeholder groups, and create meaning for and connect with the emotions and experience of practitioners (Canadian Research Transfer Network & Health Research Transfer Network of Alberta, 2002).

The KT process must also overcome barriers to decision-makers’ use of evidence, such as those identified by the National Forum on Health (1997): (a) lacking pertinent evidence; (b) lacking consensus; (c) using evidence inappropriately; (d) dealing with lag times between research and its application; (e) being overwhelmed by information; (f) failing to consider the impact on health outcomes; (g) having differing and changing values; (h) lacking accountability for decisions; (i) relying on tradition and judgment; (j) pointing to protection of privacy and confidentiality; and, (k) having to use poorly coordinated health information systems. An equally important consideration is the context of the evidence, ranging from the particular (personal) to the general (population). In the context of evidence-based practice, for example, Bowman, Snider, & Ellis (2003) suggest that stories play a key role as particular evidence, especially to describe barriers to research transfer in organizations. As Upshur, VanDenKerkhoff, & Goel (2001) suggest, evidence is an interaction between two axes: the range of evidence (from a context of particular to general) and the range of methodologies used (from an emphasis on measurement to that of meaning). They suggest that this construct: (a) integrates diverse disciplinary epistemologies; (b) legitimizes qualitative evidence; and, (c) allows values to be included in decision-making. This construct calls for generating evidence for decision-making that respects these three characteristics. From the perspective of meaning, this can include
qualitative methods, such as the methods I used in this study: semi-structured interviews, focus groups, and a search conference. Additionally, quantitative methods (such as using GIS technology as a tool for health services data analysis and mapping) can contribute to EIDM from a measurement perspective. Combining such methods can lead to more effective ways to translate knowledge and share complex information with diverse stakeholders.

This reinforces a central role of praxis: the constant iterations between theory and practice, and between knowing and acting. Unfortunately, the research and decision-making solitudes continue to exist more independent of, rather than interdependent on, each other. Success here is contingent upon the extent to which praxis is seen to provide “coherence across intersecting social worlds” (Star & Griesemer, 1989, p. 393). There are many stubborn barriers to making real progress between these social worlds; however, increased awareness of, and an awakening to, the role of praxis in this context will go a long way to building resilient relationships. As Evans (2006, p. 20) succinctly frames it, getting KT to work unimpeded will necessitate that we explicitly face our “unexamined habits of thought and behaviour.” This is the relevance of KT.

This chapter has taken a journey into a number of themes and disciplines. It has reviewed the scholarly and grey literature in order to help make sense of the inherent complexity of the health system and how different disciplines can coalesce to clarify issues related to health services research, planning, and service delivery for children and youth. I now shift to a technical journey that explores the research methodology used in this study.
CHAPTER THREE: Methodology and Data Analysis

Rationale for using a Participatory Research Approach

As reviewed in Chapter Two, participatory research is an effective and respectful way to conduct extensive collaboration with multiple stakeholders in health services and to effect action. While taking a predominantly local community-based approach, this study recognizes a health systems perspective, which was also reviewed extensively in Chapter Two. To focus exclusively on planning at the local community level would detract from the critical interrelationships and interdependencies characteristic of a complex system. The reverse is also true. As Green & Mercer (2001) and Green, et al. (1995) urge, participatory research is a broad and systematic approach that stretches from community to academia and involves stakeholders affected by, or who may potentially use, the research.

I have taken account of the historical neglect of local involvement in health services research and throughout this study have consistently engaged local stakeholders in the research process. Effecting community-based, capacity-building strategies and programs must involve individuals and communities in a meaningful way (Veazie et al, 2001; Moyer, Coristine, MacLean, & Meyer, 1999).

Linkages between research, practice, and policy are critical to the planning and delivery of health services, and ultimately to the success of the health system. Through a participatory research approach, the necessary linkages can be formed and nurtured to better understand the questions relevant to local communities, to undertake the research to appropriately answer such questions, and to facilitate action through planned change processes. The concept of health reform—change—should include local participation and action. This is where the day-to-day realities of health service delivery are actually confronted. Conversely, there is a risk of
government using such participation as a convenient means to other ends, for example, to post hoc legitimize public policy, diffuse public criticism, or delay action (Zakus & Lysack, 1998).

**Ethics Approval Process**

The ethics approval process entailed a number of stages. The initial three approval processes spanned nearly six months. The University of British Columbia Behavioural Research Ethics Board (BREB) approved the qualitative component of the study contingent upon approvals from the CFRI Research Review Committee, the NHA Research Review Committee, and the Nisga’a Health Authority\(^{14}\) (had they decided to participate). Additionally, BREB required a separate ethics approval process for the quantitative component, which used secondary administrative child health utilization data for geographic information systems mapping. This, in turn required additional ethics review by CFRI’s Research Review Committee and the NHA’s Research Review Committee. Investigator-initiated amendments and routine annual ethics reviews added to the process, resulting in some two-dozen certificates and/or letters of approval during the course of the study.

This experience underscores the challenges associated with a participatory research (PR) approach using mixed methods, covering multiple jurisdictions, involving multiple agencies, and continuing over an extended timeframe. It also draws attention to a number of ethical considerations and possible negative consequences, even harm, that must be acknowledged, particularly in the context of a participatory research approach involving participants who are local community stakeholders.

The challenges posed by using PR and related approaches in both developing and developed countries are well-described in the literature and are pertinent here in the context of

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\(^{14}\) The Nisga’a Health Authority Board decided to not participate given competing priorities of the day. Had they agreed to proceed, I would have been invited to help develop a prototype Aboriginal community ethics approval process.
ethics associated with a PR approach (Angeles & Gurstein, 2000; Botes & van Rensburg, 2000; Church, Saunders, Wanke, & Pong, 1995; Cooke & Kothari, 2001; Cornwall & Jewkes, 1995; Forester, 1999; Israel, Schulz, Parker, & Becker, 1998; Jewkes & Murcott, 1998; Minkler, 2004; Wallerstein, 1999; Wallerstein & Duran, 2003; Zakus & Lysack, 1998). I have summarized these ethical challenges into three categories, as follows:

People (stakeholders):

1. appropriate representation, especially by the vulnerable and marginalized
2. participant willingness, motivation, and availability
3. competing institutional expectations and demands
4. community sociopolitical dynamics

Participation (relationships):

1. selection of, and ongoing participation by, stakeholders
2. bias toward seeing communities as homogeneous, consensual, and harmonious
3. lack of trust and respect between participants
4. issues of participant autonomy and maneuverability
5. potential tyrannies such as the unjust distribution and use of power and control
6. terms and conditions of partnership
7. paternalistic treatment of participants
8. conflicts arising from differences in goals, values, beliefs, priorities, and language

Processes (research practices):

1. reconciling multiple needs and agendas
2. imbalances of funding, interests, and information

3. inadequate researcher conceptualization of community

4. risk of over-simplifying complex communities

5. potential inhibiting and prescriptive role of the government

6. gate-keeping by those having local influence

7. bias toward tangible issues

8. undue expectations for immediate results

9. dealing with data arising from multiple sources

10. need to balance research and action

11. ensuring on-going sustainability

The foregoing issues raise the possibility of real and/or perceived harm to the study participants being unintentionally generated through the research process. I exercised great caution to reduce the risk of negative consequences or unintentional harm to the participants and communities engaged in this study. Many of the communities engaged in this study are small and a researcher is conspicuous. Confidentiality and protection of privacy are practical concerns, particularly when participants are, for example, sole clinicians, sole managers, or parents of children whose substantive injury or illness is likely common knowledge in a small community. I was also sensitive to the possibility of raising false expectations around improving health services for children and youth. Continuous involvement of participants in the three qualitative data-gathering methods over an extended period helped me to determine whether there were any potential negative consequences arising from my research, none having come to my attention.
Gaining Access to the Research Site

I conducted the study in the North West HSDA, one of three HSDAs in the NHA. As discussed in Chapter Two, the NHA has the largest area of five HAs, representing nearly two-thirds of the total land area of the province. Its total population in 2005 (BC Ministry of Labour and Citizens' Services, 2006) was approximately 307,000 of whom 29%, or 89,030 are children and youth 19 years of age and under. The population distribution is shown in Figure 2.

Figure 2. BC Census Population by Dissemination Area Map.

Note: From http://www.bcstats.gov.bc.ca/data/pop/maps/PopDot2001_1.gif
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Approximately 13% of the residents are Aboriginal (NHA, 2003b). There are 16 Traditional First Nations Tribal Groups residing in the NHA; however, it is important to recognize that the health authority administration borders do not consistently align with
traditional lands (NHA, 2003). This is discussed further in Chapter Five (see Figure 16). The North West HSDA is a very large rural and remote geographic area representing approximately 27% of the provincial land mass, yet was home to only 84,392 people in 2005 (BC Ministry of Labour and Citizens’ Services, 2006). Of these, 25,072 or 29.7% are children and youth 19 years of age and under. The North West HSDA has 25 bands and the highest proportion of Aboriginal residents in the province at approximately 22% (NHA, 2003). A number of events ultimately led to the selection of this research site.

In 1999, I was invited to facilitate a planning process to address the North West regional service delivery needs of neonates, children, and youth. This regional collaborative planning process (1999 – 2001), with linkages to provincial and tertiary services, resulted in a draft report, “Caring for Children and Youth in North West British Columbia: Towards a new model for providing pediatric, adolescent and neonatal services” (North West Planning Group, 2001). Building on the success of this earlier work, I approached the senior management of the NHA to ascertain their interest in participating in my doctoral thesis research. I then drafted a North West health services redesign framework proposal for children and youth, which was intended to align with the NHA redesign plan. Subsequently, in 2002, this was approved by the senior management of the NHA. The NHA wanted a research approach that melded with their incremental, “made in the North” redesign strategy (NHA, 2002); one that was also premised on their mandate of community stakeholder collaboration and participation. My study was also funded, in part, by the North West HSDA.

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15 This is comparable to the 84,529 residents in 2001 (see Centre for Health Services and Policy Research http://www.chspr.ubc.ca/files/publications/2004/chspr04-12/Healthauthoritydemographics.pdf). However, the North West has experienced a net outflow of population, presumably due to the challenges of a predominantly resource-based economy. In 1995, for example, the NW HSDA population was 88,294 (BC Ministry of Labour and Citizens’ Services, 2006).

16 A band is “the basic unit of organization of First Nations for political and administrative purposes” (NHA, 2003, p. 15).
Concurrently, the BCMCFD undertook a province-wide transformation of services. The strategic shifts included community-based service delivery to enable communities to develop and deliver services, and working in partnership with families and communities to create a model that would better meet the needs of children (BCMCFD, 2002). While this proceeded in the context of a plan to reduce the overall BCMCFD budget by 23% over three years, it also created a timely opportunity for collaborative planning to ensure integration of community-based services for children, youth, and families in the North. However, several attempts to engage the support of the North Region BCMCFD proved unsuccessful. This was due in large part to their preoccupation with major structural reform and downsizing, financial challenges of the day, and senior management turnover in the North region.

In their New Era commitments, the BCMOHS and the BCMOHP\textsuperscript{17} highlight the need to more actively engage patients and consumers in planning the health system. Importantly, a number of provincial and federal commissions and reports also identify a pressing need for consumer/citizen participation in health system reform. This serves to underscore the importance and expectation of multi-stakeholder collaborative planning.

A major planning and redesign challenge persisted in terms of how the BCMOHP and the BCMOHS, including the recently formed HAs and their respective HSDAs, would address their well-documented strategy. This specified “ensuring appropriate and productive stakeholder participation in the development of planning approaches in a newly configured health structure”, and advocated that “[h]ealth services should be developed, delivered, and evaluated in collaboration with consumers and should respect the diversity of all British Columbians” (BCMOPHP, 2002b, pp. 2-3). Purportedly, attention was focused on accountability through participation based on the development of workable partnership models and the interface

\textsuperscript{17} The BCMOHP was subsequently merged into a single BCMOHS.
between communities and service providers and managers. This was a laudable effort; however, the literature suggests that our ability to understand the complexities of such partnership models is still at a very early stage (Cornwall, Lucas, & Pasteur, 2000).

At that time, I presumed somewhat naively that the NHA-wide redesign initiative would proceed concurrently with my research project. Similarly, I envisioned that the child and youth health services component would initially focus on the North West HSDA and then proceed in conjunction with my research project. I anticipated that this approach would help (re)define community and (re)define rural with health as a central pillar, focus on sustainability, and ensure linkages with specialized centres (Troughton, 1999). But, due to the political and fiscal realities of the day, many of these facilities and programs were at risk of severe curtailment of pediatric and/or maternal services, or even outright closure. Contrary to my presumptions, progress on the NHA-wide redesign initiative for integrating child and youth health services was effectively stalled; however, it was apparent that my research in the North West HSDA was being supported.

**Participatory Research in a Rural Context**

Participatory research approaches most effective in addressing a rural context are those that genuinely respect and actively engage rural participants in and with their communities, and over which they can share power and control. A rural context is a “context for action” and is characterized as: (a) an essential context for design and delivery; (b) unique, not simply an extension of urban; (c) diverse, having local and regional differences; (d) dynamic; and, (e) expressive, in developing unique manifestations of democracy and action (Ramp, 1999, pp. 11-12). In a rural health context, the need for public participation is enhanced. Individual and community health in rural settings is strengthened by public participation in the decision-making process, helping to amplify community spirit (Kulig, 1999; Ramp, 1999). Supporting this
observation, the BCMOHP, in its New Era change strategy, expects local health service delivery areas to “ensure community participation in health care decision-making and protect local input into the delivery of health services” (BCMOHP, 2001a, p. 3).

In the context of this study and the high proportion of Aboriginal population in predominantly rural and remote settings, a participatory approach to research and service delivery is essential. This is recognized at the provincial policy level (BCMOHP, 2001) and, similarly, is supported by the NHA as indicated in their Aboriginal Health Services Plan (2003b):

The Northern Health Authority believes that community consultation is key to identifying and developing plans to meet the needs of the local community, and has been identified as essential when working with Aboriginal issues. (p. 1)

Mixed Methods Design

I used a mixed methods design for this study. This is defined as one “that focuses on collecting and analyzing both quantitative and qualitative data in a single study (Creswell, 2003, p. 210). Mixed methods research is relatively new. Thus, a number of unresolved issues are still under debate, including: (a) use of nomenclature, (b) utility (c) paradigmatic foundations, (d) design issues, (e) drawing inferences, and (f) logistics in the conduct of such research (Teddle & Tashakkori, 2003). The use of mixed methods in health research is increasingly supported in the literature (Morgan, 1998).

It is important that the methodologies and approaches used in scientific investigation ensure that relevant data are observed, heard, gathered, and analyzed in order to arrive at valid findings and conclusions. Both qualitative and quantitative information are necessary for health research to provide insight into local health situations (van Oers, 1993). In the context of the research question, it is important to try to capture the relevant data, especially since certain kinds
of data are beyond the individual reach of either of these methodologies. However, the unfortunate tendency to pit quantitative against qualitative methodologies undermines the growing trend and need to mix these approaches. St Leger and Walsworth-Bell (1999, p. 107), for example, polarize this situation as an “apparently irreconcilable divide.” They assert that this is an obstacle that will not allow us to achieve “the broadest understanding of both the humanistic and the mechanistic factors involved in the researching, planning, development and implementation of health service delivery.” They attribute this to “academic snobbishness on one side and deliberate obfuscation on the other, though debate on the issue is dressed in arcane philosophical argument.” Tashakkori & Teddlie (2003) observe merits in each methodology, but also note the criticism advanced by proponents of the other orientation. They observe that social and behavioural research has been typically dominated by quantitative methods and positivist/post-positivist worldviews. More recently (particularly the last two decades), and as a reaction against the dominant quantitative methodology, qualitative methodology has emerged with constructivist worldviews. Others are more conservative in their perspective and see the distinction as unclear, perhaps better characterized as complementary strategies (Mason, 2002; Snape & Spencer, 2003). Ong (1993) simply concludes that the debate is obsolete; it’s an issue of when and why a particular methodology is used to answer a research question. Evolving health services research, and its many domains, is ideal territory for combining methodologies. This is critical to gaining insights far surpassing what single methodologies could accomplish on their own.

The next section addresses the two methods used in this study—a priority qualitative component with a nested quantitative component. While this study is a mixed methods design, I must emphasize that the quantitative component in this case is a very small aspect of this study. I use quantitative data to demonstrate some of the shortfalls in using the BCMOHS health services administrative database; that it can be mapped to enable the visualization of complex data; that it
can be used to demonstrate activity at a local (LHA) level in ways that many stakeholders are not accustomed to seeing such data; and, that it assists in dialogue around the priority health services issues facing certain jurisdictions, for example, serious historical inadequacies in child and youth mental health services throughout the North West HSDA.

**Priority Qualitative Component**

The characterization of qualitative data as a priority is described as a choice, depending on the weight given to the method, the researcher’s interests, the audience, and the emphasis of the study (Creswell, 2003). I determined that the qualitative component is the priority component in this study, given my personal propensity to a multiple stakeholder participatory approach, the receptivity to this approach during the phase of gaining access to the research site and based on my prior experience in the North West, and because I was using a PR approach. This choice is corroborated by Lincoln & Denzin (2000, p. 1049): “Qualitative inquiry is properly conceptualized as a civic, participatory, collaborative project. This joins the researcher and the researched in an ongoing moral dialogue”.

**Nested Quantitative Component**

The nested component in this study is quantitative (Creswell, 2003; Tashakkori & Teddlie, 1998). In this study, geographic information systems (GIS) software is used specifically as a tool. GIS is an enabling-technology tool, a computer-based system, which integrates, analyzes and maps spatially referenced or geographical data and carries out management and decision-support tasks (Cromley & McLafferty, 2002; Heywood, Cornelius & Carver, 1998; Lang, 2000; Richards, Croner, Rushton, Brown, & Fowler, 1999). This technology substantially improves health planning, particularly at the community level, by better organizing and linking data in planning health services, and by helping community stakeholders visualize and understand complex health issues (Lang, 2000; Richards, et al, 1999). Through the shared use of
GIS, the local citizenry can make its case, influence health policy, and assist policy-makers (Cromely & McLafferty, 2002). The forum during which this active participation and sharing took place was during the two-day search conference, which included all stakeholders, including the local public, clinicians, managers, and policy-makers. The search conference method is explained in another section later in this chapter.

**Sampling Process**

This study uses a combination of strategic, purposive, and snowball sampling processes. The aim of strategic sampling, as opposed to representational sampling, is to create a relevant range of contexts, experiences, and processes (Mason, 2002). As Maxwell (1996) reinforces, sampling is a deliberative strategy to select people, settings, events, and processes to generate information that is difficult to elicit from other sources.

The purposive sampling process includes snowball sampling, particularly in the identification of Aboriginal participants. Purposive sampling (also called purposeful or judgment sampling) identifies information-rich participants to share in-depth insight and understanding of issues that are central to the study (Patton, 2002). Snowball, or chain sampling, proceeds to identify additional information-rich cases, with the sample enlarging as key names are repeatedly mentioned (Patton, 2002). This process includes theoretical sampling, but without rigid adherence to the basic tenets of grounded theory as originally espoused by Glaser & Strauss (1967). The grounded theory method does, in fact, encourage research-specific flexibility. Ritchie, Lewis, & Elam (2003, p. 80) describe theoretical sampling as “a particular kind of purposive sampling in which the researcher samples incidents, people or units on the basis of their potential contribution to the development and testing of theoretical constructs”.

Additionally, the process is iterative and continues to data saturation. I wanted to ensure early inclusion of participants in each of the ten Local Health Areas (LHAs) comprising the study site,
and by each of the four stakeholder groups under study, and in the context of a knowledge translation strategy. Thus, at the outset of the sampling stage, I followed a process characterized by Mason (2002):

In its more general form, theoretical sampling means selecting groups or categories to study on the basis of their relevance to your research questions, your theoretical position and analytical framework, your analytical practice, and most importantly the argument or explanation that you are developing. Theoretical sampling is concerned with constructing a sample...which is meaningful theoretically and empirically, because it builds in certain characteristics or criteria which help to develop and test your theory or your argument. (p. 124)

In keeping with the intent of theoretical sampling in grounded theory, the use of two additional qualitative methods—focus groups and a search conference—provide further opportunities for qualitative methods triangulation, an iterative process, and data saturation. The aims of theoretical sampling are to fill gaps in data, categories, and emerging theory, and to refine ideas. This does not necessarily imply the need to increase the original sample size; rather, the same subjects can be involved (Charmaz, 2000). The focus groups and search conference involved the same study participants who participated in the individual semi-structured interview process.

I created and maintained a sampling matrix diagram throughout the sampling and data gathering phases to visually track participation by all ten of the North West LHAs. This was done to ensure an adequate number of diverse participants from each of the four stakeholder groups, and to establish that Aboriginal participation reasonably reflected the proportion of Aboriginal people to the regional population. Despite lengthy communications and recognition of the value in participating, the Nisga’a Health Authority ultimately did not join the study.
According to a senior manager, this was due to unexpected new timelines faced by the Board pursuant to its elections being moved forward. The Nisga’a also recognized that they did not have a research ethics protocol in place which they deemed to be a necessary condition of involvement. However, they did express interest to develop such a protocol using my research study as a prototype, should they decide to participate. Unfortunately, this did not occur, and the study proceeded without the benefit of Nisga’a participation or data, resulting in this sampling limitation. This decision may ultimately affect how and when service delivery planning by the Nisga’a Health Authority will integrate with the North West regional planning process for child and youth health services, facilitated through this study.18

Study participants were selected from four stakeholder groups: general public/service recipients; clinical service providers; managerial decision-makers; and, policy decision-makers. Also included were clinical service providers, and/or managerial decision-makers, and/or policy decision-makers in the NHA, Children’s & Women’s Health Centre of BC (C&W, an agency of the PHSA), BCMCFD, BCMOHS and, later in the study, the BC Provincial Government Social Policy Integration Team.19 A further sampling delimitation relates to the limited number of participants from other sectors such as education and justice. However, this deficit was partially offset by participation from the Government Social Policy Integration Team, and because at least three study participants had direct linkages with the education sector, for example, as a local school board chair, a local school board member, and as an employee of a school board. Finally, the sample size was delimited by the number of children and youth participants. I had originally planned to recruit at least two youth, one First Nations from the Nisga’a LHA and one Caucasian

18 The Nisga’a Valley Health Board (NVHB) was incorporated in 1984 and is responsible for its own health services. The NVHB planning processes do not currently integrate with those of the North West HSDA (NHA, 2003).
19 The role of this team included working with approximately eight provincial Ministries, and a specific cross-ministry project involving an integrated approach to services for children with special needs.
from a different LHA. However, with the ultimate non-participation by the Nisga’a\textsuperscript{20} and the already relatively large sample size, I did not pursue a replacement and decided to proceed with one youth with special needs.\textsuperscript{21}

The inclusion criteria were straightforward. People who had used or were currently using, and/or were working or volunteering in, the health system including health services for children and youth living in the North West HSDA, were eligible. Using guidelines from BREB, I ensured that no one was consciously excluded because of culture, language, religion, race, disability, sexual orientation, ethnicity, gender, or age.

Clinical service providers, managerial decision-makers, and policy-makers were contacted in person. Potential general public/service recipients were contacted initially by a third party health service providers such as a family physician, pediatric specialist, or community health nurse. As a rule, these providers were already purposively sampled and engaged in the study prior to their suggesting or initiating contact with potential subjects. Where feasible a Letter of Initial Contact was provided to potential subjects at that time. More commonly, the process entailed a clinical provider suggesting possible subjects based on suggested selection criteria I shared with them. I then followed-up via telephone and/or email to ascertain interest and, if affirmative, a Consent Form (see Appendix C) was emailed. A further telephone call was made to more fully explain and study and answer any questions. This typically resulted in the scheduling of an interview to take place during my next field visit. This presented logistics and scheduling challenges given extensive travel requirements in the North West, especially during the Winter months.

\textsuperscript{20} Participation by the Nisga’a was actively sought, without success, until December, 2005.
\textsuperscript{21} This youth proved to be very popular and contributed significantly to the study. In fact, one of the adult participants was so inspired that she requested a picture of him to remind her of why she was doing her work.
All interviewees, focus group attendees, and search conference attendees were given thank you cards including a cash honorarium (see Appendix C, p. 3 for details), a receipt, and a business card with contact information in case there were any follow-up questions or concerns. Additionally, participants were offered a capped reimbursement for expenses related to daycare and/or travel-related expenses, and reimbursement for any direct loss of income in order to attend a focus group and the search conference (see Appendix C for amounts). Complimentary food and refreshments were provided for all participants during both days of the search conference. Infrequently, financial hardships were raised and addressed on a case-by-case basis in order to ensure unfettered participation. This also required an amendment to the study’s ethics certificates of approval to allow me to exceed the cap on participant expense reimbursement as might be necessary in my judgement.

Data Gathering

I gathered data in a variety of settings, depending on subject preference and logistics. I physically visited at least once, but in several cases multiple times, all of the LHAs comprising the North West HSDA, with the sole exception of the Nisga’a Health Authority as discussed earlier. Additionally, this involved collaboration with stakeholders in other organizations, agencies, authorities, and various provincial Ministries who were engaged in some capacity with the planning, co-ordination, and/or provision of health services in the North West HSDA. Over the course of several field-visits by motor vehicle during the course of the study, I amassed countless hours and over 13,000 kilometers of travel. Occasionally, I travelled by ferry and air (including a float plane from a remote coastal Aboriginal community).

Qualitative Component

Qualitative data relevant to child and youth health services were collected, integrated, and analyzed through an iterative sequence of methods in keeping with a participatory research
approach. This sequence of multiple qualitative methods included semi-structured interviews, focus groups, and a search conference. Qualitative research often employs multiple methods in health care (Pope & Mays, 1999). The reasons for this include: bringing different insights to the study (Ritchie, 2003); answering the research questions in different ways or from different angles (Mason, 2002); enhancing data quality through methods triangulation (Denzin & Lincoln, 2000; Mason, 2002); and, testing different analyses and explanations against each other (Mason, 2002).

Originally, I envisioned that this study would include document review and naturalistic observation (participant observation; for example, attending selected meetings as invited or permitted by any of the stakeholder groups). However, this expectation proved impractical given the very limited progress made by the NHA in planning and implementing integrated child and youth health services in the North West HSDA and the NHA. This delay was confirmed with the NHA corporate office during the course of the study.

Piloting the Semi-structured Interview Question Guide

The interview questions were piloted with the recruitment of four colleague acquaintances, representing each of the four stakeholder groups in the study. This included a parent, a managerial decision-maker, a clinical decision-maker, and a policy decision-maker. This feedback generated from this exercise helped me to clarify, refine, and improve the questions prior to use in the field.

Semi-structured Interviews

In the view of Kvale (1996, p. 1), “[t]he qualitative research interview attempts to understand the world from the subjects’ points of view, to unfold the meaning of peoples’ experiences, to uncover their lived world prior to scientific explanations.” Qualitative research interviews are most appropriate in circumstances where there is a focus on meaning, where individual perceptions of processes are important in a larger context, and where historical
perspectives are required (Robson, 2002). The purpose of interviewing is to “derive interpretations, not facts or laws....aiming to understand the meaning of respondents’ experiences and life worlds” (Warren, 2001, p. 83). Generally, there are three types of interviews: structured, semi-structured, and unstructured (Robson, 2002). Semi-structured interviewing is one of three qualitative data gathering methods that I use in this study.

Semi-structured interviews, typically between 60 and 90 minutes duration, were conducted with subjects in each stakeholder group. Forty-three subjects were interviewed over a period of sixteen months, with the majority conducted between December, 2003 and July, 2004. Table 1 on the following two pages outlines the stakeholder groups, place, and date of the interviews conducted during the course of the study. Prompts were used extensively to increase the breadth and depth of responses (Legard, Keegan & Ward, 2003). Appendix D lists the questions and examples of prompts used to guide the interview sessions.
<table>
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<th>STAKEHOLDERS</th>
<th>LOCATION</th>
<th>DATE</th>
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</thead>
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<tr>
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<tr>
<td>Policy-maker</td>
<td>Prince George</td>
<td>December 8, 2003</td>
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<tr>
<td>Manager</td>
<td>Prince George</td>
<td>December 8, 2003</td>
</tr>
<tr>
<td>Clinician</td>
<td>Smithers</td>
<td>December 9, 2003</td>
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<td>Hazelton</td>
<td>December 10, 2003</td>
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<td>Terrace</td>
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*Continued next page...*
Table 1. Semi-structured Interviews—Stakeholders, Locations, and Dates.

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</tr>
<tr>
<td>Clinician</td>
<td>Smithers</td>
<td>July 17, 2004</td>
</tr>
<tr>
<td>Policy-maker</td>
<td>Hazelton (via telephone)</td>
<td>July 19, 2004</td>
</tr>
<tr>
<td>Manager</td>
<td>Old Massett</td>
<td>July 27, 2004</td>
</tr>
<tr>
<td>Manager</td>
<td>Skidegate</td>
<td>July 28, 2004</td>
</tr>
<tr>
<td>Clinician</td>
<td>Queen Charlotte City</td>
<td>July 28, 2004</td>
</tr>
<tr>
<td>Policy-maker</td>
<td>Skidegate</td>
<td>July 28, 2004</td>
</tr>
<tr>
<td>Manager</td>
<td>Prince Rupert (via telephone)</td>
<td>September 9, 2004</td>
</tr>
<tr>
<td>Parent</td>
<td>Skidegate (via telephone)</td>
<td>September 10, 2004</td>
</tr>
<tr>
<td>Manager</td>
<td>Vancouver</td>
<td>October 6, 2004</td>
</tr>
<tr>
<td>Manager</td>
<td>Iskut (via telephone)</td>
<td>March 10, 2005</td>
</tr>
<tr>
<td>Policy-maker</td>
<td>Victoria (via telephone)</td>
<td>April 13, 2005</td>
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**Focus Groups**

The popularity, use, and acceptance of focus groups has increased widely in social research (Finch & Lewis, 2003; Morgan, D., 2001; Robson, 2002), including health services research (Kitzinger, 1999). Focus groups are a type of group interview in which the emphasis is
on the generation of data, guided by the researcher, through interactive communication among, ideally, four to eight participants who act as co-researchers (Kitzinger, 1999). It is a common method of data generation in action research studies where active participation is sought (Kitzinger, 1999). It can be used as the primary method of data gathering, or in conjunction with other methods (Robson, 2002). Depending on the nature and focus of the study, focus groups can be heterogeneous (differing in background, position, or experience) or homogeneous (similar in background, position, or experience) (Robson, 2002). There are pros and cons to each approach; however, the general practice is to attain reasonable diversity (Finch & Lewis, 2003).

All study interviewees, up to the point of scheduling the focus groups, were invited to participate in a community closest to them. In several cases, this precluded participation due to a significant burden of travel by vehicle, ferry, or airplane for a two-hour meeting. Participants were advised by email that this was a semi-structured group interaction during which participants were co-researchers who would comment, reflect, and add to each others’ thoughts and perspectives that might arise in the meeting. They were advised that they would be conversing mainly with each other rather than to me as researcher. I indicated that my role was to facilitate and guide the meeting, and to address some or all of the questions which were asked in the earlier interviews. Thus, the content area was reasonably familiar to each participant. I also provided a brief overview of my early analysis of the data thus far so that emerging themes could be explored collectively.

I held three focus groups during one week in September, 2004, in Prince Rupert, Terrace, and Smithers. These were followed by one focus group held in Victoria in November, 2004. There were five to eight participants in each group (heterogeneous) and the meetings lasted about two hours. The goal was to include at least one participant from each of the four stakeholder groups (public, managerial, clinical, and policy) and generally cover the geographical context. In
practical terms this meant holding three focus groups, one in each of the three North West administrative clusters—west (Prince Rupert), central (Terrace), and east (Smithers). The fourth focus group included participants in the Lower Mainland and Vancouver Island areas who were involved with child and youth health services in the North West, including participants from BCMOHS and Health Canada FNIHB. Prince George, as home to the NHA corporate office and several study participants, was considered as a fifth site; however, stakeholder heterogeneity was not possible. Several logistical challenges were encountered such as scheduling the focus groups to optimize travel time, distance, weather conditions, and expenses for all participants, including myself, and the need to achieve reasonable stakeholder heterogeneity in each focus group. Table 2 shows the composition of stakeholders participating in each of the four focus groups, where the focus groups were held, and their respective dates.
Table 2. Focus Groups—Stakeholders, Locations, and Dates.

<table>
<thead>
<tr>
<th>STAKEHOLDERS</th>
<th>LOCATION</th>
<th>DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Parent</td>
<td>Prince Rupert</td>
<td>September 22, 2004</td>
</tr>
<tr>
<td>2 Managers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Clinicians</td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>STAKEHOLDERS</th>
<th>LOCATION</th>
<th>DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Parent</td>
<td>Terrace</td>
<td>September 23, 2004</td>
</tr>
<tr>
<td>2 Managers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Clinicians</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 Policy-maker</td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>STAKEHOLDERS</th>
<th>LOCATION</th>
<th>DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Parent</td>
<td>Smithers</td>
<td>September 24, 2004</td>
</tr>
<tr>
<td>3 Clinicians</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 Policy-maker</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>STAKEHOLDERS</th>
<th>LOCATION</th>
<th>DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Clinician</td>
<td>Victoria</td>
<td>November 26, 2004</td>
</tr>
<tr>
<td>2 Managers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Policy-makers</td>
<td></td>
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</tbody>
</table>

Search Conference

A search conference is a collective learning process that permits considerable variability in length, facilitation, participation, configuration, and rules. Emery & Purser (1996, p. 4) describe it as “a participative event that enables a large group to collectively create a plan that its members themselves will implement....It is an excellent means of planning large-scale systems change in real time, and it generates excitement, energy, and purposeful behavior”. Most importantly, they state that “people learn how to move forward together as a unified community, and...to accept joint responsibility for their common purpose”. A proprietary variation, “future search” (Weisbord & Janoff, 2000), builds on the notion of finding common ground in organizations and communities, which leads to taking personal responsibility, making expedient
action plans, and forming durable relationships across key boundaries. Greenwood & Levin (1998) describe a framework which integrates five key processes: (a) sharing stakeholders’ histories, (b) developing a shared vision, (c) engaging participants in the creation of action plans, (d) collectively prioritizing alternative action plans, and (e) creating volunteer action teams who commit to addressing the issues.

The Greenwood & Levin (1998) framework was used as a guide in this study. Additionally, a consultant in public sector strategic planning and governance, with whom I worked in another capacity, offered practical advice around structuring the search conference based on his extensive experience. Through a combination of plenary and small group dialogues, the goals of this planning conference were to:

- refine and expand upon the findings emerging from the previously conducted semi-structured interviews and focus groups
- co-create a shared history and the current reality of child and youth health services in the North West
- co-create an ideal future for child and youth health services in the North West and prioritize realistically attainable goals
- co-create action ideas and strategies to realistically attain prioritized goals
- co-create action teams to follow-up on, and be responsible for, prioritized ideas, strategies, and goals.

All of the participants in the study up to the timeframe of the search conference in April, 2005 were invited to participate. At this point, of the 43 participants, two managers had taken positions elsewhere and moved away, and one policy-maker had retired. Seventeen people participated in the two-day search conference. Table 3 shows the composition.
Table 3. Search Conference—Stakeholders, Location, and Date.

<table>
<thead>
<tr>
<th>STAKEHOLDERS</th>
<th>LOCATION</th>
<th>DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Parent</td>
<td>Terrace</td>
<td>April 19 &amp; 20, 2005</td>
</tr>
<tr>
<td>1 Youth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Managers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Clinicians</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Policy-makers</td>
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</tbody>
</table>

During the opening plenary session, I acknowledged, on behalf of the participants, the traditional territory (Tsimshian) on which the search conference took place. I also arranged for an Aboriginal Elder from the local Kitselas Band in Terrace to participate, through a prayer, in both the opening and closing plenary sessions.

In day one, participants explored shared history (to learn and build upon each other’s interpretation of history and co-generate history), followed by sessions on the ideal and probable futures (creating a shared vision and goals). This process also helped to define the key objectives emanating from broad goals. In day two, participants examined action strategies that support the goals and objectives. They also grouped and prioritized the action issues (including objectives). The final stage created action teams to address the agreed-upon actions.

Although not typical in a search conference, I actively participated on two occasions. First, during the introductory stage, I presented an overview of the research project and the findings to date. The purpose of this was to help set the context, reinforce my expectations, and remind participants of the overall purpose of the study and the methodology being used. I showed some of my photographs taken during my travels by car, ferry, and air throughout the North West. Since considerable time had passed since the earlier interviews, I also shared with
the participants (as co-researchers) some of the early themes and findings based on the information that they had individually provided during the earlier interviews. I put forward the preliminary core category (boundaries and boundary objects) based on my constructivist grounded theory analysis to date. Specifically, the participants were asked to keep the core concepts in mind during the search conference.

The second occasion for my active participation was during Stage 1 of the search conference, “Recalling the Past and Appreciating the Present”. I presented, as examples, selected child and youth health services utilization and related data: “Mapping utilization using Geographic Information Systems—The BC Ministry of Health Services PURRFECT database, and CHSPR BC Health Atlas 2nd Ed. (2003).” The purpose was to share child and youth health data that had direct relevance to residents of the North West. This was accomplished by using selected data for children and youth mapped at the level of the Local Health Area (excluding the Nisga’a Health Authority because they declined to participate in the study) using the process as outlined in the following section on the quantitative component. See Appendix F for the search conference detailed agenda.

Quantitative Component

BC Ministry of Health Services PURRFECT Database

The quantitative component (nested within the qualitative component) is for the purpose of demonstrating health services utilization for children and youth residing in the North West HSDA. It incorporates generalized secondary administrative data available from the BCMOHS Population Utilization Rates and Referrals For Easy Comparative Tables (PURRFECT)\textsuperscript{22}, Version 10.1 (BCMOHS, 2004). These data were mapped using GIS software ESRI Arcview.

\textsuperscript{22} Originally, I planned to use the UBC Centre for Health Services and Policy Research linked administrative database. However, because the intent of the mapping of child and youth health services utilization data was to demonstrate efficacy as a tool only, it became apparent that the process to link the required data, including the approval processes, was going to prove too lengthy and complex for the intended purposes and timing of the study.
Version 8.3, for the purpose of making complex data visually accessible to multiple (including lay) stakeholders during the search conference and to help explain what the quantitative data were demonstrating.

Obtaining access to the most current version of the PURRFECT database proved complex for reasons of time, timing, and study continuity. The initial ethics approval from BREB for the study was for the qualitative component only because at that point I was unable to provide detailed information on the quantitative component. This was because a unilateral pre-determination of the detailed quantitative data requirements and analyses was felt to compromise the participatory research approach. Rather than an amendment to the qualitative component, BREB suggested a separate ethics application process later in the study, and the C&W Research Review Committee required the quantitative component to be submitted as a new study. The NHA Research Review Committee was apprised through copies of the Certificates of Approval as they became available during the approval process, noting that background materials would be provided to them when and if required.

The ethics approval process demonstrates the additional challenge of using mixed methods in approval systems more accustomed to traditional research methods. This is particularly evident in terms of timing, timelines, study design and related amendments, and multiple academic and community jurisdictions, all of which are exemplified during the multiple ethics approval processes experienced this study. The transition from PURRFECT Version 9.0, my decision to await the latest version, the need for a separate UBC BREB ethics approval process for the quantitative component, and the subsequent approval processes by C&W Research Review Committee and the NHA Research Review Committee all contributed to the lengthy approval processes for this stage.

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23 Had the Nisga’a Valley Health Board ultimately agreed to participate, it would have meant yet another distinct community-based research ethics approval process and the possible additional impact this may have had on the other three approval processes.
I decided to not acquiesce to using computerized data analysis software as a tool for qualitative data analysis. While there are a number of software programs in use, such as NUD*IST, ATLAS/ti, NVivo, and WinMAX, there is continuing debate on the pros and cons of using computerized data analysis software (Coffey, Holbrook, & Atkinson, 1996; Robson, 2002; Spencer, Ritchie, & O’Connor, 2003; Weitzman, 2000). For example, in the context of grounded theory, Glaser (1998, p. 185) refers to these kinds of tools as “technological traps” to the extent that they could undermine or make superficial the conceptual skills required by the researcher, cut short the development of the researcher’s intuitive skill, or be considered an easy way to analyze data. However, he does concede that, over time, this technology will likely become more appropriate to grounded theory analysis. Others also comment specifically in the context of grounded theory method. Charmaz (2000), for example, acknowledges that such programs are very helpful in dealing with voluminous data; however, her reservations include the observation that they fit more with objectivist, as opposed to constructivist, grounded theory, and that they may inadvertently reduce interpretive work to mere automated procedures. Again with respect to grounded theory, Robson (2002) and Coffey, Holbrook, & Atkinson (1996) caution that computerized analysis could inadvertently encourage, even impose upon, the researcher to embrace a particular approach for analysis. The literature is clear that while there is a place for computer-assisted data analysis software tools, they cannot replace the researcher’s critical role in thinking and data analysis (Charmaz, 2000; Spencer, Ritchie, & O’Connor, 2003; Weitzman, 2000).

A further delimitation exists in my use of the PURRFECT database, the use of selected utilization data, and the use of selected ways to map the data. In other words, while the qualitative data provided suggestions as to where to focus (for example, teenage pregnancy rates and mental health in particular), I did not systematically review the qualitative data and list all of the possible quantitative data to be sought out. If the purpose of this study had been to
specifically identify and quantify health service needs, this would have been necessary; however, the focus of the study was to explore the process to determine needs from multiple stakeholder perspectives. Moreover, the quantitative component at the outset was intended to be a minor component with the express purpose to demonstrate the utility of mapping and visually representing selected utilization data suggested by, and relevant to, local contexts in the North West. This was adequately served with the maps presented during the search conference method.

This completes the first leg of this technical journey, which detailed the research methodology used in this study. The next leg discusses data analysis, again with the dominant focus on qualitative methods. This journey also takes us into the grounded theory method, with an emphasis on constructivist grounded theory, which I used in this study. It also discusses a number of technical steps in the gathering, transcription, and coding of data, and related processes. Finally, I review several qualitative authenticity criteria in order to verify that the approach and methods employed in this study are trustworthy and, in turn, to ensure confidence in the findings.

**Data Analysis**

**Qualitative Component**

Qualitative research is inductive, with insights and concepts arising from the data. This is in contrast with deductive research, in which preconceived hypotheses and theories are tested by the data (Creswell, 2003; Taylor & Bogdan, 1998). There are a number of characteristics of qualitative research that specifically relate to data analysis (Snape & Spencer, 2003): (a) data collection process is interactive and developmental; (b) data is detailed, information rich, and extensive; and, (c) data analysis is open to emergent concepts and ideas. Analysis of qualitative data, in its broadest sense, is a recursive exercise involving sense-making, interpretation, and theorizing (Schwandt, 2001).
Qualitative research does not subscribe to a single methodology, nor does it infer a particular method, practice, theory, or paradigm (Denzin & Lincoln, 2000). There is no single way to conduct qualitative research (Snape & Spencer, 2003), nor is there a single way to perform qualitative data analysis (Schwandt, 2001). The following two sections will first address a general grounded theory approach and then, specific to this study, introduce a constructivist grounded theory approach which was used as the basis for data gathering and analyses in this study.

**Grounded Theory Approach**

The term *approach* is significant in the context of grounded theory for a number of reasons. Grounded theory is but one option amongst many (Annells, 1996). However, “[t]he grounded theory approach is the most influential paradigm for qualitative research in the social sciences today” (Denzin, 1997, cited in Patton, 2002, p. 124). Glaser & Strauss (1967, pp. 8-9), in their original text on grounded theory, intended to “stimulate other theorists to codify and publish their own [emphasis in original] methods for generating theory….keep[ing] the discussion open-minded, to stimulate rather than freeze thinking about the topic.” Unfortunately, this stimulation has lead to dissension and divisiveness in the field, with two methodological schools arising, Straussian and Glaserian, bearing the names of their founders. This debate, often acerbic and confrontational, has been reviewed extensively in the literature over a number of years and will not be repeated here. See, for example, Babchuck (1996), Bryant (2002), Charmaz (2000), Dey (1999), Glaser (1992), Locke (1996), Melia (1996), Robson (2002), and Urquhart (2001). This debate underscores that “[t]here is no orthodoxy in grounded theory…nor [is it] necessary or desirable that such an orthodoxy should develop” (Turner, 1983, p. 347). This builds on Glaser’s own intent, for example, in his text on theoretical sensitivity (Glaser, 1978), written as a supplement to the text he originally co-authored:
This book is not doctrine... Yes, the book presents an orthodox or basic outline of a grounded theory research project. But in doing so the author hopes to stimulate thought about the methodological issues involved and the variations in the variables used to describe the generating of grounded theory as a research process... trusting that readers can see other possibilities for ordering a grounded theory research. (p. ix)

Again, when addressing the future of grounded theory, Glaser (1999, p. 837) states that “[g]rounded theory is used in part or in whole by researchers. When used in part, it is ‘adopt and adapt,’ with other research methods woven in, based on the training and judgment of the researcher involved.” Moreover, Strauss & Corbin (1998, p. 12) observe “creativity of researchers also is an essential ingredient.” And, that “[grounded theory] procedures were designed not to be followed dogmatically but rather to be used creatively and flexibly by researchers as they deem appropriate.” Earlier, they observed the evolution of guidelines and procedures through user experience, resulting in enhanced effectiveness and increased ingenuity (Strauss & Corbin, 1994). More recently, Charmaz (2003, p. 108) concludes, “grounded theory methods assumes an open, flexible approach. Hence you shape your methodological strategies while engaged in your research rather than having them planned before beginning the data collection.” And, further, that grounded theory methods can be used “as flexible, heuristic strategies rather than as formulaic procedures” (Charmaz, 2000, p. 510). This counsel is supported by the opinions of others, for example, Bryant (2002) about the “re-grounding” of grounded theory, and Dey (1999) about the “evolution” of grounded theory. However, as Bartlett & Payne (1997, p. 182) suggest, “[t]he legitimacy of adopting only parts of the grounded theory method...must ultimately rest upon the justifications put forward by individual researchers.”
Evolving since 1967, the basic tenets of grounded theory have remained fairly consistent, yet subject to a number of scholarly viewpoints in the literature (Annells, 1996; Bartlett & Payne, 1997; Bryant, 2002, 2003; Charmaz, 1995, 2000, 2001a, 2001b, 2003, 2004; Creswell, 1998; Dey, 1999; Dick, 2002; Glaser, 1978, 1992, 1998, 1999, 2002a, 2002b; Glaser & Strauss, 1967; Locke, 1996; Melia, 1996; Robson, 2002; Strauss & Corbin, 1990, 1994, 1998; Urquhart, 2001). Building on the foundation laid out by Glaser & Strauss (1967), Charmaz defines grounded theory as “an inductive methodology that provides systematic guidelines for gathering, synthesizing, analyzing, and conceptualizing qualitative data for the purpose of theory construction.” (Charmaz, 2001, p. 6396). While there is considerable flexibility, the central features of grounded theory are captured by Charmaz (1995) as: (a) simultaneous phases of data collection, coding, and analysis; (b) coding from the data, not from preconceived hypotheses; (c) memo-writing, occurring between coding and writing the first draft; (d) theoretical sampling to refine emerging conceptual categories; and, (e) intentionally delaying the literature review to increase novelty.

However, grounded theory arose from the perspective of positivism (Charmaz, 2000). Positivism is a term coined by August Comte (1798 – 1857). It is a philosophical orientation, or worldview, that: (a) addresses a single reality; (b) uses deductive logic; (c) treats the knower and known as independent; (d) believes in empiricism; (e) treats inquiry as value-free; and, (f) customarily uses quantitative methods (Lincoln & Guba, 2000; Schwandt, 2001; Tashakkori & Teddlie, 1998).

In contrast, constructivism denotes multiple realities or interpretations. Meanings are constructed when human beings engage with reality, based on historical and social perspectives; the knower and known are inseparable, and inquiry is value-laden (Creswell, 2003; Robson, 2002; Schwandt, 2001; Tashakkori & Teddlie, 1998; Veenstra, 1999). Constructivism and
grounded theory are now enjoined as constructivist grounded theory, which is discussed in the
next section.

**Constructivist Grounded Theory Method**

Constructivist grounded theory is advanced by Charmaz (2000) to argue in favour of the
need to study people in their natural settings and to redirect qualitative research. In so doing, she
downplays rigid or prescriptive grounded theory strategies, argues for a focus on meaning
through interpretive understanding, and supports using grounded theory without a proclivity to
its earlier positivist roots. This shift in focus is supported and detailed by Clarke (2005). Glaser
(2002a) has acknowledged a growing and scholarly constructivist orientation to grounded theory.
However, in a rejoinder, he characterizes this variation as being misplaced, downplays its
significance, and challenges its relevance. On the other hand, this retort runs counter to his
of constructivist grounded theory with a charge of proprietorship, observing that grounded theory
now enjoys additional views beyond that espoused by Glaser. Despite these and related debates
on the evolution of grounded theory, I chose to use a constructivist grounded theory method for
the qualitative data gathering and analyses processes in my study. My reasons for doing so
include the fit of constructivist grounded theory with my personal philosophical views outlined
in Chapter One. I turn now to some technical processes in terms of data transcribing, coding,
comparing, and analyses.

**Transcribing the Data**

All 43 semi-structured interviews, four focus groups, and the search conference
comprising 17 participants were audio-taped. Through my thesis expense funds, I purchased
transcription services. I reviewed confidentiality expectations with my transcriber based on
BREB criteria. These initial services proved disadvantageous following spot-checks in which I
compared several early interview tapes with the hard-copy transcription in hand. Subsequently, we amicably agreed to terminate these services. I was assured that all electronic versions of the transcription would be deleted, and I filed all of the hard copies of the transcripts in question, awaiting re-transcription. I then recruited another transcriber who was recommended by a colleague, and came highly qualified. Again, I reviewed confidentiality expectations with her and, additionally, shared a copy of literature on “Improving accuracy of transcripts in qualitative research” (MacLean, Meyer, & Estable, 2004). All earlier tapes were reviewed and re-transcribed as necessary. Again, I spot-checked a number of initial tapes with transcription in hand and was entirely satisfied with the quality of transcription. Tapes were provided to the transcriber in batches following fieldtrips to conduct data gathering.

Upon completion of transcription, approximately 1300 pages of qualitative data had been created, the majority representing the semi-structured interviews. One of the challenges with this process was dealing with significant time lags between data gathering, receipt of the transcribed data, and my ability to schedule time for data analysis in an ongoing fashion. Consequently, there was often a span of several months between the time of data gathering and analysis of the transcribed data.

Care was taken during transcription to not include any reference to names and locations that could ultimately lead to the identification of study participants. Additionally, I meticulously reviewed all transcripts and blacked-out any reference to potentially identifiable names and locations. These pages were then photocopied and given to the transcriptionist who revisited these portions of transcription and deleted any possible identifiers on a back-up compact disc (CD). During this stage of transcript review, I also flagged any transcription that indicated spots of unintelligible audiotape recordings. These were re-assessed if this portion of the transcript
contained any data relevant to open coding. In keeping with a constructivist grounded theory approach, the data gathering, transcription, coding, and analysis largely proceeded concurrently.

Coding Process

Open coding.

In contrast to a pre-conceived system of coding, typical of quantitative studies and some qualitative studies, coding in constructivist grounded theory entails “defining what the data are all about….creating [emphasis in original] the codes as you study your data. The codes emerge as you study your data” (Charmaz, 1995, p. 37). The initial process involves a number of features as described by Charmaz (1995, 2000, 2001a, 2001b, 2003, 2004), which I draw on extensively. While this process is presented in a linear fashion for ease of understanding, it is very much an iterative and comparative process. I began the cycle of analysis with open coding, also known as line-by-line coding. I carefully examined each line of data and the actions or events occurring or represented were defined in short, active, and specific terms. The coding was done using active terms, that is, gerunds (verbs ending in ing) to give insight into what is happening. The purpose is to scrutinize and continuously interact with the data in order to define meanings. This type of coding keeps the researcher attuned to the realities of the subjects, and does not simply assume that these realities are shared by the researcher. Through this process, the most frequently occurring codes were identified, generating several initial categories at this stage of analysis.

During the initial open coding process, I started out by coding Question One across the first set of interviews, rather than coding each interview in sequence. However, I felt that I lost continuity and flow by subject and I didn’t really get immersed in the data. Plus, several of the meaningful codes re-appeared during different questions in the same interview for which I would lose continuity by coding-by-question across the interviews. Therefore, I shifted to coding-by-interview, but not necessarily following the order in which the interviews were conducted. After
completing line-by-line coding of 10 interviews (out of 26 completed interviews and 20 transcribed up to this point), and in view of the now repetitive nature of much of the coding, I felt it was an appropriate time to embark on theoretical coding. Of these, two were from the public stakeholder group, three from the managerial group, three from the clinical group, and two from the policy group; thus achieving a reasonable balance of data.

**Axial coding.**

Charmaz (1995, 2000, 2001a, 2001b, 2003) suggests a two-stage coding process—open-coding followed by focused coding—and chooses to not use axial coding (Charmaz, 2004). This practice is also followed by Dick (2002). Strauss and Corbin state that the purpose of axial coding is “to begin the process of reassembling data that were fractured during open coding” (1998, p. 124), and “to systematically develop and relate categories [concepts]” (1998, p. 142). However, Glaser (1992, p. 61), in his forceful rebuttal to the first edition of *Basics of Qualitative Research* (Strauss & Corbin, 1990), decries Strauss’s lack of scholarship in his entire book, using as a poignant example the use of axial coding in grounded theory analysis to the alleged exclusion of theoretical coding. Dey (1999, p. 112) suggests that “the distinction between open, axiel [sic], and selective coding is a hallmark of grounded theory.” On the other hand, the basic premises and intent of axial coding and theoretical coding appear similar (that is, to connect substantive codes derived through open coding). This may be a reason for the variability in coding methods, or the apparent omission of this coding stage, by various grounded theorists. For the purposes of this study, I elected to not use axial coding preferring, instead, to follow Charmaz’s lead in proceeding from open (substantive) coding to selective (focused) coding. However, I did this using the concept of theoretical coding in order to connect the key concepts (categories) emerging during the open coding stage.
**Theoretical coding.**

"[T]heoretical codes conceptualize how the substantive codes may relate to each other as hypotheses to be integrated toward a theory. They, like substantive codes, are emergent; they weave the fractured story back together again" (Glaser, 1978, p. 72). Theoretical coding is about creating "conceptual connectors" (Glaser, 1992, p. 38) which "emerge in coding as ways of relating the substantive codes together when integrating the theory" (Glaser, 1998, p. 137). However, while Glaser (1978, 1992, 1998) consistently denounces the tendency to force data into preconceived categories, he somewhat antithetically suggests using "coding families" to assist in developing theory (Glaser, 1978, p. 73; 1992, p. 46; 1998, p. 137). Nonetheless, connecting the substantive codes toward integrating a theory is fundamental to the constant comparative method. It makes little sense to proceed in the absence of such linkages. This step, like the others, required a lot of time to find, reflect upon, and compare the substantive codes, which, in the case of this study, I performed across hundreds of pages of transcription. Colour-coding, and cutting and pasting assisted me in this process. Next in the coding process is selective (focused) coding which establishes the emergent core category.

**Selective coding and constant comparative method.**

Charmaz (1995, 2000, 2001a, 2003, 2004) describes selective (also known as focused) coding as the use of initial codes that appear frequently to sort and synthesize large amounts of data. These codes are more conceptual and directed than those derived through the open coding process. The selective coding process leads to the emergence of a core category that becomes the main theme, or story-line, of the research. This results from consciously looking "for the 'main theme'...the main concern or problem for the people in the setting, for what sums up in a pattern of behavior the substance of what is going on in the data, for what is the essence of relevance reflected in the data" (Glaser, 1978, p. 94).
At this stage, I delimited open coding to coding only those variables that related to the core category (Glaser, 1978; 1992). “The core variable [category] becomes a guide to further data collection and theoretical sampling....analysis is guided by the core variable [category]” (Glaser, 1978, p. 61). The core category emerges through the process of constant comparisons and data analysis (Glaser, 1992). The constant comparative method is a process that compares data, incidents, contexts, and concepts (Charmaz, 2003, p. 101). Through constant comparisons, I delimited the data and ensured saturation of the emergent categories, thus allowing me to focus on the data that were directly relevant to those categories (Glaser & Strauss, 1967). The criteria that I used to determine the core category are summarized by Strauss & Corbin (1998): (a) is central—relating to many categories; (b) appears frequently—indicating a central concept; (c) logically and consistently relates to the categories—the data are not forced; (d) is abstract—can be used generally; (e) can be further refined—contributes to a theory’s depth and explanation; and, (f) explains the entire set of data.

In this study, I identified not just one, but two core categories that emerged from the data. This is acknowledged to occur infrequently. Then, the other categories were related to them (Glaser, 1978; Strauss & Corbin, 1998).

**Theoretical Sampling and Theoretical Saturation**

The concepts of theoretical saturation and theoretical sampling are closely related—“theoretical sampling yields collection of data to the saturation of categories and their properties” (Glaser, 1998, p. 157). Theoretical sampling is “the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his [sic] data and decides what data to collect next and where to find them, in order to develop his [sic] theory as it emerges.” (Glaser, 1978, p. 36; Glaser, 1992, p. 101; Glaser & Strauss, 1967, p. 45). Further, “[this process] keeps data collection to a minimum, instead of allowing it to pile up too much data. It responds
to the need for more data that are relevant for the emergence of new categories and properties” (Glaser, 1998, p. 157).

Theoretical saturation is “when...no new properties emerge and the same properties continually emerge as one goes through the full extent of the data” (Glaser, 1978, p. 53). Dey (1999, p. 8) clarifies that this “refers to concepts, not data, and identifies a point where no further conceptualization of the data is required.” Strauss & Corbin (1998) describe theoretical saturation as the point when no new data is emerging, the categories are well developed, and the relationships between the categories are solidly established.

In this study, I found that these concepts are, in fact, very closely related. I was not able to strictly follow the notion of theoretical saturation due in large part to how I designed the study and several challenging geographic, organizational logistics, and travel-related factors. I conducted sampling in the context of a knowledge translation approach in which I sampled from four stakeholder groups and wanted to ensure inclusion of all the LHAs in the North West (with the exception of the Nisga’a Health Authority as discussed earlier). Nominally, this meant one participant from each of the four stakeholder groups (public, managerial, clinical, and policy-maker) for each LHA, plus sampling from the NHA corporate office, BCMOHS, BCMCFD, a children’s tertiary centre in Vancouver, and others. The distance and availabilities of most of these participants were major factors in lead time and travel logistics for the interviews, focus groups, and the search conference. Getting the tapes transcribed early and quickly and then coded and compared in a timely fashion proved onerous. These factors worked against the concept of a small set of interviews followed by early data analysis in order to determine the need for further targeted sampling to build upon the early findings. For this reason, I rarely sought out participants solely on the basis of needing to saturate the sampling or the concepts arising from the data. My experience shows that where this makes sense in theory, it is extremely
difficult in practice. I used a CBPR approach conducted in the field hundreds of kilometers away and in an exceptionally large and rugged rural and remote environment with very busy people. However, the relatively large and heterogeneous sample size in this study satisfied the saturation requirement well before the study was completed. Moreover, I used a unique triangulation of qualitative methods – semi-structured interviews, focus groups, and a search conference. As well as building up trust between myself as researcher, and the participants, trust was engendered among the participants themselves particularly during the progressive data-gathering group sessions—small focus groups followed by the large two-day search conference. As the individual semi-structured interviews progressed during the parallel course of data analysis, I was able to refine the prompts and probes during the course of the interviews and gain targeted data. This process did not, as Glaser (1998) suggests, minimize data collection because of my commitment to continue the process in a way that honored the CBPR approach and expectations garnered during the course of the study. This process, in fact, did achieve the same ends of theoretical sampling and saturation; however, it undoubtedly resulted in far more data gathering than would have been necessary had I taken a more prescriptive grounded theory approach.

**Memo Writing**

During the course of this study, I hand-wrote over 100 theoretical and operational memos in various places during my extensive travels in the North West. These served to chronicle my evolving thought process and provided an ease of reference during the write-up stage. I sketched many diagrams as a means to make sense of the data and in an attempt to draw what words could not explain very well during the formative stages of the core categories and the emerging theory. Writing theoretical memos is variously described as “[t]he *core stage* [emphasis in original] in the process of generating theory, the bedrock of theory generation” Glaser (1978, p. 83); “the crucial intermediate step that moves the analysis forward (Charmaz, 2001a, p. 687); and, “the
pivotal intermediate stage between coding data and drafting the theoretical analysis” (Charmaz, 2001b, p. 6398). The purpose of memo writing is to: “provide the content behind the categories” (Glaser & Strauss, 1967, p. 113); “kee[p] the research grounded” (Strauss & Corbin, 1998, p. 218); and, “hel[p] the researcher to spark fresh ideas, create concepts, and find novel relationships” (Charmaz, 2001a, p. 687). An additional distinction is made by Charmaz (2001b)—that constructivist grounded theorists incorporate their own assumptions and meanings, besides those of the research subjects. I have used a constructivist grounded theory method; thus, I have been reflective and incorporated my own perspective into the memo writing stage.

**Trustworthiness**

Some scholars use the term, trustworthiness, in qualitative research. This refers to the trust or confidence one has in a study and its findings (Robson, 2002). Trustworthiness, introduced by Lincoln & Guba (1985), includes four criteria: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability. Credibility (roughly equivalent to internal validity) concerns assurances that the subjects’ views fit with that of the researcher’s reconstruction and representation. This is often achieved through triangulation – “checking the integrity of the inferences one draws” (Schwandt, 2001, p. 257). It strengthens a study by combining methods (Patton, 2002), which can include employing a number of qualitative methods, or combining (mixing) qualitative and quantitative methods. Robson (2002, p. 553) expands this to include the use of “more than one perspective, theory, participant, method, or analysis.” Transferability (roughly equivalent to external validity) deals with the extent to which findings are generalizable and allow for case-to-case transfer. Dependability (roughly equivalent to reliability) ensures that the process is logical, traceable, and documented. Confirmability (roughly equivalent to
objectivity) establishes that the data and findings are readily discernible and not merely contrived by the researcher.

As Schwandt (2001, p. 259) discerns, Guba & Lincoln (1989) re-evaluated their initial set of criteria in *Fourth Generation Evaluation*. He explains that the trustworthiness criteria “were parallel, quasi-foundational, and clearly intended to be analogs to conventional criteria....[and] were principally methodological criteria and thereby largely ignored aspects of the inquiry concerned with the quality of the outcome, product, and negotiation.” Thus, Guba & Lincoln (1989) proposed another set of criteria, called *authenticity criteria*, which was better aligned with a constructivist epistemology. These are described in detail in the next section, which includes examples of how I met these criteria in this study.

**Qualitative Authenticity Criteria**

The term “authenticity criteria” reflects the “hallmarks of authentic, trustworthy, rigorous, or ‘valid’ constructivist or phenomenological inquiry” (Lincoln & Guba, 2000, p. 180). Given the approach I used, these criteria realistically reflect the characteristics of this study. These criteria include: (a) fairness, (b) ontological authenticity, (c) educative authenticity, (d) catalytic authenticity, and (e) tactical authenticity. Fairness refers to the extent to which the subjects’ concerns, issues, and values are solicited and represented in a balanced, even-handed way by the researcher. Ontological authenticity is concerned with the extent to which the subjects’ own constructions are enhanced, informed and made more sophisticated through participation in the study. Educative authenticity is about the extent to which subjects develop a greater understanding and appreciation of the constructions of others. Catalytic authenticity refers to the extent to which action is stimulated and facilitated by the research process. Tactical authenticity is concerned with the extent to which subjects are empowered to act.
**Fairness**

Fairness was sought in a number of ways. First, while purposive sampling is not representational sampling, it is important to achieve a sense of balanced input from throughout the North West HSDA, respecting the local concerns, issues, and values brought to the study. This points to the importance of including a sizeable proportion of Aboriginal representation to more closely reflect their perspectives, noting again that Aboriginal peoples are not an homogeneous entity, with some 25 bands located throughout the entire North West region.

Second, it was important to achieve a sense of balanced input from the four main stakeholder groups—public, managerial, clinical, and policy—since no one perspective could provide a balanced view. The sample size for a grounded theory study can be quite small, say, a dozen or so subjects. However, early on I aimed for approximately 40 participants to balance the perspectives from subjects living in the North West, and to include views from the NHA corporate offices, the main tertiary service provider, the provincial government through the BCMOHS, BCMCFD, and the BC Provincial Government Social Policy Integration Team, and the federal government through the FNIHB. This furthered the study’s purpose to explore issues from both a community-based and a systems approach, acknowledging and respecting the very different perspectives that these two different lenses bring.

Third, the sequence of three qualitative data gathering methods generated data from individual, small group, and large group settings. This created a growing sense of ownership of the process and findings through continued active participation and a sharing of the data as the group moved through these settings. That I invited the participants to be “co-researchers” to the focus groups and search conference added a dimension of soliciting and representing participants’ viewpoints on a more equal footing throughout the entire research process.
Finally, I analyzed data using a constructivist grounded theory approach, which "sensitizes [the researcher] to multiple realities and the multiple viewpoints within them; it does not represent a quest to capture a single reality" (Charmaz, 2000, p. 523).

**Ontological Authenticity**

Ontological authenticity was more difficult to achieve; however, the sequence of qualitative methods used in the study served to broaden participants’ perspectives and understanding of the issues. I shared my preliminary findings from the semi-structured interviews with each focus group, and these formed a basis for the questions addressed during the session, building on the individual interview responses as a small group. Again, I shared my preliminary findings at the search conference, further building and expanding upon the interview and focus group data. Thus, there was a certain shared familiarity of the issues amongst the study participants and by the time of the search conference a sense of group cohesiveness incrementally created through earlier interaction had become evident. This on-going participation facilitated the construction and growing sophistication of a co-created, shared reality amongst the group, and between the study participants and myself as researcher.

When the volunteer action teams met late on the second day of the search conference, there was palpable and sustained energy in the room in terms of taking responsibility for follow-up on the ideas, strategies, goals, and priorities collectively set by the group participants. In keeping with the principles of a search conference, there was no hesitation for a public commitment to sustainable action, which transpired at three levels as determined by the group – systems, North West HSDA, and local community.

**Educative Authenticity**

Educative authenticity, like ontological authenticity, was achieved by incrementally progressing through the focus groups and search conference, providing a real-time opportunity to
build upon and share individual perspectives. While arranging the focus groups, I specifically raised awareness that participants, as co-researchers, should comment, reflect, and add to each others’ thoughts and perspectives that would arise during the meeting, cautioning that they would be conversing mainly with each other, not with me as the researcher. Moreover, in my introduction at the focus group sessions I typically reviewed a number of ground rules that served to reinforce these expectations. These included: (a) the need for confidentiality and protection of privacy outside the focus group session; (b) that the session was intended to be conversational and interactive among the participants, not with me as researcher, and that my role was to guide the content and facilitate the process; (c) that there were no right or wrong answers; (d) that it was not about what they thought I wanted to hear or the group wants to hear, but that different views are important and that they could ask each other questions; (e) that this was an opportunity to express their thoughts, feelings, perceptions, and experiences at a deeper, personal level; (f) that they should reflect and comment on each others’ comments; (g) that they were co-researchers, as part of a participatory action research approach; and, (h) that they should respect each other by trying not to interrupt or talk over each other.

During the search conference, participants engaged with each other through a mix of small heterogeneous groups (which were reconfigured for each small group session) and plenary sessions. This helped to increase their understanding and appreciation of each other.

**Catalytic Authenticity**

Catalytic authenticity is best exemplified by the early action emanating during and resulting from the search conference. The goals of the search conference included the co-creation of action ideas and strategies and the co-creation of action teams to follow-up on, and be responsible for, prioritized ideas, strategies, and goals which were identified during the search conference. A number of priorities were identified with group consensus that the overarching
priority was engendering collaboration, integration, and co-ordination in community service planning. Through small and plenary groups the action ideas and strategies were reworked. Action teams were created to take responsibility for moving forward the prioritized strategies and goals. The plenary group ultimately decided to take action at three distinct levels: the overall system, the North West HSDA, and the local community. Action points were shared and committed to publicly by each group in the plenary report-back session. Included, for example, was a commitment to organize a regional symposium of key stakeholders in the North West to address community collaboration and how to go about integrated service delivery. This group, comprising a broad range of study participants from a number of rural and remote communities has been meeting formally and regularly via teleconference since the search conference. They held a very successful symposium in Terrace in November, 2005 with over 70 participants spanning a broad spectrum of disciplines and sectors. They have also sought my ongoing participation, but they take responsibility for the process. This was a direct action stimulated and facilitated by, and emanating from, the search conference with a stated purpose to move from talk to action.

Fairness and authenticity were further demonstrated during the findings sessions that I held in Prince Rupert, Smithers, Terrace, Prince George, and Victoria in March and April, 2006. In total, 17 study participants were able to attend these sessions. I shared my findings to date and sought feedback. These sessions were audiotaped, transcribed, and reviewed. This time with the study participants provided an excellent opportunity to reconnect, collectively share thoughts, and shape the findings in small group settings that ranged from one to eight participants. I was encouraged and gratified to hear first-hand how the participants felt about and reacted to the findings. Some of their reflections are captured below:

[H]ave you got the issues? You bet you do! I mean, have you got a grasp of understanding, what’s going on in this region they call the
North, yeah, I think you do. Right on! I think you see that this region is huge. I think that you see the disparities in the region. I think you see the thrust of what’s wanting to be government sort of pushed, as opposed to community needing to hold onto. You’ve got it. You’ve got the heart of the region there.

(Policy-maker, Findings Session)

Overall, I think it’s good. And, what I do like is the idea of the… Venn diagrams and the capturing there. That is the essence of it. (Clinician, Findings Session)

Actually never thought about it in these terms and that’s why I said to you a long time ago that what you’re doing is very special. Because, as far as I can see, what you’ve captured here is a kind of progressive model… I think the whole idea is being presented by what you’re doing… to the world of this health area it is new.

(Manager, Findings Session)

So, for me in my community, I can see a lot of benefit in having been part of your research, to have this information to take back there. And, once in my community, wearing the different hats that I wear… This is an excellent model for us to be working in.

(Parent, Findings Session)

While there was no disagreement with the findings in general, several significant points were raised which served to clarify my articulation of the findings, the Venn diagrams, and the conceptual framework. I incorporated these into several sections during the write-up stage.

**Tactical Authenticity**

Tactical authenticity is partially exemplified in the foregoing account of catalytic authenticity. Additionally, empowering study participants was made possible by, and enabled through the events leading up to, the search conference. The search conference was an “aren[a] for dialogue”, one during which it was possible to “tap participants’ energy for identifying and solving their own problems… The outcome of a successful search conference is a set of action
issues and plans that participants want [emphasis added] to pursue collectively” (Greenwood & Levin, 1998, p. 156).

During the concluding plenary session of the search conference, many action ideas were raised and shared. Among these was a commitment to plan a symposium of key stakeholders in the North to address community collaboration and how to undertake integrated service delivery. Shortly after, a planning group emerged and met via teleconference on a regular basis to plan and hold a forum on integrated services for children, youth, and families, which took place in Terrace, BC on November 3, 2005. This proved to be highly successful. Consequently, a number of on-going actions continue to develop as a direct result of this forum, including: (a) development of a listserv as a tool for on-going communication with participants, (b) creation of a website, (c) planning for an asset mapping/social network analysis initiative as a tool to identify and assess assets and the strength of these relationships in the North West as a component of definitive planning for integrated services, (d) participation in professional health human resources planning through participation in co-operative student programs such as those at the University of Northern BC, (e) a commitment to broaden participation in this initiative, and, (f) planning for a second forum to be held in the Fall, 2006 to expand upon and continue these and other initiatives.

In terms of other areas, a number of initiatives are underway in which the foregoing has a very real potential for impact. These include, for example, (a) strong linkages with Child Health BC, a province-wide, inter-organizational child and youth health services delivery network; (b) a number of research networks developed with funding by the Michael Smith Health Research Foundation, such as Child and Youth, Rural and Remote, and Aboriginal; and, (c) the CYHNC, as discussed earlier.
**Grounded Theory Criteria**

In terms of grounded theory criteria, Glaser (1998) proposes trust, and describes four criteria: (a) fit, (b) relevance, (c) work, and (d) modifiability. Fit, which Glaser compares to validity, refers to whether the concept represents the purported pattern in the data. Relevance speaks to how well the study reflects and impacts the issues that are important to the subjects. Work refers to how well the concepts and theoretical coding relate to the main concerns of the subjects. Modifiability uses the constant comparative method to ensure that data are not forced and that emergent theory is modifiable.

**Quantitative Validity and Reliability Criteria**

In this study, the quantitative component is less critical because it played such a relatively minor role. It was simply a tool to demonstrate the utility of visualizing utilization data through the use of maps. Nonetheless, two issues—validity and reliability—concerning quantitative methods must be acknowledged. Validity concerns the extent to which findings are accurate and legitimized (Schwandt, 2001). There are two aspects of validity, internal and external. Internal validity is concerned with the ability to correctly draw inferences from the data; whereas, external validity is concerned with the ability to draw inferences which are generalizeable to other situations (Creswell, 2003). Reliability, or the ability to replicate the results by another researcher (Schwandt, 2001), is another characteristic of quantitative methods.

In terms of both validity and reliability, this study relies extensively on the integrity of the Ministry of Health Services’ PURRFECT database and the utility of the ESRI ArcView v. 8.3 GIS software. To the extent that these two sources are valid and reliable, the process I used to map specific utilization data and demonstrate the utility of using maps to make complex data visual is valid and reliable. The risk to this study of inaccuracy and unreliability is small given the minor role that this tool played in the study. This limited use of quantitative data in a mixed
methods inquiry represents a significant delimitation in the quantitative component of the study by narrowing its scope (Creswell, 1998). On the other hand, it served a useful purpose in the context of the search conference. This may point to a limitation of the study in terms of a potential weakness (Creswell, 1998) accentuated through my selective use of quantitative data.

**Auditability**

Finally, I would like to raise the issue of auditability as yet another criterion of trustworthiness and authenticity. Lincoln & Guba (1985, pp. 318-319) promote the audit trail as an important way to ensure confirmability of research findings. White, Woodfield, & Ritchie (2003, p. 320) describe the audit trail as “the extent to which others can follow the research process that took place and any concerns or observed limitations about its conduct.” This includes: (a) ability to follow the research design; (b) how fieldwork is conducted; (c) sample design, selection, composition, and limitations; (d) methods used in data analysis; and, (e) the researcher’s epistemological approach (White, Woodfield, & Ritchie, 2003). Throughout the course of this study, I have maintained meticulous written records for each stage of the research process, which provides an opportunity for anyone to closely follow, and duplicate if necessary, each step of the study.

**Quantitative Component**

**Using the PURRFECT Database and GIS to Map Child and Youth Health Service Utilization in the North West HSDA**

I used GIS software, ESRI Arcview Version 8.3 to create approximately 12 maps in preparation for the search conference, at which I presented and discussed them. These maps specifically highlight two major issues (among others) facing the North West HSDA and repeatedly raised during the qualitative phase of the study. These issues were teenage pregnancy
rates and child and youth mental health, both of which remain unaddressed in a systematic way in the North West. The maps typically used data from the most recent year available (2003/04) for information such as: population 0-19 years by LHA in the North West; mental health total cases 0-19 years treated by LHA over a three-year period; mental health inpatient cases 0-19 years treated in each LHA; an estimate of mental health cases 0-19 years not served by the formal health system; pregnancy cases 0-19 years referred to a tertiary hospital by LHA; and, pregnancy cases 0-19 years handled by LHA of residence. I also included examples from the 2nd Edition of the BC Health Atlas\(^2^4\) to demonstrate the greater sophistication and utility that can be gained with additional resources. This exercise was not intended to be comprehensive; rather, these examples served to demonstrate the utility of GIS in making visual complex health services utilization data, especially with lay audiences. Their intended visual simplicity belied the time and energy that went into their production. This included, for example, the separate ethics approval process for this quantitative component, awaiting and securing the latest version of PURRFECT v.10, learning about the database, outputting the data using an Excel spreadsheet, and learning the GIS software to produce these fairly basic maps. Fortunately, I was able to secure technical assistance from a decision-support staff member at C&W who had working familiarity with the PURRFECT database, and also from a geographer\(^2^5\) who had considerable GIS mapping experience in health. Nonetheless, I experienced a steep learning curve under extremely tight time constraints given the scheduled search conference timeline and the Ministry’s delays in releasing the database.

The use of GIS as a mapping tool assisted me as a researcher and the study participants as co-researchers in getting a more complete picture of child and youth health services utilization in

\(^2^4\) Available at http://www.health-atlas.chspr.ubc.ca

\(^2^5\) Sadly, this young man, Peter Schaub, died suddenly in August, 2005 while unloading his belongings during a move to Penn State University to pursue graduate studies in geography. I am deeply indebted to Peter’s knowledge, his teaching ability, and his cheerful manner. Like so many of his colleagues, I miss him.
the communities of relevance and interest to the participants. Because the Nisga’a Valley Health Board chose to not participate in the study, the quantitative component excluded their data in the maps, although it was available through the PURRFECT database.

Of the nine available applications available on PURRFECT v. 10.1, seven were accessed or used, including: Local/Regional Referral Analysis (ADTSPEC); Age-Standardized Utilization Rates (ASUR); Hospital Comparative Reports (HOSPCOMP); MSP Referrals (MSPREF); Population Query System (PEOPLE); Summary Referral Patterns (REFERRAL); and, Vital Statistics Summary (VSTAT). Two applications were not used because they were not relevant to this study: Continuing Care Age-Standardized Utilization Rates (CCASUR); and, Utilization Rates by Health Program and Year (URPHY).

Use of the PURRFECT database, however, was not without additional ethical considerations. While all data were summarized, anonymized, and contained no patient-specific identification, I had lingering concerns about anonymity and confidentiality in very small communities in the study site. For example, because the PURRFECT database allowed data analysis at the LHA level (in addition to the HSDA and HA levels), it was possible in a rural or remote LHA with very low population to identify a specific diagnostic or procedural code and associate it with one or two cases which, in a very small community, could easily lead to identification of the child or youth. However, the BCMOHS had dealt with this issue in the past with the recognition that in small communities this would likely already be known. Further, the data is essentially public, free, and available to anyone who wants to access it via the Internet (provided the user registers on-line). Thus, at the outset this was felt to be of minimal risk in the context of this study. However, late in the study, the BCMOHS, Knowledge Management and Technology Division, did ultimately acknowledge potential anonymity problems with small numbers of cases in small communities and gave approval on the condition that maps use the
symbol "<5 cases" rather than specify the absolute number of cases when less than 5 per LHA (e.g., for teenage pregnancy cases). In keeping with this potential problem of confidentiality, I ultimately decided to not include these maps in this thesis, electing to include only two maps as examples of how GIS could be used as a tool (see Appendices G1 and G2).

**Issues Related to the Analysis of Aggregated and Mapped Data**

Two common geographical problems encountered in the analysis of aggregated and mapped data are the ecological fallacy and the modifiable areal unit problem (MAUP). Had this study centred on quantitative health services utilization data, issues related to small areas and small numbers would require concerted attention to address these problems. While these problems did not manifest in the context of the GIS mapping process that I used as a tool to augment participant dialogue in this study, it is prudent to be aware of the kinds of problems that can be encountered. I briefly outline these issues in the following two sections.

**The Ecological Fallacy**

This well-described geographical problem is sometimes called an "aggregative fallacy" (Susser, 1973 as cited in Jones & Duncan, 1995). It concerns the potential flaw in the transferability of results at the aggregate level to the individual level (Dudley, 1991; Hampson, 1991; Jones & Duncan, 1995). Jones & Duncan (1995, p. 28) warn "the aggregate relation may even be opposite to the within-place, individual relations on which it is based." Conversely, they draw attention to the problem of "atomistic fallacy" (Aker, 1969 as cited in Jones & Duncan, 1995) in which research at the individual level fails to acknowledge the context of individual action. It is noteworthy that clinical studies can suffer from the same kind of problem in terms of the transferability of results.
The Modifiable Areal Unit Problem (MAUP)

In the context of health care geography, this problem concerns the spatial aggregation of individual data and geographical boundary determination. Openshaw (1984) and Openshaw & Taylor (1981) describe in detail the nature of this problem and examine possible solutions. It is endemic to spatially aggregated data. In brief, it refers to the almost innumerable ways that a geographical region can be divided into areal units in order to report and analyze spatial aggregations of individual data and the tendency to use one particular metric instead of entertaining viable alternatives (Cromley & McLafferty, 2002; Dudley, 1991; Meade & Earickson, 2000; Openshaw, 1984; Openshaw & Taylor, 1981). Surprisingly, researchers still pay little attention to the selection of areal units or alternative arrangements; the choice is typically based on blind tradition or data availability (Dudley, 1991). Alternatively, the problem is simply ignored (Openshaw & Taylor, 1981). Similarly, the health planning and health services literature is conspicuously silent on this subject as are the reports published by provincial and federal governments and health authorities with respect to health reform, regionalization, restructuring, and redesign plans. The question is how much does it matter and what can be done about it?

Dudley (1991) provides a number of suggestions for researchers (which, by extension, are equally relevant to health services decision-makers and planners): (a) choose areal units which are relevant to the research, (b) develop a better understanding of areal data and a sensitivity to alternates, (c) investigate how alternate areal configurations could influence findings, and (d) explore alternative approaches.

This problem also extends to computer-based cartography. It is common knowledge that different maps can be produced for the same data by using different areal units (Openshaw & Taylor, 1981). More recently, with the growing importance of the role of GIS, this remains a challenge for mapping. For example, small areas are more likely to demonstrate underlying patterns; larger areas can conceal local differences. The scale of areal units affects our
interpretation of data (Cromley & McLafferty, 2002). This can be overcome by using small-area data to demonstrate more detailed patterns, or by apportioning data for large areas based on small area data (Cromley & McLafferty, 2002). Even then, small-area health data is problematic because there are usually only a few events in small areas which leads to unreliable maps, problems associated with small numbers, and unreliable analyses (Cromley & McLafferty, 2002). Additionally, issues around confidentiality are important in small areas because people have a heightened ability to know each other's business. This issue of confidentiality, in fact, was an actual problem in this study, contributing to my decision to minimize inclusion of a number of maps in the Appendix, as noted earlier.

With this technical journey through the methodology and data analysis methods used in this study, I turn now to the findings. Chapter Four: Findings I is a geographical and liminal journey that introduces and discusses the findings emerging from this study. Chapter Five: Findings II explores the concepts of boundaries and boundary objects, applying these findings to planning child and youth health services.
CHAPTER FOUR: Findings I—The Emergent Concepts

The world does not issue problems in neat disciplinary packages. Problems come up as complex, multidimensional, and often confusing congeries of issues.

(Greenwood & Levin, 2005)

Introduction

In this chapter, I weave together two main strands—process and content. I amplify my thought process, how it evolved, and how it was refined during the data analysis process. While flexible, this is a systematic, iterative, and comprehensive process, which demands constant comparison of data on many dimensions. I begin with identification of three preliminary conceptual categories emerging from the initial data gathering stage, and then I outline how analyses of subsequent data lead to two conceptual core-categories. I then discuss the findings as they emerged over the course of data gathering and analyses. This systematized, iterative process is central to using a constructivist grounded theory method. Several quotes from study participants are interwoven to illuminate the lived experience from the perspectives of four different stakeholder groups.

Initial Findings

I began data analysis by open (line-by-line) coding an initial set of semi-structured interviews. I then selectively coded 10 of the first 18 interviews (in order to achieve a reasonable balance of participants in each of the four stakeholder groups), including: three managerial decision-makers; two service recipients (public); three clinical decision-makers; and, two policy decision-makers. Five are male; five are female. Two are Aboriginal. The initial interviews were conducted in the participants’ respective communities in the North West, including: Prince George; Smithers; Hazelton; Terrace; and, Prince Rupert. The coding process involved reviewing the responses to the nine interview questions explored in each of the 10 interviews,
and meticulously documenting the coding process in order to not lose the context of the data. This initial process involved approximately 380 pages of transcripts and resulted in over 1000 selective codes; however, this number included numerous duplicates. During this process, several patterns emerged. When I compared the codes between and within the data (including at least two from each of the four stakeholder groups and the two Aboriginal participants), the similarity of responses was striking. By design, participants were encouraged to answer the specific questions, but were also free to use the question as an opportunity to expand upon their own perspectives. During the first part of the analysis, the major categories remained remarkably consistent. I wondered whether this pattern would continue during the analysis of the remaining data. At that point I was proceeding on a question-by-question basis from the interviews.

I again reviewed and then manually condensed the data to approximately 520 codes (mainly by eliminating duplicate codes). Through extensive analysis of these early data and selected codes, I identified four preliminary major categories (which I refined to three during subsequent analyses), and approximately 14 preliminary sub-categories. There was considerable overlapping terminology and the codes did not neatly categorize.

I created three conceptual categories: perceptivity, emotivity, and inclusivity. These incorporated data regarding: participants’ (a) perceptions of the provincial health system, (b) emotions generated by the health system, and (c) inclusion in the health system. These concepts are discussed in detail below. Numerous theoretical memos, especially over the mid-stage of data gathering and analysis, helped me to make sense of these early data. Building upon these memos, I will outline how my thinking progressed and became more refined during the data analysis process. I use data, including selected quotes from several participants interviewed during the preliminary data gathering stage. For emphasis and continuity with the subsequent interview process, I have also included several perspectives generated during interviews conducted later in
the study. I shared my preliminary findings during my introductory comments in the focus group sessions as a way of seeking early authenticity with the study participants, and in order to signal any need for adjustments or refinements as the study progressed. I also shared my findings during several follow-up sessions to discuss the findings. I invited all study participants and, based on availability, held sessions in Prince Rupert, Smithers, Terrace, Prince George, and Victoria to review my findings and seek feedback. The salient points are incorporated into this chapter and Chapter Five.

**Perceptivity About the Health System**

Issues in this conceptual category are organized under three sub-categories: (a) understanding of the provincial health system, (b) considering issues in health services planning, and (c) acknowledging practical issues.

**Understanding the Provincial Health System**

Participants understood the health system in a number of ways. Within and between stakeholder groups, there is no common understanding of what it is, nor what it should be. This is not surprising and is not a trait unique to the North. At the most basic level, the term *health system* is subject to many interpretations depending on where one is situated, for example, as a patient, provider, manager, policy-makers, or researcher. Consequently, this can lead to misunderstanding, misuse, malfunction, and mistakes. It is impossible to effectively use, plan, provide, manage, or govern what we don’t really understand. Individuals typically better understand component parts of the health system, but understand less well how the parts are connected and function together as a whole. This problem can be explained in terms of CAS and holism. It is worth reinforcing here the concept that was discussed in Chapter Two, that fragmentary thinking leads to fragmentary seeing and, even more problematic, experiencing the world as fragments (Bohm, 1980). In the health system, this type of fragmentary behaviour is
common-place, even tacitly encouraged, in terms of how the system is planned, structured, funded, operationalized, and managed. Managerial, policy-maker, and parental perspectives are evident in the following accounts:

I don’t really think that there is much of a system and [there] hasn’t been for a long time. (Manager)

For me, really, it’s trying to define what, where the health system ends and where the other systems kick-in because, I think, the way in which it’s most commonly tossed around is a fairly narrow definition. (Manager)

The participants are going to have ability or should gain appreciation of what the total picture is, not just their small part of it. And, that’s often what happens…we deal only in segments, you know, of care. (Policy-maker)

[Links with the children and families—they’re not strong yet. So…there’s people that fall through the cracks, often in that age group between child and adult. That tends to be an interface that the system, I feel, does not work well right now. And, so, we shuffle people back and forth….Everybody is focusing on their area, but…that whole system is not connected. (Manager)

I feel that the health system is layered….I do feel that we are on the lower level of the health system in this [North West] area. (Parent)

I think bridging that gap between, say, the bureaucrat or the policy-maker and the real person [the patient] is something that we should do more of. (Manager)

So, I’m going to contradict myself. On the one hand, I said I actually think we’ve got a pretty good system. And, now I’m going to contradict myself by saying, no, I don’t think it actually functions as a system. I think it functions as separate parts that sometimes work in concert, and sometimes don’t….I think most of us use that term [system] unconsciously. It’s just a habit to say system without one thought. (Aboriginal Policy-maker)

Participants perceive a large disparity between the rhetoric about and the reality of the health system. This transects all four stakeholder groups. There is also a significant gap between what participants describe as the current system at work and how it should be functioning.
Despite on-going reform, the health system is seen as fragmented at all levels. A health system is desired; however, from the perspective of participants, there is little or no capacity to create one that actually works well. It is not just about intervention. The system-wide seeming preoccupation with data doesn’t resonate with participants. However, knowledge and information about the system and services does matter a great deal but this, too, is lacking. The people who know are typically not consulted. Centralized policy-making creates overly rigid policies that do not reflect local realities, nor are they flexible enough to accommodate local nuances. Effective communication even within the health system is still lacking. Some policy-maker and managerial perspectives on this dearth of activity follow:

[A] lot of times policies don’t reflect how we live and, so, a lot of times we as policy-makers have to, for instance, like our group homes, the policies are so rigid that it, you know, it doesn’t let us benefit to the maximum that we can use that service...with a little bit of freedom for us to make changes, they wouldn’t limit us. (Aboriginal Policy-maker)

I have mixed feelings about policy-makers, mostly because I believe policy should work for us, not against us. And, I think if we’re going to set policy, we should be prepared to change policy to suit our needs, to provide a more effective service. So, I guess that’s what I would say about how policy-makers could be more in tune with our needs. And, I don’t think the same policy fits for...everything all over the place either. (Manager)

Many of these people are in such little communities that the data is almost meaningless for them, so you need to talk to people. I mean, you basically need to go to communities and talk to the people who see kids...the people in the community who really know what’s going on. (Manager)

[T]he biggest issue that I see in our systems is that of communication. It’s not the money. It’s not being able to have, even, expertise. It’s the ability for the different areas of the system to talk to each other. (Manager)

I think we need, obviously, we need input from families in regards to what’s working well for them, and what isn’t. (Clinician)
[W]e do see North West type of information, but it doesn’t mean as much to me because I’m not always sure that those are the issues in our community. And, part of it is the small, the small numbers in, in communities. So, you always have to weigh how critical an issue is for a whole community based on the smaller numbers. (Manager)

Another significant observation by participants is that some data, especially what is required to be captured by organizations and reported to governing boards and government, do not accurately, nor fully, reflect local realities. The meaning is taken out of the measurement—sterilized by conforming to standard methods of collecting data and forms used to report the data. The numbers belie the reality from which they were extracted. Such numbers offer little insight into the day-to-day challenges that confront those who manage, provide, or receive services. This illustrates why local stakeholders care about data and how it is used in local contexts. As one seasoned clinician reflects:

You can’t use those true stories, or those things that you just saw when you were out in the field working with them [patients] because you have to maintain the confidentiality. So, how do we get over that confidentiality barrier so that the insurance agent who’s sitting on the board and doing the planning can have an insight into what’s happening? How do we get that up there, or what do we collect to send forward? I mean, we send forward basic numbers—number of times you’ve seen the child, and number of times that they’ve cancelled, and that kind of stuff, but it really isn’t a reflection of what’s happening in their homes. (Clinician)

Specifically around mental health services, for example, data inaccurately portray real needs at the community level (especially when small communities and small numbers are concerned). The essence of this concern is captured by a Focus Group:

Our numbers don’t dictate that we need more [mental health services], but the condition of the community does. (Focus Group – Terrace)

[A]nd I sort of continually say, well, this is remote. And, often the province develops models that are urban-based, whether I would say, whether it’s the
physical care end of, whether it’s the mental health care end, the models that the province, with specialists, develops for you is an urban-based model. We then come along from the planning table and say, well, how do we revise this so that it fits that remote, rural....But, they [those in positions of authority, power, and control] should be, they make decisions about an area like this, they should be knowledgeable about the conditions. (Focus Group – Terrace)

The North West geography, especially in terms of transportation, is recognized as a challenge by participants, and this exaggerates—even controls, in the words of one participant—how rural and remote issues can be addressed. Additionally, from the perspective of the North West, the population-based funding formulas do not acknowledge the imposing distances, mountains, and often inclement weather conditions. This is perceived despite attempts made by the formula to address rurality and other factors. In fact, the formula only allocates the amount of funds available to each HA. The five HAs must respond to their own regional nuances. This is exemplified below from several stakeholders’ perspectives:

Well, I think the North West is the most difficult of all of the three areas we have [in the NHA]....So, I mean, it’s the geography....it really controls what you can do to a large extent. (Policy-maker)

Transportation is a major problem because people; we don’t have public transportation here. (Aboriginal Clinician)

I think people down in the Lower Mainland take what they have for granted in a way, and they think that everybody else has it....Well, they, they don’t really know. They have their own world and, and whatever...they have, you know. Well, you know...you live way up there kind of thing. (Parent)

Geography, in the context of this study, includes such things as mountains, water, weather, distance, transportation, where people live, and the location of health services. In many cases, these dimensions create a geographical confluence and a considerable challenge, at times life-threatening, to those who must travel to remote and often isolated communities in the course of their work. It is hard to appreciate the risk that comes with this unless one has experienced it.
first-hand. In particular, central decision and policy-makers may never have to experience such travel in and out of places that are in many cases only reachable by boat or float-plane. As one seasoned manager puts it:

[T]he highest level of decision-makers are not well-connected with the true reality of life on the ground for people that are actually traveling in and out of places. (Manager)

For this manager, one of her “reality of life” trips by air into a remote coastal Aboriginal community is indelibly etched into her memory, given her near-death experience:

Well, I mean, I can remember actually very well flying into Hartley Bay the day after the space shuttle went down. And, it was a deceptive day, calm after the storm. And, we went in over the glacier rather than around the waterway, and what we didn’t run into. It was just horrific! It was just me and the pilot. And, the stuff…wasn’t properly secured and there was stuff flying all around. We had to go so high that the air pressure, and I was, and I know I was mentally impaired, but I was trying to stop the pilot from being hit by the stuff. We crested the glacier, ran into humungous headwinds. The engine cut. We had to ski down the glacier while the pilot prayed to start the engine. (Manager)

On the other hand, some people simply accept geography as part of living in the North, embraced and normalized into everyday life. For these residents, traveling outside of the North is the challenge, as exemplified by this parent:

I don’t see that [geography] as a factor being here....Yeah, this is normal. I love it here. I mean I go to Vancouver, and I can’t handle it. It is too busy....This is where we’re comfortable, and down South is just not a comfortable place for us....I have no objections to even traveling up in the North area for care. (Parent)

**Considering Issues in Health Services Planning**

How planning is approached and who is involved in the process are critical to success. It is not just a matter of token involvement—people want to be involved right from the beginning of the process, but in a genuine way that respects their perspectives, knowledge, and experience.
It is the people who live in these communities that have the best sense of their realities and needs. Planning is felt to be generally poor; help is needed, but leadership is missing. The planning process needs to work from the ground up, not just from the top down which is more typically the practice, in spite of health reform initiatives. There needs to be horizontal coordination across the so-called “silos”. The top means more than the BCMOHS in Victoria—it includes the NHA corporate offices in Prince George as the top “over there” from the perspective of the North West, parts of which are several hundreds, even thousands, of kilometers, from Prince George. This is accentuated by the centralization of some infrastructure support services, such as human resources and payroll. This tremendous distance poses symbolic and real barriers to meaningful relationships. It is also costly in terms of time and money. However, it is seen as a cost of doing business as suggested by this policy-maker:

[A]ll this [participatory planning] costs money and time, you know, particularly for managers. Administration has to be willing to allow managers to have that kind of time, and not just be putting out fires. (Policy-maker)

When combined with cultural boundaries, such as between Aboriginal and non-Aboriginal perspectives of planning services, difficulties caused by geographical distance are compounded by other forms of distance (for example, power, professional, economic, cognitive, and social) as discussed earlier in Chapter Two. As this Aboriginal manager exemplifies, it is important to reduce the distance and barriers between the centralized FNIHB bureaucracy in this case and the community:

[To be honest, I think there’s a lot of bureaucratic nonsense that gets in the way of quite obvious decisions....[I]n a perfect situation you would hold meetings directly with the community...and they would openly discuss their needs and what they think could better improve access to services and services to children and youth. (Aboriginal Manager)
With respect to planning, specifically for child and youth health services in the North West, this is seen to be markedly deficient. The problems are similar to those expressed about the health system, such as lack of strategy, coordination, and integration. This view is shared across all four stakeholder groups, as evident below:

[I]t’s disjointed [the planning] and...I haven’t seen a lot of strategic planning around children’s services, frankly. (Manager)

I think that there’s a lack of serious planning [for health services for children and youth in the North West]. I think that there’s a lot more coordination that could be done. (Policy-maker)

I don’t think that [child and youth health services in the North West] have been planned in any kind of integrated manner. (Clinician)

[I]f the grassroots of the area aren’t involved from the absolute beginning, it’s [planning health services] not going to work. Because you can have, you can go away, write a nice little report – they need blah blah blah blah blah – and, if they don’t think they need blah, blah, blah, then forget it. You ain’t going to get there. What you’re going to have to do is find out what they think the need is, and then work from there. (Clinician)

I think planning should be done on an area basis from people who know what is normal for the area. What they normally see....They need to plan locally, and then pass it up. (Parent)

**Addressing Practical Issues**

**Inter-sectoral.**

As participants would attest, sectors typically fail to collaborate to the extent required to achieve integration of services important to children and youth. Additionally, various levels of civic government play an important part in services related to health. The main sectors associated with child and youth health services include: health, child and family development, education, justice, and recreation.
From the perspective of participants, both the problems and the sectors that are supposed to solve them remain in their respective silos, or stovepipes as they are still popularly described. This, despite repeated calls to cut across these boundaries (which, in this case, function as barriers). Attention needs to be paid to developing practical coterminous boundaries for, at least, the BCMOHs, the BCMCFD, and the BC Ministry of Education. Federal boundaries with respect to Aboriginal health services further compound this problem. Gaps between jurisdictions and sectors create boundaries that are perceived to be, if not actually, insurmountable for the average person seeking services. Policy-makers, managers, and a clinician candidly describe this problem:

Oh, this business of the jurisdictional problems is everywhere. (Policy-maker)

All of these stovepipes...we still have them, you know. (Policy-maker)

Everyone’s in their own bubble, you know. Hospital’s in a bubble. Community public health’s in a bubble. Probably policy-makers are in a bubble. (Manager)

See, part of the problem is it’s a jurisdiction thing again. Public health didn’t want to give up that funding. I do home care assessments. But, I’m not supposed to because that’s supposed to be done by somebody down...now how the hell can you do a homecare assessment out of an office over a phone in Terrace? You cannot see what’s going on in that home. (Clinician)

You know we use that term fragmented...or silos...and it’s the integration across those paths that’s missing. And, part of the goal of our recent restructure in BC was to start, together, to knit together some of those services and to reduce those barriers or silos, and we haven’t done that yet. I don’t know if it’s because of...professional turf issues, or if it’s just, you know, people in the system can’t get out of their own way. And, people like...me, can’t get out of my own way to figure it out, right. But, we need to weave the threads. (Manager)

There’s been a real gap because of the jurisdictional issues between Federal and Provincial [re: working in Aboriginal communities]. (Aboriginal Manager)
Inter-cultural.

When the needs and values of distinctly different cultures clash, in this case Aboriginal with non-Aboriginal, the challenges of collaborating are accentuated. In spite of longstanding jurisdictional issues, such challenges must first be acknowledged before they can be addressed in the context of collaborative planning for health services. Very small, remote Aboriginal communities (many of which are coastal villages inaccessible other than by boat or air) are the least acknowledged, but perhaps the most inured over time. The importance of this was evident at a Coastal Communities Health Summit held in 2006, in Prince Rupert, BC. This summit specifically highlighted the gap in health and health services between BC Aboriginal and other coastal communities and the need to improve relationships (Loveridge & the Coastal Community Health Summit Planning Committee, 2006). In BC, there is still a large gap between the health of Aboriginals and the rest of the population (BC Provincial Health Officer, 2002). This observation is well-documented in the literature, including reasons that were discussed in Chapter Two. The following accounts exemplify how some of the participants perceive such issues:

[W]e have so many Aboriginal communities that aren’t even on the radar, probably of the North West Health Service Delivery Area, or the NHA….and because we have so many of these small areas [Aboriginal] that wouldn’t be on the provincial radar either. (Manager)

First Nations health is an issue….we’ve got a ways to go on First Nations health, let me tell you. (Policy-maker)

[W]e’re not exploring and we’re not supporting indigenous knowledge and indigenous models, like that, I think, is the way that we have to go. I don’t think that mainstream health care system, however we describe it, is working for Aboriginal people in the North…and I think that the whole idea of paying attention to the determinants in real, practical ways around poverty and isolation and culture is key. (Aboriginal Policy-maker)
Give us a free-hand in making decisions of how services should be delivered. You know it’s not going to be ‘cause most of the policies are made, in regards to health or other social services, are made down South, and they don’t really have any relevance to how we live in the North in this isolated area [remote First Nations community]. (Aboriginal Policy-maker)

They [policy-makers] need to hear, not just sit around the boardrooms, and consider whatever they’re considering. But, they need to hear from the common man, and the layperson, and the professionals, where the problems are. And, where the successes are because those are just as important. (Aboriginal Policy-maker)

When you talk about health system, I would say that the one that we are forced to use and forced to accommodate to us doesn’t always work for us, and that’s given federal and provincial guidelines and policies that are put into place at the time. Our own health system, it seems to work better because there’s no rigid guidelines that we have to use...They take it individual by individual. (Aboriginal Policy-maker)

As the following policy-maker recognizes, the health system has not addressed the unique issues facing Aboriginal families. That there is something different is one thing; understanding it is yet another. More important, doing something about it remains elusive.

Child and youth in a...European background family is one thing. Child and youth in an Aboriginal family is something else. And, you know, we have to understand what that something else is. (Policy-maker)

I think that we need to get more information from the community and from other jurisdictions around culturally appropriate models for children and youth. (Aboriginal Policy-maker)

In spite of such difficulties, an approach which truly respects inter-cultural issues and engages in a participatory approach does achieve breakthrough results. In one North West community, the following process exemplifies how efforts to work together pays-off in unanticipated ways when problems are addressed in a collaborative, respectful way:
It’s a hard struggle to work collectively…. We found that the people needed to spend time just hearing and listening and then, all of a sudden, you know, that over, we kind of went to this next stage where [we] started working collectively, and we ended up with a kind of, a whole new, way of looking. We looked at an Aboriginal more of a traditional structure of looking at the child in the centre with everybody around. (Clinician)

But, the converse can be true at the individual level. Stereotyping and outright racism may be less visible in terms of the general populace, but at the level of interaction between Aboriginal consumers and non-Aboriginal providers, racist behaviour does surface in day-to-day life. It may be concealed and invisible, but it is real to those who experience it, such as this Aboriginal manager who sought services as a patient:

I’ve had doctors at clinics treat me like I was just this dumb Indian. And, I was just there to get drugs. And, this, just happened last year. And, so, it’s real.
(Aboriginal Manager)

**Priority health service needs.**

With respect to specific health service needs, the dearth of services for children and youth with mental health and addictions in the North West was raised numerous times by different stakeholder groups. By design, this study did not set out to undertake a needs assessment for children and youth; however, as the need for mental health and addictions services was raised so many times, I felt ethically-bound to highlight this plight. Drawing from the literature and the data gathered in this study, I outline below the issues and the need for services for children and youth in the North West, particularly in remote communities. This huge issue also arose frequently during the recent Public Consultation process undertaken throughout the North by the NHA in May/June, 2004. The report specifically notes that “[m]ental health services (particularly for youth) are perceived to be in crisis.” (Northern Health, 2004, p. 5). One of the senior managers in the North West summarizes the problem as follows:
Basically, people talked about the lack of child health services, in particular, mental health. That’s the big one. It was around the drugs, the alcohol, teen pregnancies, the suicide attempts, the behavioural problems in schools.

(Manager)

Yet, given that this problem is characterized as a “crisis”, surprisingly little, if anything, has changed on the ground in the ensuing two years from the perspective of the participants in this study. Even worse, the problem is seriously under-reported in very small communities due to issues of privacy and confidentiality and the relative ease of identifying at-risk children and youth. This is a serious paradox of protecting privacy literally at the expense of life in some cases—a situation of cautious legalism prevailing over common sense, with children, youth, and families caught in the moribund middle ground. This dilemma is captured well by an Aboriginal manager in a remote Aboriginal community who experiences this problem first-hand and is frustrated and angered:

[W]e’re not allowed to [collect data on mental health cases] because we’re too small, too easy to identify.... There could be a bigger number and if we could find some way that we could gather this data without somebody being identified it would be good. But, at this time, we don’t think we can do it unless all communities get together and decide to do it and just do one central, you know, data collection place.... I just feel real angry. It’s just like our kids don’t count to anybody. (Aboriginal Manager)

Other perspectives consistently highlight the pervasiveness of this issue in the North West. If progress is being made in the area of child and youth mental health service delivery, it is not yet evident at ground level. This, of course, again exemplifies jurisdictional issues among, for example, the BCMOH, BCMCFD, BCMOE, NHA, NW HSDA, and FNIHB, and several other organizations and agencies involved with mental health services. Comments were made about this by study participants, for example:

Mental health, children and youth – it’s kind of another planet. (Policy-maker)
I’m not sure how often the psychologist or psychiatrist comes from Vancouver…but we don’t have those kinds of services here. (Aboriginal Clinician)

We’ve got schools in the North West that 50% of the population is considered special needs. This is because of alcohol and drugs. Like, let’s, you know, address these issues. (Aboriginal Manager)

[All I hear about are the gaps in services for children and youth in terms of psychiatric services primarily. (Manager)

During the focus group session held in Terrace, one of the clinicians gave the following account of the reality she constantly faces in the remote community in which she practices several hundred kilometers from Terrace. This poignant example underscores the day-to-day reality of living and working in a remote area and the considerable challenges to providing safe, effective services without the immediacy and luxury of readily available support, either in infrastructure or human resources:

We have one mental health worker there who works with the kids in the school. And, he’s so overwhelmed with the numbers that he’s got to do because he also has to try and help us out with adults because we don’t have adult mental health counselors there. And, it seems we’re always running in circles. Acute situations often lead to parents actually picking up the child and driving south with them. We can’t get BC Air Ambulance in quickly. They won’t come in the dark. They won’t come in when it’s raining. They won’t come in when it’s snowing. They don’t like coming in when it’s windy. So, it’s very frustrating to try. Beds are a frustration. We don’t have beds. We’re not a twenty-four hour facility so there’s a lot of overtime put in just to hold people until we can get them somewhere. Mental health is terrible. The last patient we had we sent them down to Terrace in the back of a police car in handcuffs and, like, that’s not right. We shouldn’t be doing that to people. But, that was the safest way to get him down without chemically restraining him. And, we couldn’t get the plane in, so it would have meant two or three people would have been stuck at the facility overnight with him just to try and control him until we could [get] him out. And, then the kids that are in the schools, like, they’re getting older; they’re getting stronger. And,
so, it’s getting harder to control them without some kind of chemical restraint.
And, if they decide that there’s a problem in the family, like we can’t help them quickly there. We just can’t. We just don’t have the resources and our mental health worker is going to burn out on us and that’s what happens...just one person there is just not capable of dealing with everything. So...I agree with everything everyone’s been saying. And, then I think of where I am and, I think, yeah, you know, we’re, we’re tough. These guys are tough trying to get things done. And, it’s no better here than up there. (Terrace Focus Group)

That mental health issues appear so removed from attention in spite of widespread prevalence and a chronic shortage of services is not surprising, nor is it unique to the North West. Similar issues are encountered in urban settings. Recent literature confirms that psychiatric disorders are the leading health problem among children and, simultaneously, draws attention to the extent of under-serving children and youth with mental health needs (Waddell, McEwan, Hua, & Shepherd, 2002; Waddell, McEwan, Shepherd, Offord, & Hua, 2005; Waddell, Offord, Shepherd, Hua, & McEwan, 2002). Moreover, the challenges of translating research to policy and practice in children’s mental health nation-wide stubbornly persist in spite of the overwhelming evidence pointing to the need to change children’s mental health policy and practice and how it is approached (Mussell, Cardiff, & White, 2004; Waddell, Lavis, Abelson, Lomas, Shepherd, Bird-Gayson, et al., 2005). The ambiguous and non-rational policy-making process, combined with intersectoral fragmentation at multiple levels, on-going fiscal restraint, competing priorities amongst stakeholders, and the media’s role in shaping the public’s perceptions of the issues, all contribute to this wide-spread problem. Indeed, these issues largely reflect the mental health services climate in the North West. In particular, the constraints imposed by fragmentation across the sectors including health, education, social service, and justice was expressed as frustration and bewilderment in this source—mirroring the findings in this study as outlined earlier. These constraints were illustrated again during a findings session with study participants:
Children and youth mental health...is a really good example in the health system. Some of it we [NHA] own, but we really can’t do anything with it because that comes to us by contract from [BC]MCFD and that’s driven by the child and youth mental health plan...then there’s the work that the pediatricians on the ground might do. (Manager, Findings Session)

In their review paper, Waddell, McEwan, Shepherd, Offord, & Hua (2005) suggest that at any given time 14% (one out of seven children aged 4 – 17 years living in Canada, United States, and the United Kingdom) have clinically significant mental disorders requiring specialized services but, of these, less than 25% receive specialized care. Thus, there is a tremendous unmet need. Here in BC, the Child and Youth Mental Health Plan for British Columbia (BCMCFD, 2004, p. 23) suggests a 15% prevalence rate in communities. This equates to approximately 140,000 children and youth in BC (defined in the Mental Health Plan as <19 years of age) who “have a mental disorder with extreme functional impairment.” Only 20,000 (or approximately one out of seven impaired children) are served annually by the formal mental health system. Astoundingly, this means that approximately six out of seven are not served by the formal mental health system. The authors unsurprisingly conclude “there is a substantial shortfall in the capacity of the formal mental health system to meet the needs of BC’s most seriously mentally ill children.” Using the more widespread figure of 14% prevalence rate, I mapped this as an example of the utility of mapping (see Appendix G2) which was discussed during the search conference. In absolute numbers for 2003/04 for the 0 – 19 year-old (inclusive) population, Table 4 estimates how many children and youth are affected in each LHA in the North West HSDA. (Note: This may be slightly over-represented because the PURRFECT database stratifies to 19 years (inclusive), whereas the Child and Youth Mental Health Plan for BC refers to children <19 years).

Recently, a mental health plan for children and youth in the North Region was developed by BCMCFD, which outlines the planning process that commenced in 2002 and addresses the
issues, challenges, objectives, initiatives, and next steps at the regional and sub-regional levels (Reid, 2004). This plan underscores the urgency of the long-standing and yet unresolved issues facing children and youth with mental health needs in the North.

<table>
<thead>
<tr>
<th>0-19 yrs. (incl.) Popn. 2003/04</th>
<th>LHA</th>
<th>Estimation of # of Children &amp; Youth With Significant Mental Disorders (14%)</th>
<th>Estimation of # of Children &amp; Youth Receiving Formal Mental Health Services</th>
<th>Estimation of # of Children &amp; Youth NOT Receiving Formal Mental Health Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>1308</td>
<td>QCI*</td>
<td>187</td>
<td>27</td>
<td>160</td>
</tr>
<tr>
<td>212</td>
<td>Snow Country</td>
<td>30</td>
<td>4</td>
<td>26</td>
</tr>
<tr>
<td>4922</td>
<td>Prince Rupert</td>
<td>703</td>
<td>100</td>
<td>603</td>
</tr>
<tr>
<td>1860</td>
<td>Upper Skeena</td>
<td>266</td>
<td>38</td>
<td>228</td>
</tr>
<tr>
<td>5531</td>
<td>Smithers</td>
<td>790</td>
<td>113</td>
<td>677</td>
</tr>
<tr>
<td>3651</td>
<td>Kitimat</td>
<td>522</td>
<td>75</td>
<td>447</td>
</tr>
<tr>
<td>301</td>
<td>Stikine</td>
<td>43</td>
<td>6</td>
<td>37</td>
</tr>
<tr>
<td>6978</td>
<td>Terrace</td>
<td>997</td>
<td>142</td>
<td>855</td>
</tr>
<tr>
<td>230</td>
<td>Telegraph Creek</td>
<td>33</td>
<td>5</td>
<td>28</td>
</tr>
<tr>
<td>24,993</td>
<td></td>
<td>3571</td>
<td>510</td>
<td>3061</td>
</tr>
</tbody>
</table>

* QCI = Queen Charlotte Islands
Emotivity Generated by the Health System

The second major conceptual category introduces a deep-rooted emphasis on emotions, feelings, and need for control that participants regularly expressed. This category is imbued with pessimism spanning all four stakeholder groups. This undercurrent of emotivity pervaded responses and spanned all stakeholder groups to varying extents. However, this needs to be balanced with many success stories, only a few of which were shared. The parental stakeholder group (especially of children with special or chronic needs) expressed these feelings with the greatest intensity which, in these cases, can be attributed to their chronic frustration in dealing with the system over many years, at many levels, with many disciplines and sectors, often at great distances. This parental group epitomizes the many challenges of dealing with the interface, or boundary, dynamics in what can still be characterized as a poorly functioning health system. Additionally, these issues span jurisdictions other than health services, such as education, recreation, and justice. Some of these dynamics are captured in the following accounts by parents, clinicians, managers, and policy-makers. They collectively reinforce what parents have been asserting, often unheard by people in positions of authority, for a very long time. Many of these sentiments reflect findings elsewhere and can be best understood in terms of skewed power relationships, unequal interests, and disproportionate information (Church, Saunders, Wanke, & Pong, 1995).

As Forester (1999, p. 80) suggests in reference to deliberative participatory planning, "emotions are potentially modes of vision onto the world....We can learn not only about the emotion, then, but about the practical and often malleable world that has engaged it." During my study, many and varied emotions were expressed by participants in the context of the health system, a malleable world in Forester’s terms, and these will now be discussed. I identified five

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26 Forester (1999, p. 1) defines deliberative practice as “learning about others as well as about issues, learning about what we should do as well as about what we can do.”
sub-categories of emotional reaction: (a) lacking knowledge, (b) feeling unheard, (c) experiencing frustration, (d) reacting censoriously, and (e) taking charge.

**Lacking Knowledge**

The participants’ expressed lack of knowledge is mainly in reference to knowledge about health services planning and addressing needs. While stakeholders recognize that a lot of planning and related activities occur, exactly what these activities accomplish typically remains unknown. Some perspectives of policy-makers and a manager follow:

I don’t know what’s going on [regarding coordination of services and communication]. (Policy-maker)

Again, you get stuck with your blinders on, and you approach it only from the inside. Well, it helps to hear the outside piece as well. Right or wrong, it forces you to look at what you’ve been doing. (Aboriginal Policy-maker)

I don’t know how to go about addressing all those things [to help improve health services for children and youth in the North West]...but it seems like there’s lots of studies that have gone on in the past. (Aboriginal Clinician)

Similarly, in addition to having the right skills, it is important to acknowledge that the right perspective and attitude are also required when addressing issues that extend beyond the mainstream of health services delivery. For example, working in health services in rural and/or remote areas requires a perspective, attitude, skills, training, tacit knowledge, and even a patience that extends beyond what may be required in urban settings. It is not simply a matter of transferring skills—it is adopting a lens to become aware of, and better understand, the issues from the perspective of those living in their local realities. This point was raised during a focus group session:

I think that there are skills outside our traditional kind of technical skills that we maybe want to look at as a requirement for people that are going to be working on those margins. (Victoria Focus Group)
Feeling Unheard

Feeling unheard in, perhaps even feeling abandoned by, the health system eventually leads to a point where people may even pull away from involvement in the activities. Continuing reform initiatives and change contribute to these sentiments. For example:

[T]he ordinary person, well at least from up here [in place], we don’t have a voice because there’s nobody on the other end listening. (Parent)

I’ve seen the systematic dismantling of… the authority level of the grassroots grouping of people…. I feel like I’m worth nothing ‘cause I don’t know what I can contribute. I don’t know where we’re going with this thing [a particular planning activity in a North West community] (Policy-maker)

We started off with social planning. We identified youth as an issue because health service delivery was an issue. But, it seems so overwhelming…. We’ve started up so many things. It’s disheartening, you know… because people are not getting the bigger picture. (Clinician)

I don’t know if they [NHA] listen to people. I don’t know if they understand what people need. You know, I think if they did, it would be a better run system…. maybe the same thing is true [about the province], I don’t know that they are really listening to the people. (Policy-maker)

[W]e’re all humans and everyone of us wants to believe that our voice is heard. (Aboriginal Policy-maker)

These dynamics are equally evident in the following accounts by two parents and a manager:

If I look at the administrators in, say, the education system and, say, that principal of special services, well, they just smile at you really nicely, and they listen to you and stuff, and then they just do nothing…. [T]he ordinary person, well at least from up here [in place], we don’t have a voice because there’s nobody on the other end listening…. I also think that people have a problem with who gets on these Authorities and things like that. I really believe that a lot of these times it’s who you know; not necessarily the best person is put on these. It’s… political. (Parent)
Honestly, government has no clue [about how families cope with sick children in the health system]. (Parent)

Because, like I said, we, because we live in the North in our normal areas, and we live in small communities, and we raise our children on reserves, we're looked at as someone who can't think for themselves because we have no insight.
(Aboriginal Manager)

Experiencing Frustration

Some of the sentiments expressed include feeling scared about service reductions, feeling hardship, feeling overwhelmed, seeing injustices and unfairness in the system, and “turning a blind eye on the real issues.” Frustration is evident at multiple levels in the health system. At the policy level, frustration results from the historical failure to expand thinking about the health system as a system. Traditionally, the focus has been on healthcare services, particularly acute, episodic care provided in hospitals, and a lack of acknowledgement of how community-based issues and services factor into the process. This vexation is expressed in the following views by policy-makers:

Part of my frustration with the system over the years is that the thinking in health is health care....It’s hospital-based; it’s not a community focus and not community-based. And, that puts a different, you know, it’s a thinking process.
(Policy-maker)

I think that the best innovations will probably come from the remote areas....There’s so much pressure to base everything we do on evidence and, of course, I believe we should make our programs and services based on good evidence. But, if we just only do that, we won’t ever have any innovation. And, it also doesn’t acknowledge the evidence of indigenous knowledge...I’m very frustrated by that, and I hope that...when we improve access in those areas we don’t just duplicate and replicate what’s working in a big...city, ‘cause I don’t think that’s the greatest model anyway. (Aboriginal Policy-maker)

Well, everybody gets caught up in doing their own jobs and their thinking, their own approach to their jobs, and sometimes we lose sight or the perspective of
those that we’re dealing with…. [W]hen you’re problem-solving, you focus on the problem at hand and the result, the end result. And, how you get there is sometimes just as important as where you get. (Aboriginal Policy-maker)

Frustration with the health system is also evident in those who use the system. In this case, for a parent of children who required services over a number of years at the local and specialized tertiary levels in Vancouver, the issues are mysterious, but the solution is simple:

[T]he health system, for me, needs to be all integrated, you know. It needs to be the same everywhere…. So, I don’t know what could be done to change it. I don’t even know where the problem is. I just know that it’s very frustrating. (Parent)

From a managerial perspective in Aboriginal health services delivery, the sentiment is strikingly similar, and shared across the province, as expressed in this recollection and comment:

[I]f everybody knew what we knew, and we only know this because this [is] our job and we spend hours and hours each day learning about these things, I think things would definitely change…. It’s one of these things where you get so overwhelmed… I think a lot of [Aboriginal] communities feel like that… They’re overwhelmed by the amount of steps that they have to take to get sometimes minimal services which is through proposal, or whatever, to supplement their current services. We don’t have the numbers out here [in remote community]. We don’t have the numbers in terms of not only voice from my level, but numbers community-wise to make them sit up and look at us. (Aboriginal Manager)

From a clinician’s perspective, frustration mounts due to the persistent lack of a coordinated system and, over time, leads to an understandable detached acceptance that nothing is going to change, as the following account indicates:

From the service provider point of view they, some of them, just either they’re just working in that system and it’s been that way for a long time and they just do the best they can knowing that there isn’t really a coordinated system in place. It’s really disjointed and then they just, I think, have become frustrated over the years. (Clinician)
Even in small group settings, such as the focus groups held in Prince Rupert, Terrace, Smithers, and Victoria, frustration bubbled up as exemplified in the following excerpts:

[T]here’s a fear too of people, in general, of letting go of, like professionals letting go of kind of their areas of power and just kind of dropping some of the barriers...I think there’s a perceived threat...that there won’t be enough work for everybody which is absolutely delusional in my mind. (Prince Rupert Focus Group)

I think it’s political process. That frustration needs to move that political agenda forward and make the focus of the day a specific...group...or what have you....’cause if we don’t have that political pressure going at the end of the day, you don’t get it ...the money often seems to follow political agendas. (Terrace Focus Group)

And a very uncomfortable place, a very unhappy place, I think, to be because you cannot please either the masters who give you the money, or the community that you’re actually wanting to serve and to serve well...I’m the sandwich filling. (Terrace Focus Group)

[T]hat’s where I think this system gets in the wrong...the health care professionals start falling back on the rules and regulations and forgetting what they’re about. And, it’s fear that does it. I understand it’s a fear thing. (Smithers Focus Group)

[T]hat’s where I get really frustrated. I hear people talking about government...as if this isn’t human beings that are in there just like us. They’re trying to do their job and somehow we’ve got to get past that and understand what is it that drives them is the same kind of things that drive you—the fear of not doing it right. (Smithers Focus Group)

[M]aybe we don’t take enough responsibility for how our actions are going to demoralize future actions for collaboration...like we maybe give in to our frustrations and quit something, instead of thinking the fact that this project isn’t working out is going to turn people off from partnering again for many months. (Victoria Focus Group)
Reactions by stakeholders in the health system include judging managerial performance, the NHA, the educational system, how priorities are set, the politicians where the buck is seen to actually stop, and government (federal and provincial) replete with their central ideologies.

And people who are...making the policies and...having the decisions, I think they have to really care about these kids. They can’t see them as numbers. They have to see them as their own children. (Parent)

I honestly think that, I don’t know, that’s probably me just being judgmental, but they’ll [politicians] get the care that they want because they’re in those positions, you know. And, their kids will get it first, over average kids. So, if they were, you know, average families suffering through it, or put themselves in those shoes. (Parent)

[T]he upper end or the higher ups put it out there that they care, but they don’t. I’m not fooled by it, ‘cause if they care, they would respect more what’s actually going on....the people in the positions of authority and power, decision-makers, have no clue. Like it’s, we have to dig under the fingernails and take those people and show them real life, but do they care? Not so far. They don’t show it they care. (Parent)

Ultimately, this frustration leads to finger-pointing and blame. People in positions of power and authority, such as politicians, bureaucrats, and administrators typically get blamed, often unfairly, when things don’t seem to be going right from the perspectives of those affected by their decisions. This reaction is especially true when cause and effect are not closely related in time or distance; thus, people have great difficulty in understanding the events and are left to their own devices to figure out what has happened. Sometimes, people have the refreshing realization that they should start to examine their own assumptions about others with whom they are dealing or, perhaps affecting in untold ways. This came to light during one of the focus group sessions:
I think that's another place we maybe need to go, is to examine our own assumptions on the knowledge and abilities and comprehension abilities of people in communities. (Victoria Focus Group)

**Taking Charge**

The emotivity generated by the health system (or the lack of it from the perspective of many stakeholders) unsurprisingly leads to a number of reactions, such as fighting for services, challenging providers, learning to be assertive, taking charge of coordination of services, taking matters into one’s own hands, and going against government(s). This was most evident amongst parents, particularly those who have children with special needs requiring chronic care management, often requiring frequent, extended, and costly trips to tertiary care centres such as BC Children’s Hospital and Sunny Hill Health Centre for Children, which are both in Vancouver, hundreds of kilometers from the North West.

[I’ve had an experience where I refused to go [to BC Children’s Hospital] because I’ve just been down there, you know. (Parent)

I believe that...you’ve got people like me who will find where the best is for [health services]...and go after it until they get it. But, it’s not without cost and it’s not without patience. (Parent)

For clinicians practicing in remote communities, taking charge also means things like going on vacation when you want or need to. This can be very difficult to do given very limited human resources, knowing what the situation is like during an extended absence and, thus, carrying a burden of guilt when away. This is succinctly stated by the following clinician:

Like even when we go on holidays, like you feel guilty ‘cause you know the other person’s alone. (Clinician)

For others, the personal need to take charge is thwarted by fear, fear of doing something that may be perceived by others as wrong even though such action would be well within practice
standards be they in clinical, managerial, or policy arenas. In small communities this can be
accentuated due to the intimacy of the environment and the tendency to know other peoples'
business. Thus, this kind of taking charge may be more related to having a personal degree of
freedom, choice, or flexibility to work within accepted parameters of practice. This is highlighted
below by a manager:

    So, I should be able to, within my own practice, make some decisions about what
    the best approach would be, and not be chastised if I'm meeting basic
    standards...I don't think we have enough flexibility in our roles. (Manager)

Again, as Forester (1999) reinforces, this is an area where practice is leading theory, but
which has not been valued in public decision-making or recognized to any great extent in the
literature. I am, through this study, more cognizant of the important role that such emotions play
in stakeholders' perceptions of, and behaviour in, the health system. This takes us to the third
conceptual category—inclusivity in the health system.

**Inclusivity in the Health System**

**Seeking the Essence of Community**

In an effort to gain an appreciation of the anticipated differing perspectives of
community, participants were asked what the term “community” meant to them. Participants
made multiple references to this concept in a number of the other questions. The range of
conceptions of community is striking. Like systems, this term evokes a broad range of feelings
which are typically not sought, acknowledged, respected, or accounted for in a meaningful way
in typical planning processes. This lack conjures up perceptions of a large boundary and
distinction between North and South, not just in a geographical sense. In the context of attempts
to collaborate with Aboriginal communities, such disparities (perceived and real) effectively
undermine good intentions. Coding these data gave rise to three sub-categories: (a) perceptions
about community, (b) potential for creating a sense of community, and (c) pragmatic issues when addressing community.

**Perceptions about Community**

From an Aboriginal perspective, one of the issues draws attention to the need to better understand the concept of community. This is captured well by an Aboriginal Manager. She reflects on her role in working with, and genuine respect for, communities:

And it’s taken many generations to get to that, the place that we’re at, and that it’s been those people in the communities that are making the changes. And, I’m just one of the people and, that tries to connect things together. And I, so I, I’ve taken that weight off my shoulders knowing that it’s working with everybody, because it’s the communities that know how to make those changes. And, they’re the ones with the wisdom and the insight and the experience, and, so,...I could probably talk for the rest of the interview about that, just that aspect alone, because it’s so big in many of us First Nations people that get into these kinds of positions. (Aboriginal Manager)

Paramount in this discussion is recognition of the importance of community – not only in the sense of geography but, more importantly, in the creation of a sense of community. Despite the rhetoric and intentions by health decision-makers and policy-makers to engage in community participation in genuine and meaningful ways, especially in the most recent round of health reform initiatives in B.C., the evidence is sparse. Hanson & Campbell (1999, p. 246) suggest that the “essential aspects of health reform must include the empowerment of individuals and communities to identify their own problems and needs, and opportunities for citizens to be able to assist in implementing those plans.” As Talen (2000) warns, difficulties around the idea of community need to be addressed, not just ignored to expedite planning. Perceptions of community, while variable, centre more on the essence of community, less on the geographical boundaries that physically contain communities. Communities are seen to be healthy or
unhealthy, or supportive of health or disease as expressed by this policy-maker and manager, respectfully:

I mean the whole system that, I guess, the whole community, needs to understand what makes up a healthy community versus an unhealthy community, and try to bring some of those other players, the business community, other parts of government, local government for sure, and try to engage them into what’s going to make a difference, and involve them in the planning process. (Policy-maker)

The community creates conditions that either support the disease or...are supporting conditions that improve health. (Manager)

**Creating a Sense of Community**

In terms of the potential for creating community and the desire for local input into the planning process, being asked and being heard are critical. People want to work together and in the North communities feel that they have a spirit of co-operation that surpasses that of large urban settings. These sentiments are expressed in the following:

[T]he idea of community is that people actually try and work together. And, I think certainly we see more community spirit in a place like [place in North West] than you do in big cities. (Clinician)

[T]here needs to be a recognition from the province....Get to understand what the communities are, what makes them tick. (Policy-maker)

[T]he communities are asking for input....Communities want to have a say in the health services. (Manager)

Community is not only about location, but it’s also about mindset. It’s about issues of commonality. (Aboriginal Policy-maker)

Communities are different. Different communities have different resources....Different communities have different problems. (Manager)

But, I also know, for instance, a lot of when I’ve been at community events where a practitioner has come, or maybe a senior manager, they’re always blown
away by what they see, and it’s almost a surprise to them, and it really moves them and transforms their practice. And, that’s healthy. Maybe there should be more of that. (Aboriginal Policy-maker)

**Pragmatic Issues**

At a more pragmatic level, the challenges to focus on the real issues has highlighted a number of broad concerns. Examples are: how to work with Aboriginal people, how to focus on children and youth, how to approach the issues, and how to engage families in the process. Including parents and encouraging active participation are critical to raising awareness of the issues and drawing attention to the needs of children and youth in their own communities.

Additionally, as one clinician participant pointed out, there are already significant barriers in place, such as freedom of information and protection of privacy legislation that, while necessarily protective, effectively inhibits in some cases the sharing of information that is key to collaborative planning and service delivery. Finding the appropriate balance between confidentiality, privacy, and collaborative efforts in the best interests of children, youth, and families is a very practical concern. The following thoughts exemplify such concerns:

I think if parents knew more about what’s going on in their community you have a better chance of more people speaking up, and then there would probably [be] a lot more done in our community. (Parent)

I think it’s, somehow we’re missing an ability to get communities to sort of focus around the kids. (Manager)

You know, for one thing, what’s lost, as far as I’m concerned, is the small communities have lost a voice. (Policy-maker)

I don’t think it’s effective planning. I don’t think the rubber hits the road where it needs to. There’s a lot of confusion, not only for parents, but for the health care workers as to who is supposed to do what, to whom, when, and where. It’s very difficult. (Manager)

[T]his issue around dealing with, around the margins, when you have a culture of exclusivity which you do when you have turf ideas, you know, this is my area,
it's not yours, is that we also generate confrontation. We generate a kind of inward-looking that does not necessarily benefit the person who needs the help and, in this case, the child. (Victoria Focus Group)

It is difficult sometimes to comprehend how tortuous it is to facilitate and coordinate necessary services when facing a huge bureaucracy. The following account brings to life some of the issues commonly facing managers in small remote communities:

So, another example that we've got going on now regularly is children have in our community, it's a very damp community, we have problems with otitis media. And, so the doctor will see them regularly many times through the course of the year, and often prescribe antibiotics and we all know what the problems are with that. We, know that we have had pediatricians who sort of recognize the longer term implications of otitis media, what it can do to a child, not only in terms of their educational, intellectual, emotional development, but also their, the long-term hearing implications have said, oh well, this child needs to have an audiology examination. So, we then say all right, we, our nursing station sets up that appointment for the child. But, of course, the service isn't available in the community, so they have to go to Terrace. The way Health Canada has set it up, we are the health authority to send people to Prince Rupert because that's our closest, easily accessed medical centre, but anything beyond that is another health authority. It's Tsimshian health authority that actually would coordinate and pay for the transportation from Rupert to Terrace even though it's an hour and a half away. You know, Terrace is an hour and a half away from Rupert. So, the expectation, though, is set up, because people here are First Nations, that the transportation will be paid for. So, even if you said to a family, oh, Health Canada won't pay for that for the transportation, but you need to take your child, some would and some won't. But, the general thought is if the transportation isn't going to be paid for the service isn't required. I don't need to have my child see an audiologist. Okay, so let's assume that we have a referral. Now, let's assume that the doctor has now made the referral that the child needs to see an audiologist so then we go ahead and set up the appointment. But, then we have to worry about the patient transportation. Health Canada has set up policy that say patient transportation will not be paid for for children to access speech pathology and audiology examinations unless there are one of five different conditions, pre-conditions, that exist. Even if so pre-conditions exist, you have to write to Health
Canada, to Prince George. You have to fax Prince George a benefit exception request to get approval for that medical transportation payment. Now, I recently did that for a child who has neurological hearing loss in one ear, so he’s absolutely deaf in one ear, and he had other issues going on with his quote unquote good ear, and after having been seen by a pediatrician he was referred to Terrace for an audiology examination on his way to see an ENT. Requested the benefit exception. It was denied. I wrote a two-page letter to Health Canada appealing that decision and I, you know, I gave, I had to go through the patient’s chart, pull out the actual physician’s findings, include that in my letter, explain why this child really needed to be able to see an audiologist. I did not get a response, sorry, a letter. I did not get a letter response from Health Canada in Vancouver, but on the fax page that I had sent them, there were seven different notations by seven, well, by different people sending it along their system to say whether or not, well, to ask the question – should we pay for this. And, one of the nurses who was in charge of a benefit area wrote the penultimate note on the fax cover page was, well, if we provide this service now, it may save money in the long-run. Which anyone would be able to understand. And, then it came back to me as an approval and then we were able to send that child out to get the services that were required. So, you know it’s complex. (Manager)

**Wanting to Participate and Act**

While the interview process sought to elicit the extent to which participants were, or could be involved with the health system, none specifically focused on participants’ desire or need to participate. There is a dyadic relationship between feelings about participating as opposed to the reality that makes this possible, or not, as is often indicated by participants. I determined that there are four sub-categories with specific relevance to the local community level: (a) feeling need, (b) creating conditions for awareness, (c) creating conditions for connecting, and (d) exemplifying collaboration.

The concept of wanting to participate highlights a number of sensitive and fragile issues that embody both community and participation. These have been well-described in the literature and elucidate why communities feel misunderstood and challenged in their efforts.
Feeling Need

Feeling need in this context means that this need is meaningful and extends beyond rhetoric, includes multiple stakeholders, and recognizes that there are barriers that stand in the way of these needs being met. Meeting such needs extends beyond the capabilities of any one entity and requires supportive and collaborative partnership arrangements working collectively to meet individual needs. These sentiments are expressed by the following policy-maker, clinician, and managers:

[W]e feel that probably some kind of partnering arrangements with people that are in the local areas is the best. (Policy-maker)

I think only families can decide what’s best for them, and how can we work collectively to support them. And, making and empowering them to make their own decisions about what’s best. (Clinician)

I think that the process, the only process really, that’s going to work is to have enough of the stakeholders engaged together in identifying the priorities because part of the reason that it doesn’t work is that there is always competition for a limited resource base. So, the best process is one that kind of gets past that competing for resources and everybody agreeing on what today’s priorities are going to be, no matter whose turfs that’s on or, you know, what’s going to be best. (Manager)

[A]s a health administrator [in a remote Aboriginal community], I have trouble knowing where to turn and whose responsibility it is, and who should I be pressing for a service for my clients. The clients have very little hope at all….hope of getting through the system. (Manager)

Sometimes, however, there are recognized problems with the politics of local decision-making. It is simply easier to have decisions made elsewhere. While this negates the value of local community involvement, this tactic is used to stop politicking that might derail critical decision-making from occurring. This would have to take place without giving the appearance of manipulating the whole process; however, at times this is seen as necessary despite the inherent
risk. This possibility is reflected in the following account by a manager, who feels that the end justifies the means in some cases:

And sometimes it’s easier if decisions aren’t made locally. Sometimes it’s easier, particularly if they’re not decisions people like, or that they’re not made locally. Or, if they involve, say, the politics within families or of family. There are situations where in a small bowl you have a lot of politicking that goes on that actually stops things from happening. So, if things are imposed, say, from Prince George, then those politics become irrelevant. And, it is a fine balance between informing and involving people and making a decision that is not going to be too politically manipulative. And, those manipulations I’ve heard and seen them happen, particularly in the North West. (Manager)

Creating Conditions for Awareness.

Creating conditions for awareness includes sharing knowledge with each other and across sectors. It involves the identification of barriers that prevent this sharing, and embracing novel opportunities that enhance the ability to help knowledge flow freely. Unfortunately, such knowledge is community-specific with varying capacities for sharing. This speaks to the often overlooked and underestimated characteristic of community heterogeneity, as this policy-maker observes from his first-hand experience in the North:

Unfortunately, this is another thing I’m finding. You have to go community by community ‘cause one community offers one thing and another doesn’t. (Policy-maker)

Creating Conditions for Connecting

Creating conditions for connecting includes linking within and between communities. With respect to Aboriginal cultures, this means having an interest in, and seriously looking at, alternative models of service delivery that respect local traditions. This also means respecting the heterogeneity of Aboriginal peoples throughout the North West. Identification of barriers, tangible and intangible, to creating such linkages is a key component of this process. These conditions are expressed in the following excerpts:
[T]hat's where my passion is—the idea of looking at the determinants of health, and looking at making communities healthy, and empowering people to have a sense of belonging and place and, you know, addressing working collectively. (Clinician)

[T]hat [Aboriginal health services] needs to be linked better with our other health services in each community...I think in terms of community development and community planning. (Manager)

For instance, I had an application for the health services and they would not accept an email copy, so I had to drive it down to Terrace [from a remote Aboriginal community]. It's forty-two below and I didn't pass one or two vehicles, and if something had happened I'd have froze to death. (Aboriginal Policy-maker)

Exemplifying Collaboration

Generally speaking, there is a perception that collaborative planning doesn't happen very often, particularly when more upstream issues such as determinants of health are concerned. This sentiment is expressed as follows:

I think that we've been talking social determinants theory for a long time, but I don't think we've actually implemented it. So, I think that government needs to, all the Ministries need to plan more collaboratively....it has to happen on a level where there has to be a strong community development process. (Aboriginal Policy-maker)

On the other hand, collaboration is currently exemplified by a number of isolated communities throughout the North West. These attest to the success of a collaborative approach. It is important to recognize and build on the strengths of such communities. For example, in one community, there is a long history of collaborative work to address child, youth, and family issues and share this information broadly in the community:

[W]e do have a child and youth family committee that's been running for about 15 years....What we do is we put out help cards which identifies all the major
resources in the community on little cards around town. And, we have a bulletin board where we try to promote at the post office. (Clinician)

Although there are many success stories, what hasn’t worked more generally is an approach to planning for sustainable change. This problem is consistently experienced and is reflected in the sense that what works in one community doesn’t work in another. For example, one community has funding, while another doesn’t. Many factors mitigate against continuity; for example, program-based (programmatic), sporadic funding. Many projects are successful on a one-off basis; however, when the one-time funding ceases, the program dissolves. Thus, there are success stories, but they are not sustainable success stories. They are dependent on one-time programmatic funding, political whim and, often, a sole person. In many cases, if this sole human resource leaves, the entire program folds. Often, long-standing relationships are dissolved and new ones must be established. This kind of stop and start funding, combined with the coming and going of human resources, make it very difficult, often impossible, to plan over the long-term. More systemic funding is required with an inherent longevity, instead of people having to fight to keep their program funding intact. The demise of so many programs is rooted in the institutionalization and fickleness of programmatic funding, not in the failure of the program itself. This problem is expressed below:

The problem is our funding cycles and how we sunset excellent strategies just when they’re gaining power. I think funding is a huge problem and it irritates the hell out of me. Like, I just hate how we just don’t have a consistent way of sustaining what works. (Aboriginal Policy-maker)

**The Common Thread**

**Reflections on My Geographical Journey**

My travels to remote Aboriginal and other communities in the North West during July, 2004 afforded me a wonderful opportunity to reflect on the initial major conceptual categories
and their sub-categories. Figure 3 is a map of the portion of the North West in which I traveled extensively.

**Figure 3. Northern Communities Map.**

Note. This map was researched and produced for the people of Northern BC by Northern Health. Prepared by BCStats, September, 2005. Copyright © 2005 by Northern Health. Reprinted with permission.
Figure 4. A typical stretch of Highway 37 between Kitwanga and Dease Lake (488 km).

Figure 5. Dease Lake Health Centre.
Figure 6. A narrow portion, along the Stikine River, of about 115km of gravel road connecting Dease Lake and Telegraph Creek— a 2 ½ hour drive in summer.

Figure 7. The main intersection near Telegraph Creek. The Health Canada funded (First Nations and Inuit Health Branch) Health Centre (First Aid Post) is just up the hill.
The long and geographically isolated road north from Kitwanga to Dease Lake forcefully demonstrated how much of British Columbia is rural and remote (see Figure 4). Highway 37 traverses Dease Lake northward toward the Alaska Highway in the Yukon Territory. The Dease Lake Health Centre, which also houses the BC Ambulance Service (see Figure 5), serves a large rural and remote geographical area. Westward from Dease Lake, my journey to, and stay in, Telegraph Creek (see Figures 6, 7, 8) was a highlight for me. This community was an important part of the 1800s Gold Rush era as a staging area for pack trains en route to the gold fields.

During this data gathering fieldtrip, I interviewed three Aboriginal participants. I appreciated their availability because, as it turned out, I had arrived during fishing season. There was a growing anxiety that the community might have missed the fish-run in the Stikine River. The Tahltan people were very busy. They had other priorities. This was a likely reason why locating a parent to interview never materialized, and why a clinical decision-maker was unavailable at the last minute. I came to appreciate first-hand the remoteness of this very small, isolated Aboriginal community, literally at the end of a gravel road. It felt as isolated as it looked on the map. This feeling was accentuated by the fact that the staff of the Stikine RiverSong lodge (see Figure 8) go home at night. I’m sure that I was the only person in the building that night, the original upstairs floor of which creaked with each step. The Stikine River, adjacent to the lodge, contained myriad whirlpools—visible on the surface, independent, and ethereal—carried in the context of the much larger and fast flowing river. I would recall this image later in the context of CAS.

Two days later, I was aboard the Tsimshian Storm (see Figure 9), and reflecting on my earlier sojourn in Telegraph Creek. It struck me how, unless one physically travels here like the local people, it is hardly possible to take in the vast geographic distances and the omnipresent sense of isolation. Even though my brief journey here was long and costly in a number of
respects, it was well worth the first-hand experience. Hopefully, I was able to achieve a little more engagement and credibility with the local people by my presence, rather than just conducting another telephone interview—yet another outsider, for yet another research project that they would never hear about. Fortunately, the ferry schedule allowed me to travel to Hartley Bay\(^{27}\) (see Figure 10) by water, and out by air (see Figures 11 and 12), allowing me to experience and enjoy both perspectives. While a new, and hopefully not just a one-time experience for me, I can genuinely appreciate this as a way of life for the local residents.

As we ferried south, the ocean tide was out exposing many tiny islands in the Inside Passage with their marker buoys tilted lifelessly until the tide returned. I reflected on my lack of real appreciation for the cyclic, global tidal force of nature and it’s silent, almost invisible, yet very powerful local impact, day-in, day-out. This observation, while fleeting, reinforced for me the utility of the metaphor of complex, adaptive systems to help understand how we could learn from the commonplace of nature and those closest to it. “The greatest concealment is by the commonplace” (source & date unknown).

At one point during my three and one-half hour journey by water, I also reflected on the concept of local community and the conditions that create it including, for example, life, sustainability, place, connectivity, and localness. I wondered whether people in such communities, especially because of their local, unique vantage point, held answers to success in community and connecting to life in ways that others, especially those in urban settings, fail to see or appreciate.

From a sea-level perspective, the Inside Passage is not a static, open, and unencumbered water passage as it appears in a small-scale travel map. This raises the importance of geographic

\(^{27}\) While most people have barely heard of Hartley Bay, this community was at the centre of attention when the BC Ferry, Queen of the North, ran aground and sank near Hartley Bay in March, 2006. This tiny community rallied in the middle of the night and assisted in the rescue of dozens of passengers and crew.
scale. "The map is not the territory" (source unknown) as another maxim reinforces. Similarly, a recurring refrain in the North laments that, to the extent that politicians and those in positions of power and control fail to experience the problems, they just don't "get it." Such perspectives reinforce the primacy of planning for health services close to the local level of relevance, not after the plans are made, and not after the funds are allocated, as typically occurs.

Later, I reflected on the concept that localness is embedded in the major conceptual categories discussed earlier. Or, perhaps more accurately characterized, it is the strength of relationships between local realities and the broader health system that is paramount. At this stage of the study, in addition to open-coding of several initial interviews, I had undertaken early theoretical coding by connecting selective codes in the early interview set. This is what led to the preliminary categories and their sub-categories discussed earlier. I studied the 1014 selective codes hoping now to establish a preliminary core conceptual category—perhaps placed-based health services planning. There was a fit, both locally and system-wide, which spanned all four stakeholder groups. I planned to explore this direction in more detail in the next set of interviews during my fieldtrip to the Queen Charlotte Islands. I recognized that there was a dearth of health services research taking a "place-centred theoretical perspective" (Kearns, 1993, p. 141), even though relationships between people, place, and health experience are, in fact, important (Kearns & Joseph, 1993). I also pondered whether such relationships were emerging as a conceptual category in relation to health services planning. Connecting these concepts to form a coherent framework based on empirical data generated through constructivist grounded theory now presented a challenge.
Figure 8. The *Stikine RiverSong* lodge in Telegraph Creek.

Originally, this building was a Hudson’s Bay Company Store built in the late 1800s. From Room 3 upstairs, I enjoyed a great view of the Stikine River.

Figure 9. The *Tsimshian Storm* passenger/supply ferry.

I boarded from Prince Rupert to Hartley Bay, taking approximately 3 ½ hours via the Inside Passage.
Figure 10. Hartley Bay.

Hartley Bay is an isolated coastal community of approximately 200 residents (predominantly Gitga’at tribe, Tsimshian Nation). Access is by water or air. An extensive network of boardwalks replace roads—there are essentially no motor vehicles.

Figure 11. The Float Plane.

I traveled on this during my approximately one hour return trip from Hartley Bay to Prince Rupert.
Figure 12. Aerial View of Mountainous Territory and the Picturesque Inside Passage.

Heading North between Hartley Bay and Prince Rupert.

Figure 13. Skidegate Health Centre, Skidegate, Queen Charlotte Islands (Haida Gwaii).

Note the dominant Raven and Eagle—highly symbolic\(^\text{28}\) to the Haida people.

\(^{28}\) In Haida mythology, the Eagle symbolizes power, wisdom, and authority; whereas, the Raven plays a central role as a hero, a trickster, symbolizing supernatural powers. The Haida consists of two social groups (or moieties). See, for example, [http://www.blueravenco.com/mythology2.html](http://www.blueravenco.com/mythology2.html), [http://www.nativeonline.com/animal.htm](http://www.nativeonline.com/animal.htm), and [http://www.civilization.ca/aborig/nwea/nwcam11e.html](http://www.civilization.ca/aborig/nwea/nwcam11e.html)
Exploring Dyadic Relationships

I began to focus on relationships among people, place, and priorities. In this concept, place is central. I explored a number of relationships and ideas centering on these three components, eventually striking upon the idea of de-emphasizing the components and emphasizing the relationships generated among them. A number of preliminary dyadic relationships emerged, some of which spanned all three components. These are shown in Table 5.

<table>
<thead>
<tr>
<th>CONTEXT</th>
<th>RELATIONSHIPS</th>
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<tr>
<td><strong>PEOPLE</strong></td>
<td>local community – system</td>
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<td></td>
<td>knowledge – lack of knowledge</td>
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<td></td>
<td>powerful – powerless</td>
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<td>controlled – controlling</td>
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<td>trust – fear</td>
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<td>single perspective – multiple perspectives</td>
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<td><strong>PLACE</strong></td>
<td>local community – system</td>
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<td>rural – urban</td>
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<td>practice-based – academic</td>
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<tr>
<td><strong>IDENTIFIED PRIORITIES</strong></td>
<td>local community – system</td>
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<td>provincial – federal</td>
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<td></td>
<td>Aboriginal – non-Aboriginal</td>
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<td>health sector – non-health sectors</td>
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<td></td>
<td>invisible – visible</td>
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<td>potential (hope) – practical (reality)</td>
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Table 5. Dyadic Relationships
Relationships appeared to be paramount. In this context, and consistent with the basic tenets of CAS, a sense of community, place-based health care geography, and knowledge translation build on the notion that “relationships are primary” Capra (1996, p. 37). He, like Bohm (1980), advances the need to shift our thinking from parts to the whole, and from objects to relationships. From this arises the notion of “the living world as a network of relationships” (Capra, 1996, p. 37), reinforcing a pattern of dynamic processes at multiple levels. Volk (1995) refers to metapatterns, such as borders, binaries, and layers all of which are abundant in natural and man-made, socially-constructed systems such as the health system. Volk (1995, p. 59) describes the border metapattern as a “synergy of separation and connection”, and a border as being both a wall and bridge. Further data analysis sparked my thoughts on how the earlier concept of place could be incorporated.

The need for collaboration based on interdependency reinforces the concept of place, for example, “to describe and understand the relations between overarching structures that influence our lives...and our own ability to exercise agency in our everyday lives” (Cresswell, 2004, p. 35). This dynamic is at work continuously, involving multiple stakeholders in the health system on a day-to-day basis. This suggests a need to identify and understand these often very different perspectives and the varied epistemologies that bear upon these perspectives. Perhaps this treads clumsily on the “common ground” referenced earlier. I thought of this more as uncommon places, but places that must first be made common in order to fully appreciate any differences and to satisfactorily resolve them. This represents a paradox which, in Bohm’s (1996) terms, must be first revealed in order to be managed. For example, the BC health system reform initiatives outlined earlier have effectively decentralized a number of functions and responsibilities to the five geographic HAs, which in turn have decentralized a number of responsibilities to their respective HSDAs. In the context of dyadic relationships, this reinforces what Chambers (1997, p. 146-147) describes as “reversals and reality” including shifting from:
1. “closed to open” (shifting from dominant outsider professional knowledge and values to those of the local people);

2. “measuring to comparing” (de-emphasizing the preoccupation on absolute measurements and reinforcing the utility of comparison, reflection, and judgement);

3. “individual to group” (gaining advantages of group knowledge);

4. “verbal to visual” (making greater use of visual analyses such as mapping in order to promote group relationships and processes);

5. “higher to lower” (to bring outside professionals and inside locals to the same level of participation, often physically, and to help equalize power differentials);

6. “reserve and frustration to rapport and fun” (to alleviate suspicion and bolster confidence of the local people, which can often lead to having fun during the process).

In the context of relationships in the health system this raises the concept of “praxis of place” (Casey, 2003, p. 2247), as introduced in Chapter Two. I pondered whether this could be expanded to the level of a recursive praxis between places. Such recursiveness elevates our level of understanding to more deeply appreciate and understand the issues from multiple perspectives. This is similar to “temporal epistemology” (Osberg & Biesta, 2003), also raised in Chapter Two. This knowing is concerned not with the world as it is, but rather, deliberately intervenes to create novel conditions with which to recursively interact with the real world in increasingly complex ways.

At this point, I contemplated whether paradox was the emerging core conceptual category. Bohm (1996) distinguishes between problem and paradox. The former is “a doubtful or difficult matter requiring a solution” (Concise Oxford Dictionary, 1995); whereas, the latter is “a seemingly absurd or contradictory statement, even if actually well-founded.” This is an important
distinction. Bohm (1996) cautions that we need to see the difference between their dyadic relationship and respond appropriately. For example, human relationships do not present problems to be solved; they present paradoxes to be dissolved. Bohm (1996, p. 66) proposes the concept of “root paradox”, wherein “the activity [emphasis in original] of...thought is controlled by the very thing that it appears to be trying to control.” He proposes that “the mind, through centuries of conditioning, tends, for the most part, to be caught in paradoxes, and to mistake the resulting difficulties for problems” (Bohm, 1996, p. 68). I struggled with the idea of “root paradox” as the storyline and whether this, too, centred around place. I mused whether the root paradox was between the individual and the system and, in terms of CAS, whether the paradox was between order (stability) and chaos (instability).

Place became even more relevant as I reflected on Aboriginal/non-Aboriginal perspectives that I had come to appreciate during my interviews to date. In particular, this was because of the meaning that Aboriginal people attribute to place—meaning that non-Aboriginals perhaps have difficulty understanding. During the course of my interviews with Aboriginal participants, I consistently heard about the importance of their long-standing connection with the land and how significant this relationship is to their health and well-being. I began to better appreciate this deeper connection as the study progressed and I visited several rural and remote Aboriginal communities in the North West. I gained some insight into the meaning of place because of this respect for, and reliance upon, the land and the sustenance that it offers to those who value this connection. Land, in this sense, includes the waters—inland rivers, lakes, and the ocean.

Around this time, I serendipitously came across a paper by Wheatley that addresses community and paradox. It discusses the idea of boundaries as “the place of meeting and exchange....the place where new relationships take form, an important place of exchange and
growth.” (Wheatley, n.d., p. 2). To me, this reinforced and brought cohesion to the notions of place, boundaries, paradox, relationships, and community. I struggled with the emerging concept, asking: does place = boundary?

I tried to conceptualize the relationships between community, stakeholder groups, and individuals. I centred on place and how this might look in the overall context of the health system. The intersections of these relationships form boundaries which create paradoxes. I surmised whether the root paradox was the intersection of place with the health system. I wondered whether this boundary dynamic caused patterns of thinking and behaviour that lead to the anger, frustration, blame, helplessness, and need for control and power so evident amongst participants. It was at this point that I began to query whether the concept of boundaries was emerging as the core category. The emphasis seemed to be less on the boundary itself, and more on the interactions between boundaries. On the other hand, the lack of boundaries seemed more to the point; that is, the breaking down of walls, barriers, and boundaries instead of honoring them. I was drawn to more ecological terms, such as edge, which I was already accustomed to understanding such as in complex, adaptive systems theory—the edge of chaos. Was edge dynamics emerging as the core conceptual category?

I then began to explore the ecological boundary literature. I was drawn to an ecological framework because of its systems and its organic nature. This was consistent with complex adaptive systems theory and would offer insights in terms of the living, dynamic, and changing nature of human and social interactions. I conceptualized boundaries as places or intersections at different levels, between different stakeholder groups, at different times (temporality), and at different levels of complexity. Because I was actively in the process of core category coding, I was trusting that the characteristics/dimensions would emerge from the data. If I could identify some of the dimensions, my plan was to share these with the focus groups and ask them, as co-
researchers to further develop this idea. This approach was true to a participatory research approach, consistent with constructivist grounded theory, and would help me to expand this concept.

At this point, I explored some of the concepts in the relatively sparse boundary literature to ascertain if there was a way to expand upon the categories and properties. This helped to reinforce that boundary dynamics was an emergent core conceptual category.

**Introducing the Concept of Boundaries**

The constructivist grounded theory approach taken in this study supports this non-ordering of boundaries and non-predefining of categories. I heeded the caution in grounded theory that a review of the literature (in this case boundary and boundary object literature) should occur late in the study. This obviates the tendency to see data directed more by the literature than emergence, thus forcing the data in preconceived ways. Therefore, later in the study I did seek out and review relevant boundary and boundary object literature in organizational science and, to a lesser extent, ecology and information science. I felt this was appropriate because I had no prior knowledge of, nor real appreciation for, this body of knowledge. Still, I needed to be careful that this did not inadvertently distract me from letting the findings emerge, as opposed to being forced, from the data.

In the next chapter, I develop this concept of boundaries, introduce the closely related concept of boundary objects and expand upon these. I then apply these concepts in the context of the community-based approach that I used to address child and youth health services in the North West.
CHAPTER FIVE: FINDINGS II –
Boundaries and Boundary Objects

[B]oundaries...are the place where new relationships take form, an important place of exchange and growth as an individual chooses to respond to another. (Wheatley, 1998)

The creation and management of boundary objects is a key process in developing and maintaining coherence across intersecting social worlds, (Star & Griesemer, 1989)

Introduction

In this chapter, I introduce and develop the concepts of boundaries and boundary objects. The basic tenets of knowledge-exchange and linkage among multiple stakeholders, including researchers and decision-makers29, form a necessary part of the development of this approach. I use empirical data from this study to develop a theoretical framework for the concept of boundaries (in particular, knowledge boundaries) and boundary objects, and demonstrate how this works in a participatory planning process for child and youth health services in North West BC. It is in this context of knowledge boundaries that CBPR functions as a boundary object to strengthen the local relevance of research, establish continuity with local practice, and influence broader health policy.

An important issue facing researchers engaged in CBPR is how the findings generated through this approach can be applied in the process of health services planning. This issue necessarily focuses on the elusive interfaces between health services research, health services delivery, and health policy. The research – practice boundary interface is historically well-acknowledged by community participants in this study. As Ahmed, Beck, Maurana, & Newton (2004, p. 142) urge, “[c]ommunities and academic institutions must desire and learn how to work

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29 Use of the term decision-maker in this study refers to participants in all four stakeholder groups – public, clinicians, managers, and policy-makers.
together.” This sentiment is expressed particularly well from the perspective of an Aboriginal manager:

[W]e’ve all just been researched to death and with no results coming out of that research, and we’re just now at that point where we’re going, okay, you know, let’s do something. Now, everyone’s feeling that, I think. (Aboriginal Manager)

To achieve this, attention must be focused on the interfaces, or what I shall characterize as boundaries, between multiple stakeholders in the health system. This is not just a matter of addressing the cliché “breaking down the barriers”. Consistent with KT, a much more sophisticated exploration and analysis is necessary. As Hernes & Paulsen (2003, p. 3) assert, “[w]hat emerges is a need for boundaries to be rediscovered and respecified.” Implementing research means discovering the boundaries that really matter in the intersecting worlds of multiple stakeholders and the boundary objects that provide coherence in the realities of people who work in, and are served by, the health system.

**Boundaries**

Boundaries are conceptualized and categorized in many ways including, for example: physical, social, mental (Hernes, 2003, 2004); physical, temporal, psychological (Diamond, Allcorn, & Stein, 2004); efficiency, power, competence, and identity (Santos & Eisenhardt, 2005); physical, psychological, and social (Bruhn, Levine, & Levine, 1993); closed, compact, porous, and open (Bruhn, Levine, & Levine, 1993); metaphors of containment, membranes, sociocultural construction, and of diminished relevance (Marshall, 2003); objective and symbolic (Heracleous, 2004). From an ecological perspective, boundaries can be classified by virtue of origin and maintenance, structure, function, and dynamics (Strayer, Power, Fagan, Pickett, & Belnap, 2003). As dyadic metapatterns, boundaries can be broadly classified as walls (separator) and bridges (connectors) (Volk, 1995).
Contrary to what management and organizational literature popularized in the 1990s (e.g., Gilmore, Hirschhorn, & O’Connor, 1994; Hirschhorn & Gilmore, 1992), the suggestion that boundaries in organizations are disappearing is seemingly a myth. This suggests a contrast to other jurisdictions in the global arena, such as international trade agreements, communications, and information technology that are working towards eliminating traditional boundaries. As Hernes & Paulsen (2003) suggest:

> Just because boundaries may be less visible in the modern organization, does not make them less important. In fact, it makes them even more important as topics of investigation....What we are witnessing is not an effacement of boundaries, but a proliferation. (p. 4)

Despite decades of interest in boundary phenomena in various disciplines, the study of boundaries in organizations and management has received surprisingly little attention to date (Heracleous, 2004; Hernes & Paulsen, 2003). Even then, the study of boundaries has typically been driven more by "armchair theorizing" than reality (Heracleous, 2004, p. 97; Hernes & Paulsen, 2003). As Hernes & Paulsen (2003) purport, the task is essentially:

> discovering boundaries that matter in relation to the phenomena that we select, and then adopting the perspective that stands the best chance of informing us about the phenomena in question....[I]f we look closely enough, we can see and read boundaries in places where they traditionally have not been assumed to exist. And by consequence they show how we can take steps to unravel some of the mysteries of contemporary organization. (pp. 10-11)

While "boundaries are elusive phenomena", they are places where "individuals may be considered to be almost perpetually in 'liminal' situations, where they both move between boundaries and carry the boundaries with them" (Hernes & Paulsen, 2003, p. 6). Boundaries are
personal, as suggested by Epstein (1989, p. 576): “people become invested in boundaries because their sense of self, their security and their dignity, all are tied to particular boundary distinctions, and these personal investments are bound up with authority and hierarchy.” Boundaries, like the concept of place, are deeply significant and imbued with personal meaning. As individuals’ boundaries intersect with the boundaries of others, their individual investment is subject to disruption, depending on the extent to which the personal investments of others align, or don’t, with their own. This is particularly significant in terms of authority and hierarchy. If one has power, control, and authority the boundary issue may not be so significant to that stakeholder. If one doesn’t, however, this is a really significant boundary issue, around which many personal investments may become revealed and put at risk. Achieving meaning and coherence across intersecting social worlds is a formidable task, far greater than simply having common knowledge or interests. One way to accomplish this is through boundary objects.

**Boundary Objects**

The concept of boundary objects is even less well understood than boundaries and needs rediscovery and respecification. Boundary objects were first introduced by Star (1989) in the context of how to successfully attend to distributed and heterogeneous problems. This arose from two case studies: (a) the interactions of a community of 19th century neurophysiologists in England (including researchers, hospital administrators, attendants, animals, journalists, and patients); and (b) the interactions of those involved in the development of a zoological museum (1900 – 1940) at Berkeley, California (including biologists, collectors, university administrators, animals, trappers, farmers, and conservationists). Star & Greisemer (1989) define boundary objects as:
those scientific objects which both inhabit several intersecting social worlds...and [emphasis in original] satisfy the informational requirements of each of them....They have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation. (p. 393)

The concepts of boundaries and boundary objects have been recently expanded and applied in a number of academic fields and disciplines. These are outlined in a later section. There are very few examples in health services, such as Bruhn, Levine, & Levine (1993), Kerosuo (2003), and Rodriguez, Langley, Beland, & Denis (2003).

A precise definition of boundary objects is elusive; they can be variously described as things, concepts, methods, entities, and models. They exhibit a number of dyadic properties, such as abstract and real, specific and general, conventionalized and customized, and flexible and focused (Garrety & Badham, 1999; Henderson, 1991; Star & Griesemer, 1989). Later sections in this chapter address in more detail the concept and properties of boundary objects and will be illuminated with empirical data from this study. In particular, this includes how stakeholder knowledge is addressed both in terms of boundaries and boundary objects.

**Boundaries and Boundary Objects in Other Industries**

Expanding upon the earlier work of Star and Greisemer, the concept of boundary objects has been studied, adapted, and applied in a number of diverse and largely overlapping areas including: information technology (Levina & Vaast, 2004); design and engineering (Boland & Tenkasi, 1995; Henderson, 1991); technology development, new product development and manufacturing (Carlile, 2002, 2004a, Carlile & Lucas, 2003; Garrety & Badham, 1999; Kartsten, Lyytinen, Hurskainen, & Koskelainen, 2001); environmental policy and science (Guston, 2001); and, organizational management (Brown & Duguid, 1998; Wenger, 1998).
Carlile (2002, 2004a, 2004b) and Carlile & Lucas (2003) have taken an empirical approach to the study of boundaries and boundary objects. They have developed and applied an integrative framework for managing knowledge across boundaries largely in the context of settings associated with innovation. This includes new product development in the automobile industry, and technology development and competitive advantage in the aerospace industry. Carlile’s Integrated/3-T framework for managing knowledge across boundaries will now be introduced and discussed. See Figure 14.

**Figure 14. Carlile Integrated/3-T Framework.**

Carlile’s Integrative Framework—A Description

Carlile (2002, 2004a) builds an integrative framework on the premise that there are knowledge boundaries between specialized domains (Brown & Duguid, 2001), and that knowledge use in organizations—for example, new product development—is problematic. Three progressively complex boundaries are described: transfer, translation, and transformation. Organizational actors share and assess each other’s common and domain-specific knowledge. Common knowledge, as a boundary object, is used to communicate across domains; however, when novelty exists two important issues arise: “the capacity of the common knowledge to represent the differences and dependencies now of consequence and the ability of the actors [emphases in original] involved to use it” (Carlile, 2004a, p. 557). This also raises the problem of “path dependency” which describes a more powerful actor’s reuse of common knowledge in a way that constrains the ability of others to deal with novelty in the situation. Carlile builds on three levels of increasing complexity in communications: syntactic, semantic, and pragmatic (Shannon & Weaver, 1949, as cited in Carlile, 2004a, p. 557). These levels are important in terms of understanding what transpires at knowledge boundaries, and in understanding the role and characteristics of boundary objects. These knowledge boundaries and boundary objects are summarized below, based on work by Carlile (2002, 2004a). For streamlining purposes, Carlile (2002) adapts the four categories of boundary objects (repositories; standardized forms/methods; objects/models; and, maps of boundaries) developed by Star (1989). He places them into three categories to address similarities between objects/models and maps, as follows: (a) syntactic—repositories, (b) semantic—standardized forms and methods, and (c) pragmatic—objects, models, and maps.
**Syntactic Boundary and Boundary Objects**

At the syntactic (information-processing) boundary level, knowledge simply moves (is transferred) between a sender and receiver, relying predominantly on a common lexicon or syntax, such as a computer programming language. Ideally this knowledge is transferred accurately, and this may work reasonably well in environments with stable conditions; however, when novelty (change) arises it does not work well. This may be due to differences in, and dependence upon, multiple actors’ knowledge at a boundary. Actors’ failures to recognize mismatches caused by this changing context can lead to an underestimation of the efforts needed to address changes in the previously stable conditions. Thus, the effectiveness of this basic level of knowledge transfer at actors’ boundaries is limited.

The characteristics of boundary objects appropriate to this boundary level are, fundamentally, shared language or syntax. This is also requisite in any subsequent boundary level activity. Typical boundary objects at this level are repositories, such as libraries and databases, which aid actors in representing knowledge at the boundary interfaces.

**Semantic Boundary and Boundary Objects**

The next level is the semantic (interpretive or translation) boundary where increasing novelty causes actors’ knowledge differences and knowledge inter-dependencies to become unclear, resulting in interpretive differences and communication problems. Such discrepancies need to be resolved, and this is accomplished through the development of common meaning. Boundary objects at semantic boundaries provide a means for actors to describe their certainties and uncertainties in order to address and learn from the problems they are facing. The concreteness of the boundary objects is predicated upon the nature of the problem, for example, whether it is more processual or structural in nature. Typical boundary objects at this level include standardized forms and methods, such as functional specifications in automobile
manufacturing. Thus, such objects are characterized by representing and learning at the boundary interfaces.

**Pragmatic Boundary and Boundary Objects**

The third and final level identified in the Carlile framework is the pragmatic (transformation or political) boundary which arises when ever-increasing novelty results in the need for actors to resolve their different and conflicting interests to create common interests. This boundary level recognizes that “knowledge is invested in practice” (Carlile, 2004a, p. 559). Boundary objects important to the pragmatic level help actors to apply their respective knowledge toward transforming old knowledge in use at the boundary. In new product development, typical boundary objects at the pragmatic level include, for example, computer assisted design models, and computational fluid dynamic tools. Typically, these objects are models and maps, characterized by representing, learning, and transforming at the boundary interface. I turn now to a brief illustration of how a tangible boundary object has changed dramatically over time. While this example comes from a sector very different than health, there are generic lessons worth considering.

**Learning from the Clay Model**

One of the lessons learned from the empirical approach taken in the automobile manufacturing industry is the likelihood of mismatches between knowledge and the users of knowledge (Carlile, 2004). This mismatch is expressed in terms of how the clay model of the automobile during design stages remained the dominant boundary object in the 1960s and well into the 1990s despite growing pressures on production time and quality. Prevailing organizational culture also fostered a resistance to change. The reason for this is attributable to the dominance of the engineering disciplines responsible for vehicle styling and that of marketing. However, this dominance was eventually superceded by safety issues. A three-
dimensional dynamic modeling technique facilitated the growing need for collaborative engineering and the static clay model became outmoded. For the purposes of this illustration, I am emphasizing not the clay model itself, but the challenges around the collaborative efforts that are required to innovate in complex environments. An automobile is obviously a lot different than health services. Thus, this focus is not on the product, but the need for different stakeholders to collaborate, resolve different interests, and apply specialized knowledge in the midst of changing conditions.

This scenario provides a number of potential lessons for child and youth health services planning. First, is the issue of knowledge about child and youth health services and who uses such knowledge. Historically, this knowledge has been in the heads, and its use in the hands, of the professionals, experts, politicians, and bureaucrats with traditionally centralized power, authority, and control. Only recently has the move to decentralize, devolve, regionalize, and share responsibility occurred. Even then, considerable central control is still in effect, for example: fiscal resource accessibility; performance agreement content and reporting; operating and capital budget approval processes; labour relations and negotiation; physician remuneration; pharmaceuticals administration; ambulance services; and highly specialized services. Thus, in shifting away from centralized control by a few, there has also been a significant shift in the dominant knowledge required to effect such changes. Similarly, the historical understanding of the role of hospitals and doctors in the context of Canadian Medicare is now giving way to, for example, new models of service delivery, new roles for privatization, primary health-care reform, inter-organizational service delivery networks, public-private partnerships, and virtual technologies. Relatively speaking, these are much more dynamic and responsive to the needs of the public than the traditional roles of institutions and providers of care.
Second, is the mind-set that is often still attached to the “clay model” of planning health services. In terms of planning, the clay model is still dominant because some of the most powerful stakeholders are still tied to it, perhaps unconsciously. This is demonstrated by makers of policy and managerial decisions who continue to exercise this power, control, and authority simply because they can. This phenomenon, known as “path dependency”, occurs when powerful actors reuse common knowledge in such a way that it inhibits others from addressing the novelty they face (Carlile, 2004, p. 557). When this takes place in a top-down manner with little or no collaboration with those most affected by the process, the results can be very limited in scope and limiting in effectiveness. Examples of such outmoded limitations could include: regulations, standards, business plans, population-based funding formulas, operational reviews, and cost-benefit analyses. Many examples emerged from the data and will be discussed later in this chapter in the context of boundary objects.

Third, while safety is a growing concern, as it is in the automobile and aerospace industries, financial sustainability of the health system appears to be garnering even more concern. Financial sustainability is often achieved at the expense of service cutbacks.

Fourth, is the relatively slow way the health “industry” characteristically approaches these issues. This revolves around a number of factors, such as: politics, labour relations, legislation, and multiple legislative, professional, and geographical jurisdictions. Health services research has not been well coordinated or applied systematically to address these systemic issues, although this is changing in keeping with the mandates of several research funding agencies. While health services research is being conducted, the awareness-building and general uptake of the results of the research has been mostly lacking for reasons outlined in the discussion of KT in Chapter Two. What ought to be common knowledge is, in fact, uncommon. Such shortcomings point to a need to consider a new, more pertinent framework for planning child and youth health
services, one that acknowledges, respects, and addresses knowledge boundary mismatches, such as those outlined earlier.

**Knowledge Boundaries in Health Services Research and Delivery**

The investment in boundaries is pronounced when addressing knowledge and how knowledge is managed by stakeholders within and across a number of domains—individuals, families, organizations, communities, and populations. These domains align with those generally recognized in health services research (Lohr & Steinwachs, 2002). I posit that such an investment in boundaries and the process of knowledge exchange (boundary objects) at multiple stakeholder interfaces (knowledge boundaries) are key to complex health services planning and research. However, this area has enjoyed little exploration to date. “The aim of health services research is to produce knowledge that may be applied by policy-makers, practitioners, programme planners and other decision-makers in order to improve the public’s health.” (Goering, Butterill, Jacobson, & Sturtevant, 2003, p. S2:14). With this aim comes “the complexities [emphasis added] of linkage and exchange relationships” (Goering et al., 2003). While knowledge boundaries had little attention historically, these relationship complexities were the subject of knowledge utilization for decades. For example, Caplan (1979, p. 459) originally characterized the “Two-Communities Theory” in the sense that “social scientists and policy makers live in separate worlds with different and often conflicting values, different reward systems, and different languages.” Further, Caplan showed that:

> [t]he connection [emphasis added] between knowledge producers and users has to be thought out carefully if efforts to improve utilization based on the Two-Communities theory are to succeed. To couple existing knowledge and the production of new knowledge to user needs requires collaborative arrangements [emphasis added] which will be congruent with the nature of the
utilization problem and the existing system of inquiry used to acquire and process information. (p. 468)

While this metaphor has been central to many studies on knowledge utilization in social science, there has been an historical “lack of a comprehensive theoretical framework addressing multiple levels of reality.” (Oh, 1997). More recently, other scholars, such as Lavis, Ross, Hurley, Hohenadel, Stoddart, Woodward, et al., (2002, p. 146) have recognized the issues posed by the “two-communities” characterization. They promote the need for increased interactions between researchers and potential users because such activities are requisite to “the ‘real’ work of research, not a superfluous add-on.” This is supported by a recent systematic review of the literature that “identified such interactions as the only factor that has consistently been shown to influence the uptake of research knowledge by health system managers and public policymakers” (Innaver, Vist, Trommald, & Oxman, 2002, as cited in Ross, Lavis, Rodriguez, Woodside, & Denis, 2003, p. S2:26). Most important, is the realization by these authors (Ross, et al., 2003):

Perhaps we need to re-think the linear continuum we have (sometimes implicitly) assumed between scientific rigour on one end and practical know-how at the other end. Rather than threatening the science, we may be on the threshold of enriching it with new types of knowledge production processes. (p. S2:33)

Similarly, Gibson (2003, p. 29) argues against solitary use of the two-communities construct to change the research-policy relationship. Rather, “[t]he way [emphasis added] we think about the problem of the relationship [emphasis added] between research and policy has a major impact on the way we think about solutions to the problem.”

In addition to the attention to knowledge production, is a call to re-conceptualize what is meant by knowledge itself (Fahey & Prusak, 1998, p. 226). This highlights the need to change the dominant conception of knowledge as a “stock” to knowledge as a “flow”. As these authors
point out, this distinction is critical to how we think about knowledge. For example, as a stock, it is a thing that can be captured, stored, and transmitted (such as in a library or electronic database). As a flow, it is created by, and inseparable from, individuals and is in constant flux and change (as in a dialogue). Wheatley (1999) places failure of communication in organizations squarely on our tendency to treat information as a stable thing at the expense of the other dimensions such as its dynamic, unpredictable, and changing nature. This is an important distinction and reinforces the historical tendency to emphasize “knowledge as stock…reinforc[ing] organizational tendencies to manage and massage ever more complex and interconnected databases and to construct even more elaborate information structures” (Fahey & Prusak, 1998, p. 267). Finally, they make the critical point that knowledge creates a dynamic, shared context: “In the absence of shared context, individuals’ differing perspectives, beliefs, assumptions, and view of the future are most likely to collide and thus immobilize decision making.” (Fahey & Prusak, p. 268).

It is this need for a shared context that is critical to the concept of knowledge boundaries and boundary objects. It is also critical to our understanding of why creating the conditions for enabling differing worldviews to be freely expressed and honoured is so important. Without this shared context, the local perspective is at risk of being left out, contradicted, or negated in the context of the larger and more powerful system and prevailing hegemony.

**Honouring Local People and Knowledge**

The notion of local is paramount and intimately connected with knowledge and practice. Scholars in action research (AR), such as Greenwood & Levin (1998, p. 110), emphasize the importance of involving local people as essential partners, recognizing that “local knowledge systems are complex, differentiated, and dynamic.” They assert that:
All human beings have detailed, complex, and valuable knowledge about their lives, environments, and goals. AR centers on an encounter between the worlds of practical reasoning and the worlds of scientifically constructed knowledge. AR processes bridge these worlds by integrating practitioners and professionals in the same knowledge generation process. (p. 109-110)

This study confirms that research and service delivery can enjoy far greater congruence and interaction at the local community level than thought possible. From the perspectives of participants in the North West, their local realities are neither appreciated nor understood. These sentiments were illustrated in Chapter Four. This is a widespread problem in rural settings.

To repeat a key point, Chambers (1997) suggests that the realities of life and conditions are embodied in five characteristics—local, complex, diverse, dynamic, and unpredictable (lcsddu). He purports that professionals in positions of power are out of touch with reality in three main ways: professionalism, distance, and power. This contributes to the historical and pervasive wrong-headedness of our typical approach to dealing with the reality of local issues from professional, distant, and power-laden central places, such as academe. In the context of health services research, this observation is supported by researchers such as Anderson, Cosby, Swan, Moore, & Broekhoven (1999, p. 1012). In the context of knowledge translation, they critically observe “the perceived juxtaposition between the benefits arising from using research vs. the benefits from doing research [emphases in original]. This may ultimately be one of the most important barriers to research transfer from academic institutions to community agencies.” Thus, it is important to address this apparent juxtaposition between doing and using research. This can be approached by recognizing the concept of knowledge boundaries between academe and community, and how boundary objects can be engaged to facilitate multiple stakeholders’ understandings of, and bring coherence to, these complex intersecting social worlds.
Towards a Conceptual Model of Knowledge Boundaries and Boundary Objects

In Chapter Two, I discussed the importance of community based participatory research. Here, I propose linking this research approach to the concepts of boundaries, boundary objects, knowledge, knowledge translation, and localness. The balance of this chapter takes a journey into liminality. It explores the concept of knowledge boundaries and boundary objects in the context of planning child and youth health services in North West BC using a CBPR approach. I discuss the findings which emerged using the constructivist grounded theory method for qualitative data analysis in this study, as amplified in Chapter Three. I then introduce a conceptual model developed in non-health areas—new product development in the automobile and aerospace industries.

Knowledge Boundaries

The concept of knowledge boundaries is perhaps most developed in the bodies of literature of information sciences and of organizational science and management. Despite the implied urgency and complexity of boundary management in the health care field (Rodriguez, Langley, Beland, & Denis, 2003), the concept is minimally developed in the health services research and health services delivery literature and less so in practice (Bruhn, Levine, & Levine, 1993; Kerosuo, 2003; Rodriguez, Langley, Beland & Denis, 2003). Brown & Duguid (1998, p. 101) refer to the prevalence of the “knowledge-based boundaries” of academe that isolate disciplines and prevent the interchange of knowledge for cross-disciplinary research. Again, Brown & Duguid (1998; 2001, p. 199), while not specifically using the term knowledge boundary, describe the concept in terms of: “sticky” knowledge (keeping and moving knowledge within organizations) and “leaky” knowledge (the undesirable outward flow of knowledge, particularly across organizational boundaries to competitors). By way of a knowledge boundary
example introduced in an earlier section of his work, Carlile (2002) characterizes knowledge boundaries as problem-solving and knowledge creation across four primary functions in the automobile industry: sales/marketing, design engineering, manufacturing engineering, and production. Actors in this industry setting have and use their own domain-specific knowledge, but sharing this knowledge across specialized domains (i.e., knowledge boundaries) is often impeded (Carlile, 2002, 2004b).

For the purposes of this dissertation, I suggest that stakeholders in health services also use domain-specific knowledge, which, in the health system, encompasses several domains. I limit these to four stakeholder groups as discussed earlier. Similarly, the sharing of knowledge across domains (specialized and others) is often difficult, even impeded, for reasons discussed in Chapters One and Two.

**Classifying Knowledge Boundaries in Child and Youth Health Services**

During qualitative data analysis, I discovered a number of boundaries in the health system. In a separate analysis, I specifically searched for boundaries in the context of planning for child and youth health services. As Hernes (2003, p. 51) suggests, there is a need for “studies that do not order boundaries into predefined categories.” I analyzed transcripts of all semi-structured interviews, focus groups, and the search conference. I did not analyze for specific boundary types and then force the data into them. Rather, my approach was empirical, in order to carefully review the data to ascertain what major types of boundaries may emerge and which ones were most relevant to health services planning. This process was messy and time-consuming. The boundaries that I eventually identified and refined through this process did not, perhaps unsurprisingly, fall into neat categories. This is contrary to what the literature suggests from a theoretical perspective, but supports the call for empirically-derived categorization. I classified the boundaries in two major ways—intangible (largely dyadic, invisible, and
processual properties) and tangible (largely dyadic, visible, and structural properties). These are summarized in the following Table 6 and, in several cases, reflect in vivo nomenclature.

<table>
<thead>
<tr>
<th>INTANGIBLE</th>
<th>TANGIBLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face-value problems – Real problems</td>
<td>North – South</td>
</tr>
<tr>
<td>Real problems – What is done</td>
<td>Rural – Urban</td>
</tr>
<tr>
<td>What is right – What is done</td>
<td>Federal – Provincial</td>
</tr>
<tr>
<td>Caring – Uncaring</td>
<td>Health [care] system – Non-health [care] system</td>
</tr>
<tr>
<td>Lower-levels – Higher-ups</td>
<td>Ministry – Ministry</td>
</tr>
<tr>
<td>Poor – Rich</td>
<td>Primary – Tertiary</td>
</tr>
<tr>
<td>Powerless – Powerful</td>
<td>Community health – Acute care</td>
</tr>
<tr>
<td>Visible problems – Invisible problems</td>
<td>Community – Community</td>
</tr>
<tr>
<td>Status quo – Novelty</td>
<td>Community – Health system</td>
</tr>
<tr>
<td>Big picture – Details</td>
<td>Discipline – Discipline</td>
</tr>
<tr>
<td>Periphery – Centre</td>
<td>Sector – Sector</td>
</tr>
<tr>
<td>Child priorities – Other priorities</td>
<td>Individual – Health system</td>
</tr>
<tr>
<td>Multiple perspectives – Singular (political) perspective</td>
<td>Local – System</td>
</tr>
<tr>
<td>Local approach – Central (political) approach</td>
<td>Local transportation – System transportation</td>
</tr>
<tr>
<td>Local incapability – Central capability</td>
<td>Local – Regional</td>
</tr>
<tr>
<td>Inside perspectives – Outside perspectives</td>
<td>Local – Health Service Delivery Area (HSDA)</td>
</tr>
<tr>
<td>Historical views – Contemporary (scientific) views</td>
<td>Parts – System</td>
</tr>
<tr>
<td>Local nuances – General solutions</td>
<td>HSDA – Health system</td>
</tr>
<tr>
<td></td>
<td>Health Authorities – Ministry of Health</td>
</tr>
<tr>
<td></td>
<td>Information confidentiality – Information sharing</td>
</tr>
<tr>
<td></td>
<td>Union – Non-union</td>
</tr>
<tr>
<td></td>
<td>Aboriginal – Non-Aboriginal</td>
</tr>
<tr>
<td></td>
<td>Traditional medicine – Western medicine</td>
</tr>
<tr>
<td></td>
<td>First Nations health – Mainstream health system</td>
</tr>
<tr>
<td></td>
<td>On-reserve – Off-reserve</td>
</tr>
</tbody>
</table>

These two major boundary categories depict numerous dyadic relationships. On the surface, these boundaries are often simply interpreted as walls, or barriers that lead to endless conflict and
failure to resolve problems. Perhaps this is not surprising in the context of a perspective in which boundaries are considered to be illusions, separating the inseparable (Wilber, 1999). With this counterintuitive approach, Wilber (1999, p. 457) suggests that “[i]t is...the boundaries themselves which create the seeming existence of separate opposites.” This is explained as follows:

The point is that all of the lines we find in nature, or even construct ourselves, do not merely distinguish different opposites, but also bind the two together in an inseparable unity. A line, in other words, is not a boundary. For a line, whether mental, natural, or logical doesn’t just divide and separate, it also joins and unites. Boundaries, on the other hand, are pure illusions—they pretend to separate what is not in fact separable. In this sense, the actual world contains lines but no real boundaries. (p. 458)

This is further expounded by Wilber (1999) in the sense that such dyads are symptomatic of taking illusory boundaries as real. Thus, to resolve the issues, the root cause must be sought—the illusory boundaries. Such a perspective appears contradictory to the boundary characteristics that I raised earlier. I have been careful to characterize boundaries as both barriers and bridges. In some cases, boundaries separate; in others they join; and, often they do both. A biological example of the latter is the cell membrane which functions as a structural and functional barrier to protect the cell contents and serves as a bridge to allow the movement of cellular nutrients and wastes across the membrane. In this context, boundaries are not, as Wilber suggests, “pure illusions”. I have demonstrated through the data gathered during the course of this study many tangible boundaries (in addition to many intangible, even “illusory” boundaries). The root cause to which Wilber refers is not just at the illusory boundary. Rather, the dynamics that need to be addressed reside at the boundary interfaces (tangible and intangible) and what occurs there—the boundary objects, whose role will be discussed in following sections of this chapter.
The dual role of boundaries is supported by Wheatley (n.d., n.p.) in the context of communities and the paradox of “individualism and connectedness.” In this conception, boundaries change from being protective walls to become places of meeting, exchange, and growth. She urges living—indeed thriving—within this paradox in the context of community. She laments that when the fundamental questions of “why and how we might be together” continues unanswered, “the institutions we create to serve us become the battle grounds that serve no one.” We are reminded again of the relationship between wholeness and fragmentation (Bohm, 1980). Bohm describes the issue as, whereas the nature of reality is a coherent, unbroken, and flowing whole, we have a propensity to make sense of the whole by thinking in convenient, but artificially fragmented ways. Compounding this tendency is the further inclination to directly accord and, thus, confuse our thought with reality. Deceptively, this leads us to see and experience reality as fragmentary. This illusion of the world-as-fragments seriously undermines the unbroken and flowing wholeness of life, of reality. Put another way, this fragmentation simultaneously creates and reifies illusory boundaries. We then behave, often subconsciously, in ways that support this way of thinking, speaking, and acting.

It is important to examine how we establish boundaries, despite the fact that many are artifacts with little basis in reality because this is how we confer meaning to ourselves and our environment and how we construct our social reality (Zerubavel, 1991). A useful way to exemplify and understand the application of boundaries is in the context of how people live, work, play, and socialize over time and develop a perceptible bond. Wenger (1996, p. 4; 1998) describes this as a “community of practice”, one in which “knowing, belonging, and doing are not separable: What we know, who we are, and what we do seamlessly come together in one experience of participation.” Concomitantly, boundaries are created to distinguish those within and outside of such communities of practice by, for example, perspectives, languages, and styles. This also occurs between separate communities of practice, boundaries of which must be crossed.
to enable interactions and coordinated work (Wenger, 1996). Wenger emphasizes that this is more than just organizing local activities; rather, it is essential that a broader context be recognized and a more global connectivity be sought.

An example of a type of tangible boundary (a geographic boundary) is the distinction between the “North” and “South” in the province of BC. This refers to the rural/remote realities (periphery) felt and experienced by residents in the North, and their perceptions of urban realities (central) experienced by those in the Lower Mainland area, including Victoria. Many Northerners feel that this where the real power, control, and authority for health services are vested. This sentiment is reflected in the following examples:

I really see a disconnect between the Northern part and the Southern part….so you really do have to physically move here and experience it. Because it’s really hard for your brain to comprehend or grasp how large this province is and how large the North is. (Aboriginal Manager)

[I]n the North, we usually feel that no one understands us from down South. (Manager)

I feel the province is divided into two communities—Southern and Northern. (Parent)

[Y]ou know, we can be fighting within BC—the North against the South is always a common battle. The North feels that we don’t have enough, and South has too much. (Policy-maker)

The need for something that will enable inter-agency collaboration in order to work across inter-agency and inter-organizational boundaries is well-recognized in the North West. Without having any preconceived answers, there is a strong desire to learn how to do this. Participants aspired to listen and take direction from those with the knowledge and experience, which doesn’t necessarily mean the professionals. Parents are specifically acknowledged as
experts in their own right when it comes to their children. Some views about this are shared below.

So you need something in the system that enables that interagency collaboration to go on. (Search Conference participant)

[But] what we really want to do is learn to work across boundaries....learn more about working across sectors, the Ministry for Children and Family Development, Health, and Education. (Search Conference participant)

[We] need to be working on the boundary areas without having any preconceived ideas about what the outcome might be...that we listen to their [users of the services] perspective because we need to take direction from them. They’re the one with the lived experience. (Search Conference participant)

And, I think when we’re talking about collaboration that parents should be invited as well. Like, it shouldn’t just be all the agencies talking about what’s best for the kids. The parents are the experts, you know. (Search Conference participant)

It is noteworthy that the term boundary appears in these excerpts from the data. I introduced the concept of boundaries and boundary objects as part of my preliminary findings early in the search conference. As co-researchers in the study, the participants were expressly asked to consider these concepts and think about what are the boundaries and boundary objects in the context of child and youth health services in the North West. I asked that the participants think about what is happening at the boundary interfaces and build on this idea. I further asked that they think about boundaries in terms of what, where, when, why, and how the boundaries are important for their own worldviews. And, what are the boundary objects—the things, concepts, and ideas that transect these boundaries.

I was encouraged that these two conceptual core-categories (boundaries and boundary objects) were acknowledged, used, and authenticated as the search conference progressed. Had I not already analyzed the earlier data and developed the two core conceptual categories, this may
have merely indicated a respectful compliance with my request. This suggests that these participants intuitively recognized a number of boundaries without naming them as such. These boundaries, to some extent, became synonomous with what they perceived when working across, for example, sectors, cultures, jurisdictions, disciplines, and Ministries. These represented challenges with which these participants were intimately familiar. On the other hand, boundary objects, as a concept, was less familiar.

**Classifying Boundary Objects**

Four types of boundary objects are described and summarized by Star (1989), as follows:

1. **Repositories**—objects that are indexed and standardized, such as libraries and museums
2. **Ideal Type or Platonic Object**—symbolic representations that assist in communicating and cooperating, such as early atlases, which are not necessarily accurate
3. **Terrain with Coincident Boundaries**—common objects that share common boundaries but different contents, such as the state of California, various maps for which are created dependent upon differing needs of cooperating actors doing autonomous work
4. **Forms and Labels**—fixed methods of communicating across heterogeneous work groups to ensure transfer of accurate, unchanging information.

While Star (1989, p. 51) describes these boundary objects as a “powerful abstraction”, they address inconsistent, ambiguous, and illogical problems. And, whereas these objects were created by the stakeholders in two very different cases, Star calls for further research to address the creation, expansion, and use of boundary objects. In particular, this research must recognize that “the construction of such objects is a community phenomenon, requiring at least two sets of actors with different viewpoints.” (Star, 1989, p. 52). This notion is amplified by Star & Greisemer (1989, p. 389) who raise “the challenge intersecting social worlds pose to the coherence of translation...[which] cannot be understood from a single viewpoint.” They advance
the need for an "anti-reductionist" approach and "ecological analysis" which "does not presuppose an epistemological primacy for any one viewpoint; the viewpoint of the amateurs is not inherently better or worse than that of the professionals." They elaborate as follows:

Boundary objects are objects which are both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. They are weakly structured in common use, and become strongly structured in individual-site use. These objects may be abstract or concrete. They have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation. The creation and management of boundary objects is a key process in developing and maintaining coherence across intersecting social worlds. (p. 393)

Developing and maintaining coherence at these intersections of social worlds—boundaries—reinforces the relevance of boundary objects. At these intersections various representations of stakeholders' worldviews, including the integrity of shared information, are called upon in order to satisfy multiple realities and concerns (Star & Griesemer, 1989).

This also raises another closely related issue—epistemology—how we come to know reality. This was briefly introduced in Chapter One in the context of my own epistemological awareness. Representational epistemology is described as "an epistemology that holds that we can know things about the world by making representations of it and that the purpose of these representations of [emphases in original] the world is to enable us to move towards an understanding of what the world is really like" (Osberg & Biesta, 2003, p. 2). This is in sharp contrast to an alternative epistemology they propose—a temporal epistemology—which draws from complexity theory. Temporal epistemology includes the concept that knowledge and the world are not separate systems, but one evolving system, and implies that "the quest for
knowledge is about finding more and more complex and creative ways of interacting with our environment” (Osberg & Biesta, p. 3). Francis Bacon (1560-1662) conceived of this metaphorically as “twist[ing] the Lion’s tail” (quoted in Hacking, 1983, p. 225, as cited in Osberg & Biesta, 2003, p. 8). This takes us to a different conceptual level, in which our interacting with the world leads to more complex understandings. These replace previous understandings, which leads to further and even more complex understandings in a continuous, iterative way (Osberg & Biesta). It is in this context that boundaries and boundary objects come to life. As a specific method, CBPR, particularly the search conference, is a boundary object (to be discussed in a following section). For example, building on the epistemological perspective, Brown & Duguid (1998, p. 104) suggest that boundary objects help to forge links among communities [their use of the term communities includes, but is not solely limited to, the notion of “communities of practice” and state that “[t]hrough them, a community can come to understand what is common and what is distinct about another community, its practices, and its world view.” This attribute of boundary objects—to help us understand boundaries that separate world-views—is one of their most important properties.

In the context of Aboriginal culture, this focus on epistemology and world-views is highly significant. This importance is captured by the powerful image of “jagged world-views colliding” that describes the yet unresolved conflict between Aboriginal philosophies and positivist science (Leroy Little Bear, 2000, as cited in Castellano, 2004, p. 103). I found that Aboriginal participants in the North West wanted to hear about and understand the history and context of those to whom they are attempting to relate. Not only is the health system mysterious to many Aboriginal people, it should ideally be explained in a context familiar to lay people with a greater respect for them, their histories, where they live, their cultures, and indeed, their prevailing world-views. Failing this, planning for, and the delivery of, health services will be stuck in misery and mystery. The following two Aboriginal policy-makers summarize this well:
So, I think we have to undergo a huge demystification process [of the health system] and, secondly, I think that the average person has to bloody wake up about health in a way, and really advocate at a community level for good services. (Aboriginal policy-maker)

[I]t would help me understand a lot better where a person’s coming from if I know what their history is. I can understand that person better if I know where he’s coming from, I think that’s a very real issue....Our people are very pessimistic about the whole health system because of our history. We, especially the Haida, the native people, feel we’re being forced to jump through hoops more and more. (Aboriginal policy-maker)

Figure 15 uses a tree to symbolize, in Aboriginal culture, a number of inter-relationships. In particular, the depiction of world-view as being below ground, essentially invisible to others, is fitting to our understanding of boundary dynamics. In this case, the ground level is the boundary between the visible tree and the invisible supporting world-view and the earth. To more fully appreciate and understand the mindset of Aboriginal peoples, it is important to get beyond merely scratching the surface of the ground; we must dig deeper, a lot deeper. For example:

It comes down to balance. That’s another thing. The health of First Nations depends on their land. I mean, that’s who we are. We’re that connected....Our sense of self-worth depends on the land....[T]hat is our health...those pieces of land....At the deeper level it’s about saving these places. (Aboriginal Manager)

[W]hen our names, our clans, our history is tied to the land, that’s the approach, the mindset, that you come from. (Aboriginal Policy-maker)
Cultural boundary issues also become manifest in geography. Problems are created by an historical lack of alignment between traditional Aboriginal territorial boundaries and those, for example, of health administration, school districts, regional districts, electoral municipalities, and transportation. As can be seen in Figure 16, in the North West this affects all but two territories (Nisga’a and Haida Gwaii). While these differences are evident in boundary objects such as
maps, the process of how to address these differences is much more challenging. Acknowledging and respecting these differences is much more plausible than changing them, and is more important and effective in terms of moving forward in a collaborative environment. Engaging the right boundary object in the right context for the right reason is paramount to success.

Figure 16. Traditional Aboriginal Territorial Boundaries in North West BC.

Note. This is from the "First Nations Peoples of British Columbia" Map. http://www.bced.gov.bc.ca/abed/map.htm Copyright © Province of British Columbia. All rights reserved. Reprinted with permission of the Province of British Columbia. www.ipp.gov.bc.ca
Boundaries and Boundary Objects in the North West

Emerging from the constructivist grounded theory approach I used to analyze qualitative data generated in the study, were the boundary and, consequently, the boundary object core-categories. This prompted me to conduct yet another analysis of the qualitative data by stakeholder group (public, managerial, clinical, policy-maker). I identified the main boundary dynamics in each transcript (43 semi-structured interviews; 4 focus groups; and, the 2-day search conference). Consequently, I undertook a comparative analysis of the qualitative data generated by the four stakeholder groups and three methods. This is a form of participant and methods triangulation. I categorized over 40 boundaries into two major conceptual categories, tangible and intangible.

However, this didn’t resolve the boundary objects question and inspired yet another line-by-line analysis of the data. This proved laborious because at this point I had scant appreciation of what constituted a boundary object in the context of child and youth health services planning. There was little literature to review. Boundary objects were recognized as important in industries and other fields outside of health. Also, in order to be true to a constructivist grounded theory approach, boundary objects need to emerge from the data, as opposed to “forcing” or manipulating the data to reveal these entities. Initially, I carefully identified anything that resembled a boundary object. However, this was frustrating because almost every object became suspect. After reviewing examples outside of health, I identified boundary objects that were germane to child and youth health services planning in the North West, indeed, the purpose and site of the study. Still, this stage of the analysis yielded over 200 boundary objects. After further review and refinement, and using a laborious process of manual cutting and pasting, I compiled these boundary objects into four main categories. Three of these categories neatly coincided with...
the boundary object characteristics developed by Carlile. However, one category did not. It is this latter category which provides the basis for adapting and building upon Carlile’s Integrated 3-T Framework.

To that end, the concept of the framework is described to set the stage for its adaptation and revision in the context of child and youth health services planning as part of a public sector health industry. Following this, the fourth level boundary and associated boundary objects that emerged from the data gathered in the North West study are discussed.

**Syntactic Boundary and Boundary Objects**

From the North West data in the current study, a number of boundary objects emerged in the syntatic category. They include, for the most part, national, provincial, and local repositories of public sector information and data. These are listed in Table 7.

<table>
<thead>
<tr>
<th>Table 7. Boundary Objects at the Syntactic Boundary Level Identified in the Data.</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Statistics Canada</td>
</tr>
<tr>
<td>• Canadian Institute of Health Information</td>
</tr>
<tr>
<td>• Provincial health data warehouse</td>
</tr>
<tr>
<td>• McCreary Report</td>
</tr>
<tr>
<td>• BC Health Guide</td>
</tr>
<tr>
<td>• Internet Public Health Information System</td>
</tr>
<tr>
<td>• Northern Health [Authority] website</td>
</tr>
<tr>
<td>• Service inventory</td>
</tr>
<tr>
<td>• Planning and evaluation database tool</td>
</tr>
<tr>
<td>• Database of researchers and communities</td>
</tr>
<tr>
<td>• Canadian Institutes of Child Health</td>
</tr>
<tr>
<td>• Canada’s Food Guide</td>
</tr>
</tbody>
</table>
Semantic Boundary and Boundary Objects

From the North West data, several boundary objects are identified in the semantic category. These are listed in Table 8.

<table>
<thead>
<tr>
<th>Table 8. Boundary Objects at the Semantic Boundary Level Identified in the Data.</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Public Health Act</td>
</tr>
<tr>
<td>• School Act</td>
</tr>
<tr>
<td>• Indian Act</td>
</tr>
<tr>
<td>• Health Professions Act</td>
</tr>
<tr>
<td>• Health Transfer Agreement</td>
</tr>
<tr>
<td>• Performance Agreements</td>
</tr>
<tr>
<td>• Policies</td>
</tr>
<tr>
<td>• Standards</td>
</tr>
<tr>
<td>• Information Sharing Protocols</td>
</tr>
<tr>
<td>• Inter-ministerial Agreement</td>
</tr>
<tr>
<td>• Canada Health Act</td>
</tr>
<tr>
<td>• Safety Act</td>
</tr>
<tr>
<td>• Contribution Agreement</td>
</tr>
<tr>
<td>[with Health Canada]</td>
</tr>
<tr>
<td>• First Ministers’ Accord</td>
</tr>
</tbody>
</table>

Pragmatic Boundary and Boundary Objects

From the North West data, unlike the automobile and aerospace industries, very diverse examples of this category show the complexity of the health system in a predominantly public sector setting. These are listed in Table 9.
Table 9. Boundary Objects at the Pragmatic Boundary Level Identified in the Data

<table>
<thead>
<tr>
<th>Population health model</th>
<th>Health cards [for community resources]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care reform</td>
<td>Westminster model</td>
</tr>
<tr>
<td>Health Authority redesign plan</td>
<td>Indigenous models</td>
</tr>
<tr>
<td>Business plan</td>
<td>Aboriginal health services plan [NHA]</td>
</tr>
<tr>
<td>Asset mapping</td>
<td>Aboriginal health initiative program</td>
</tr>
<tr>
<td>Integrated case management model</td>
<td>Medicine wheel</td>
</tr>
<tr>
<td>Small Communities Initiative Program</td>
<td>North Coast Health Improvement Society</td>
</tr>
<tr>
<td>Functional assessment model</td>
<td>Reserves [First Nations]</td>
</tr>
<tr>
<td>Logic model</td>
<td>Integration project [Federal/Provincial]</td>
</tr>
<tr>
<td>Population-based funding formula</td>
<td>Service delivery redesign</td>
</tr>
<tr>
<td>Individual education plan</td>
<td>Integrated service delivery plan</td>
</tr>
<tr>
<td>Evidence-based practice</td>
<td>Provincial Child &amp; Youth Mental Health Plan</td>
</tr>
<tr>
<td>Child care plan</td>
<td>Budget</td>
</tr>
<tr>
<td>Provincial child health network</td>
<td>Community link funding</td>
</tr>
<tr>
<td>Provincial Health Services Authority</td>
<td>Demonstration projects</td>
</tr>
<tr>
<td>Northern Health Authority</td>
<td>Learning site initiative</td>
</tr>
<tr>
<td>North West Health Services Delivery Area</td>
<td>Addictions model</td>
</tr>
<tr>
<td>Local Health Areas</td>
<td>Baby Friendly Initiative</td>
</tr>
<tr>
<td>School District</td>
<td>Access maps</td>
</tr>
<tr>
<td>Tsimshian Health Authority</td>
<td>Frameworks</td>
</tr>
<tr>
<td>Tahltan Health and Social Services Authority</td>
<td>Clusters [administrative in NW HSDA]</td>
</tr>
<tr>
<td>Longitudinal study for children &amp; youth</td>
<td>Nisga’a Health Authority</td>
</tr>
<tr>
<td>Surveys</td>
<td>Health portfolio [for band council]</td>
</tr>
<tr>
<td>Cost-benefit analysis</td>
<td>Clinical decision-making trees</td>
</tr>
</tbody>
</table>

Continued next page...
Phronetic Boundary and Boundary Objects

The concept of *phronesis* is of Aristotelian origin, and is best understood in the context of two other concepts: *episteme* and *techne*. Although I introduce these concepts here, I discuss them more fully in Chapter Six during the development of a conceptual framework. Episteme is concerned with “contemplative ways of knowing....accord[ing] rather closely to...the term
theory [emphasis in original].” Techne “is a form of knowledge that is inherently action oriented and inherently productive....the objective...is application of technical knowledge and skills.” Additionally, techne practitioners, while engaging local stakeholders, are experts who privilege their own knowledge over that of local stakeholders and do things for, not with, them (Greenwood & Levin, 2005, p. 50). Phronesis, on the other hand, is practice-oriented and underscores the notion of “know[ing] how to act in real-world contexts with real-world materials.” (Greenwood & Levin, 2005, p. 51). More specifically,

$p$\textit{hronesis} is best understood as the design of action through knowledge construction with the legitimate stakeholders in a problematic situation. The sources of \textit{phronesis} [emphasis in original] are collaborative arenas for knowledge development in which the professional researcher’s knowledge is combined with the local knowledge of the stakeholders in defining the problem to be addressed. Together, they design and implement the research that needs to be done to understand the problem. They then design the actions to improve the situation together, and they evaluate the adequacy of what was done. (p. 51)

Toulmin (1996, p. 210) reminds us that the outcome of action research (cf. CBPR) is phronesis: “practical wisdom is shown [emphasis in original] in concrete, particular, local actions to remedy a situation.” Similarly, Greenwood & Levin (1998, p. 111) characterize action research as “the process of bridging local knowledge and scientific knowledge, a process that will create both new local knowledge and new scientific understandings.” One particularly effective way to accomplish this is by emphasizing a relatively little known method, the search conference—a method within the family of community-based research approaches. This method was discussed in detail in Chapter Three. A search conference is a collaborative, participative two- or three-day event at which a relatively large group of key stakeholders meet. Their purpose is to collaborate across boundaries in order to interpret history, develop common goals, create
and prioritize concrete action plans, link these plans with action groups for collective action, and establish lasting relationships (Emery & Purser, 1996; Greenwood & Levin, 1998; Weisbord & Janoff, 2000). The search conference typifies a boundary object at the phronetic boundary level. However, it is but one example in the context of action-oriented participant collaboration to address in real-time the issues that are timely and relevant to local realities.

The boundary objects most relevant to phronetic boundaries are best described in terms of praxis, continual iterations between theory and practice, between knowing and acting. These boundary objects comprise the fourth category referenced above. During the course of qualitative data analysis undertaken to specifically identify and categorize boundary objects, I concluded that these emergent boundary objects simply did not, and could not, fit with the Carlile framework. As these boundary objects were categorized they, in turn, created the fourth boundary level: phronetic. These boundary objects are very diverse, extending beyond the usual elements of the health system, and include the following examples drawn from the empirical data, shown in Table 10 on the following pages.
### Table 10: Boundary Objects at the Phronetic Boundary Level Identified in the Data

<table>
<thead>
<tr>
<th>Public forums</th>
<th>Cluster table</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provincial planning table</td>
<td>Retreat [NHA]</td>
</tr>
<tr>
<td>Health Watch Committee</td>
<td>Regional advisory committee for children &amp; youth [Prince George]</td>
</tr>
<tr>
<td>Inter-governmental joint management table</td>
<td>Children &amp; youth mental health team</td>
</tr>
<tr>
<td>Regional Advisory Committee for Mental Health</td>
<td>Public participation process</td>
</tr>
<tr>
<td>Community development approach</td>
<td>Family health committee</td>
</tr>
<tr>
<td>Turf wars</td>
<td>Community Development Institute [UNBC]</td>
</tr>
<tr>
<td>Participatory research methodologies</td>
<td>Community development position</td>
</tr>
<tr>
<td>Parent Advisory Committee</td>
<td>Social planning committee</td>
</tr>
<tr>
<td>Town meeting</td>
<td>Community consultation process</td>
</tr>
<tr>
<td>Kitchen table [discussions]</td>
<td>Tobacco reduction committee</td>
</tr>
<tr>
<td>Peoples’ stories</td>
<td>Community health representative</td>
</tr>
<tr>
<td>Social Planning Council</td>
<td>North Coast community assets development committee</td>
</tr>
<tr>
<td>Community Days</td>
<td>Community meetings</td>
</tr>
<tr>
<td>Strength-based approach [to planning services]</td>
<td>Perinatal committee</td>
</tr>
<tr>
<td>Videoteleconferencing</td>
<td>Interagency committee</td>
</tr>
<tr>
<td>Friendship Centres [Aboriginal]</td>
<td>Social services coordinator</td>
</tr>
<tr>
<td>Childrens’ Festivals</td>
<td>Change agents</td>
</tr>
<tr>
<td>Bridging events [Aboriginal – Non-Aboriginal]</td>
<td>Regional facilitator</td>
</tr>
<tr>
<td>Village elders</td>
<td>Organizational development change agent</td>
</tr>
<tr>
<td>Feasts [Aboriginal]</td>
<td>Navigator [for access to services for client]</td>
</tr>
<tr>
<td>Potlatch</td>
<td>Case management services</td>
</tr>
</tbody>
</table>

*Continued next page...*
<table>
<thead>
<tr>
<th>Fish Camp</th>
<th>Relationship manager</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childrens’ Fair</td>
<td>Community coordinators</td>
</tr>
<tr>
<td>Women’s Knitting Group</td>
<td>Interagency coordination</td>
</tr>
<tr>
<td>Knot-tying course</td>
<td>Fetal alcohol diagnostic workshops</td>
</tr>
<tr>
<td>Sex education parties</td>
<td>Northern Emergency Conference</td>
</tr>
<tr>
<td>School Health Committee</td>
<td>FAS training centre</td>
</tr>
<tr>
<td>Service Fair</td>
<td>Telehealth</td>
</tr>
<tr>
<td>Service delivery initiative on integration [gov’t agents]</td>
<td>Primary health care meetings</td>
</tr>
<tr>
<td>Listserv</td>
<td>SPARC</td>
</tr>
<tr>
<td>Bulletin boards [on community issues]</td>
<td>Regional council</td>
</tr>
<tr>
<td>Flexible funding [that meets family needs]</td>
<td>Wrap-around</td>
</tr>
<tr>
<td>First Nations Chiefs Health Committee</td>
<td>Annual music festival</td>
</tr>
<tr>
<td>Council of the Haida Nation</td>
<td>Quilting group</td>
</tr>
<tr>
<td>Antenatal classes</td>
<td>Child development party</td>
</tr>
<tr>
<td>Child, youth, family committee</td>
<td>Dances</td>
</tr>
<tr>
<td>Child &amp; youth care plans steering committee</td>
<td>Potlucks</td>
</tr>
<tr>
<td>Child &amp; youth planning team [NHA]</td>
<td>Injury prevention committee</td>
</tr>
<tr>
<td>Family focus groups</td>
<td>Social planning network</td>
</tr>
<tr>
<td>Family support worker</td>
<td>Social action group</td>
</tr>
<tr>
<td>Bridging committee</td>
<td>Provincial task group</td>
</tr>
<tr>
<td>Planning process [as a chalkboard]</td>
<td>Secure web-based conversations</td>
</tr>
<tr>
<td>Team meetings</td>
<td>Interagency conference</td>
</tr>
<tr>
<td>Workshops [Aboriginal ways re children]</td>
<td>Multicultural festival</td>
</tr>
</tbody>
</table>
What these examples highlight at this boundary level is their fluid, real-time participatory and collaborative characteristics in locally-situated, multi-stakeholder, boundary-crossing settings. Such boundary objects, through a conscious or unconscious praxis meld knowledge and action. This is accomplished in ways that are meaningful and relevant to local stakeholders and their real-world circumstances. Thus, this is much more than the transformation of knowledge at the pragmatic boundary level. At this level, knowledge and action become unified by means of the boundary objects deemed appropriate by local stakeholders to meet their local circumstances, specifically in places of relevance. In this way, the local, complex, diverse, dynamic, unpredictable realities of life can be met, as suggested by Chambers (1997, p. 32). As Casey (2003, p. 2245) proposes in a “place-world...we would pay much more attention to the peculiarities and heterogeneities, the special stories and local customs of any particular locale.” This attention, in particular the special stories at the local level, (a) signifies CAS, (b) demonstrates CBPR, (c) respects place, (d) supports KT, and (e) enables the meshing of the boundaries between research and action (i.e., the real-time implementation of the research findings). In real-world research, this is critical because communities are now much more emphatic about local relevance and moving beyond the talk. Actively engaging and enabling local stakeholders, indeed, heightens this expectation. As one of the participants highlighted at a follow-up findings session:

Just the fact that you’ve got another whole set of boundary objects defends the fact that this is where people want to go. (Clinician, Findings Session)

And, communities deserve nothing less than such a commitment, or CBPR has little reason to engage the community in the first place. For example, as Israel, et al. (2003) promote, and as recognized in Chapters Two and Three, approaches are developed that are uniquely appropriate to the community and specific situation. Similarly, as Viswanathan, et al. (2004) reinforce in
their systematic review of the literature, CBPR effectively bridges the gap between research and community.

At this juncture it is also illuminating to draw upon the hierarchical relationship between data, information, knowledge, and wisdom. Clarke & Rollo (2001) suggest a knowledge management framework that distinguishes these knowledge entities, summarized as follows (see Figure 17):

- Data: facts without context or judgment
- Information: data with relevance
- Knowledge: information with insights
- Wisdom: the best use of knowledge

Figure 17. The Relationship Between Data, Information, Knowledge, and Wisdom.

If the knowledge boundary hierarchy and knowledge hierarchy frameworks are juxtaposed, the generally corresponding relationships between the former and the latter become apparent. In this context, to achieve insight and wisdom requires working at the phronetic boundary level with boundary objects that imbue praxis. This, of course, requires the co-existence of the underlying boundaries and boundary objects. However, the focus more appropriately resides at the uppermost level of the hierarchy if real-world problems are to be addressed in ways meaningful to those experiencing them.

The essence of research/practice praxis, is richly evident in the data representing the responses by North West study stakeholders. These participants characterized and elaborated upon the issues from their perspectives as managers, parents, clinicians, and policy-makers with remarkable consistency and cohesion. For example, in the context of how best to go about planning child and youth health services in the North West, this senior manager suggested:

Well, I mean it's a community development process, I think, that we're talking about which means every, every sector in the community ideally has, I mean, [it] takes a community to raise a child is...sort of a truism, but it's...a true truism....So it's really the whole community, so the municipal council would be involved, school districts, school boards and, sort of, their policies. But, what venue do you use; what format do you use, I mean, for these consumers? I mean it really needs to start with the people who are affected by the service, but what format? And, I am just thinking that we ought to be a bit, we ought to look at developing some mechanism like that. (Manager)

Similarly, these varied stakeholders (managers, clinicians, policy-makers, public) intuitively, but not necessarily explicitly, embrace a community-based approach as a boundary object. This formulation is illustrated by the following examples drawn from the qualitative data. Similar messages from multiple stakeholders, including Aboriginal participants, serve to reinforce the critical importance of a CBPR approach that respects, engages, and applies the knowledge at the community level and connects this to the broader system.
As the North West study progressed, constructivist grounded theory based on several of the initial semi-structured interviews yielded preliminary findings, including the concept of boundaries. Thus, when the focus groups took place, the early findings were shared, including early thoughts on boundaries. That these concepts resonated with study participants was reflected in the conversations, including use of the term boundary. The following excerpts from focus group data are illustrative:

**Examples of Focus Groups’ Perspectives**

Because really, at the end of the day, it’s solution-finding in the gray area....But, you also need somebody else, often from another agency, another sector, to jump into that gray area with you, and say, we will do it together, school district, and MCFD, or health, or whatever....it means operating in the gray and, hopefully, in a partnership way in the gray. (Focus Group – Terrace)

To my mind, like the way I think, my vision is integration—everyone is equal, everyone has something to offer, and everyone has a voice. Everyone needs to be listened to. And, I think that the answer comes from not dividing and conquering, but everyone dialoguing in a respectful manner. Everyone being listened to—I mean, listened to. I found that the biggest thing working with Aboriginal people; we’re trying to build allies and build relationships...how can we listen better, talk less, put our own agenda aside, just temporarily on the shelf so that we can listen with our full self, and then learn more about where that person’s coming from. (Focus Group – Smithers)

[Although there’s been many attempts over the years to look at intersectoral services, but I think that if we accept that those sectors are going to remain, what we can do is we can focus on the margins. And, we can focus on changing the relationships in the margins. (Focus Group – Victoria)

**Examples of Search Conference Perspectives**

Again, at the search conference, preliminary findings were shared with the study group, including the concept of boundaries and boundary objects. This was articulated in only a cursory way, partly because this was not the appropriate venue to wax academic and, perhaps more
importantly, the concept was not yet developed to a point where it could be explicating. However, in keeping with constructivist grounded theory, the teasing-out of the essence of boundaries and boundary objects as core-categories was critical to the real-time exploration of this concept in a child and youth health services planning milieu at the community level. This gradual, iterative process was made possible using the qualitative methods sequence of semi-structured interviews, focus groups, and a search conference which created a form of methods triangulation. The following examples are typical perspectives that were expressed at the search conference:

[T]he tertiary level isn’t aware of what’s really available and the strengths that are out in the community, and there seems to be significant lack of communication. (Search Conference – Terrace)

But what we really want to do is learn to work across boundaries....learn more about working across sectors, the Ministry for Children and Family Development, Health, and Education. (Search Conference – Terrace)

[W]e need to be working on the boundary areas without having any preconceived ideas about what the outcome might be...that we listen to their [users of the services] perspective because we need to take direction from them. They’re the one with the lived experience. (Search Conference – Terrace)

And I think when we’re talking about collaboration that parents should be invited as well. Like, it shouldn’t just be all the agencies talking about what’s best for the kids. The parents are the experts, you know. (Search Conference – Terrace)

**Good and Bad Boundary Objects**

One of the yet unanswered research questions posed in the literature concerns a distinction between good and bad boundary objects (Carlile, 2002). It is beyond the scope of this paper to comprehensively address this question; however, selected examples from the North West study will serve to support this notion. Again, this demonstrates the value of a CBPR approach and how, as a method(ological) boundary object itself, this can begin to address additional research questions posed in the literature, for example, “how the current capacities and
abilities might need to be changed to address the novelty now present” (Carlile, 2004a, p. 566).

Examples of three good and three bad boundary objects follow:

**Good boundary object, but not well-understood by others.**

[W]e need to connect a little bit more between, first of all, we need to, what we’re hoping to do now is to dialogue like in preparation for this issues, what we call issues, for our bridging opportunity, we hope to dialogue so that we have an opportunity and they’ll listen. Like the social planning committee [a phronetic level, participatory methods boundary object; emphasis added], in preparation for the issues forum, we hope to set up a series of dialogues between people in the Aboriginal, non-Aboriginal community, but you could also do it between, say, people providing tertiary care and people providing prevention, where we have opportunities to ask appropriate questions and they just listen. And to ask more questions so that we are not being critical of each other so much as hearing the heart of what’s being said so that we can come to a common ground. And, you know, sort of focus on what we have in common and work collectively, instead of each going off in our own direction, working at our own little issue.

(Clinician)

**Good boundary object, but unappreciated by those outside of Aboriginal culture.**

[S]ystemically, there is little or no recognition of the value of historical Aboriginal input, the potential for input into our medical system. I think that Canadian society and, certainly in the North in particular, but the whole world, we quash First Nations sensibilities, their history, their intelligence, and their wisdom, that they had developed over millennia in terms of medicines, you know, plants, foods, their spirituality, their communal way of interacting, at our collective peril. Many provincial and federal systems sort of try to acknowledge that, oh, you know, when you’re doing your report, you should say how, you know, this has enhanced the First Nations lifestyle. But, really, there is no systemic approval or way of enhancing that, or putting that in place, acknowledging that it’s successful. There, for example, in every program, you cannot, you couldn’t have a feast. Feasting [a phronetic level participatory methods boundary object] is huge in [place]. It’s a huge part of the culture here. It’s what links people together; it’s what keeps them connected to their past. Yet, you can’t acknowledge that. You can’t have a feast at the end of a [funded]
program to say that people have done well, or to acknowledge whatever.

(Manager)

**Good boundary object, but perceived as bad by Aboriginal users.**

The more knowledge that’s spread into the community, the better able people are to take care of their children and and be connected to what’s happening with them, and feel like they have some control or some kind of place to be able to take proper care, I think a lot of, and, of course, speaking from the Aboriginal perspective, a lot of Aboriginal people really feel worried. And, if they’re worried about their children, they’re always worried about asking questions if they’re concerned about something because so many children have been apprehended from miscommunication. So, a lot of people, they may be really caring and, but, they won’t phone a nurse or they won’t phone a Nurseline [as part of the BC HealthGuide and related initiative, a syntactic level boundary object; emphasis added], or they won’t go somewhere because they’re, they’re afraid that it might reveal something that might be construed as being that they’re not taking, not taking proper care of their kids. (Aboriginal Manager)

**Bad boundary object, lacking sensitivity to Aboriginal users.**

So even when you apply to go to the Aboriginal Head Start program they don’t do the application form [a semantic level standardized form boundary object; emphasis added] like the kid has a mother and a father….So every time we filled it in we had to fill in a little line, both our names, and show both of us as mother and father and signed, squished in….And the form, I brought that up to the woman, and she goes like, you know what, you’re the first person to ever ask that, she said. Because the assumption is always made that there’s single parents that have the problems and it’s their kids, you know, obviously, come from single families, that they have these issues. (Aboriginal Manager)

**Bad boundary object.**

I was talking to a fellow from the Ambulance Service…and he said one of the things that we have a real problem with if they’re and there was one example where there was a child who was injured on-reserve, but they couldn’t find them because the reserve hadn’t registered their new roads and their new subdivisions with the local municipality. And it’s the local municipality who produces and gets the maps [a pragmatic level boundary object] produced and those are the maps that the Ambulance Service use. (Aboriginal Manager)
[B]ut, really, when, until a certain situation comes up nobody knows what the hell to do about it because policies and procedures [a semantic level boundary object] made by the system go this way, yet common sense says, well… (Focus Group – Prince Rupert)

Summary

CBPR is gaining momentum in the health field as evidenced by the substantive literature (scholarly and grey) base accumulating to date. However, this approach, while methodologically sound and proven, has not yet enjoyed recognition (particularly in the decision-maker community) as a means to blur the boundaries between research and action to the extent that it is purported to be capable. CBPR is essential to sharing knowledge about, creating the conditions for, and enabling action in the context of Icddu realities (Chambers, 1997).

While CBPR is held out as a means of applying research findings to community health problems (Ahmed, Beck, Maurana, & Newton, 2004) and as a collaborative approach to bridge the gap between research and practice (Viswanathan, et al., 2004), it is much more than a mere approach. This study takes the less well-known concept of boundaries and, in particular, boundary objects, and elevates CBPR to another conceptual level—a phronetic level. It employs real-time interactive boundary objects as legitimate means to apply practical wisdom in concrete, particular, and local terms to solve relevant problems (Toulmin, 1996).

This study draws from an integrative framework for managing knowledge across boundaries, which was developed in the context of innovation and new product development (Carlile, 2002, 2004a, 2005). The concept has been further developed and applied in the public sector industry, and through this study to health services. Qualitative data were analyzed using constructivist grounded theory with emergent core conceptual categories of boundaries and boundary objects. Boundaries and boundary objects in this study support and substantially expand the concept.
Approaches to community-based research with a view to implementing findings in concert with stakeholders, particularly local, community stakeholders, will require new ways of conceptualizing and conducting planning processes, and concurrently effecting action. The implications of such an approach are exciting and should serve to better serve the real intent of community-based approaches in health services. This necessarily engages multiple stakeholders in other parts of the health system and, in fact, other systems, especially stakeholders in positions of power, control, and authority. This will require extensive time, energy, and resources. Considerable time, energy, and resources have already been devoted to reform, however minimally and sporadically for child and youth health services. This is acutely recognized by participants in the North West study. They want to do something about it and are collectively doing so. Based on empirical research in a real-world setting, the boundary object theory and model developed through this study is enabling participants in the North West to take “talk to action”. Similarly, it is hoped that this re-conceptualization of research and planning will be of value in other jurisdictions.

In the next Chapter, I reflect on the findings discussed in Chapters Four and Five and suggest their implications for a health services planning model. Through a series of Venn diagrams, I develop a shared conceptual model for planning child and youth health services that integrates the basis tenets of CAS, CBPR, KT, and place. The value of this model is its ability to help all stakeholders focus on the problem and solutions most relevant to local realities in the context of the broader health system, and creates a real-time means to link research, practice, and policy.
CHAPTER SIX: Discussion, Implications, and Concluding Remarks

The allegory pictures an underground cave with its mouth open towards the light of a blazing fire. Within the cave are people chained so they cannot move. They can see only the cave wall directly in front of them. This is illuminated by the light of the fire, which throws shadows of people and objects onto the wall. The cave dwellers equate the shadows with reality, naming them, talking about them, and even linking sounds from outside the cave with the movements on the wall. Truth and reality for the prisoners rest in this shadowy world, because they have no knowledge of any other. However, as Socrates relates, if one of the inhabitants were allowed to leave the cave, he would realize that the shadows are just reflections of a more complex reality and that the knowledge and perceptions of his fellow cave dwellers are distorted and flawed. If he were then to return to the cave, he would never be able to live in the old way, since for him the world would be a very different place. No doubt he would find difficulty in accepting his confinement and would pity the plight of his fellows. However, if he were to try and share his new knowledge with them, he would probably be ridiculed for his views. For the prisoners, the familiar images of the cave would be much more meaningful than a world they had never seen. Moreover, as the person espousing the new knowledge would now no longer be able to function with conviction in relation to the shadows, his fellow inmates would likely view the world outside as a dangerous place, something to be avoided. The experience could actually lead them to tighten their grip on their familiar way of seeing. (Morgan, 1997, pp. 215-216)

Introduction

In this final Chapter, I summarize the study—its purpose, the questions posed, the methodology used, and the major findings, including how they related to the literature. I address a number of implications based on the findings presented in Chapters Four and Five, including implications for stakeholders in health services research and planning, several recommendations for further research, and some concluding remarks. On the other hand, this chapter is not really final in the usual sense of the term. This study was, and continues to be, a journey. Some journeys have a clear beginning and end but this one does not. If this journey stops here, I have
failed to accomplish what I set out to do. This journey must continue. To my delight, and as summarized in Chapter Three, it is progressing through the local planning initiatives in the North West, taken up by participants during, and sustained after, the search conference before this study was completed. This and several other initiatives exemplify catalytic and tactical authenticity, and the on-going impact this study has had to date.

Summary of the Study

My aim in this research was to explore an approach for planning child and youth health services in North West BC and to close the gap between research and practice. I emphasized a multiple stakeholder, community-based, participatory research and planning process. I investigated the question of how to effectively engage stakeholders at the local community, regional, and provincial levels of the health system in order to find practical, action-oriented solutions to improve service delivery for children and youth living in North West BC. The significance of this study is found in how it approached the research problem, the sequence of qualitative methods used to conduct the research, and how it linked research and practice to address the complex health service issues facing children, youth, and families in North West BC.

I organized this thesis as a journey that took place in four inter-related domains: (a) intellectual, (b) technical, (c) geographical, and (d) liminal. Over the course of the study, I refined the research question to address: How does a participatory research process inform planning and guide stakeholders involved child and youth health services in North West BC? I posed three related questions: (a) How can a complex, adaptive systems lens assist in reframing multi-stakeholder conceptualization of the health system? (b) How can community be (re)defined, and how does multi-stakeholder involvement contribute to community-based participatory planning processes for child and youth health services? and, (c) What is the role of
health care geography in understanding the spatial characteristics of health services utilization, and how can this be used in participatory planning processes?

I reviewed four bodies of knowledge in the literature, including: (a) complex, adaptive systems; (b) participatory research; (c) health care geography; and, (d) knowledge translation. Community and community-based planning were included in this review. I introduced the concepts of boundaries and boundary objects later, in the context of the findings.

The study incorporated a mixed methods design. The qualitative component was given priority consistent with the multiple stakeholder participatory approach. Qualitative data were collected, integrated, and analyzed through a sequence of methods in keeping with the participatory research approach and constructivist grounded theory method. This sequence of qualitative methods included 43 semi-structured interviews, 4 focus groups, and 1 two-day search conference held in Terrace, a rural community in North West BC. The quantitative component, while important, was relatively minor. A provincial secondary administrative database (PURRFECT) and geographic information systems (GIS) software were used during the search conference expressly as a tool for, and to demonstrate the utility of, mapping child and youth health services utilization in local geographical contexts.

For data analysis, I used a constructivist grounded theory method for the qualitative data gathering and analysis process. From the data, three major conceptual categories emerged: (a) perceptivity about the health system, (b) emotivity generated by the health system, and (c) inclusivity in the health system. I then developed a common thread around a number of dyadic relationships. Two core conceptual categories—boundaries and boundary objects—emerged from the data. In keeping with the tenet of grounded theory to delay the introduction of literature until later in the study, I discussed in Chapter Five how the boundary and boundary object findings related to the literature. I developed these in the context of an existing framework of
knowledge boundaries and boundary objects, and substantively contribute to that framework. I then introduced three knowledge boundary levels: (a) syntactic, (b) semantic, and (c) pragmatic, based on earlier empirical research in the organizational science literature. However, this earlier model did not include a fourth level which, in the context of a public sector industry (health), emerged from the data as (d) phronetic. From the data generated in this study, the characteristics of boundary objects at this phronetic level were shown to be fluid, real-time participatory and collaborative, in locally-situated, multi-stakeholder, boundary-crossing settings. These boundary objects meld knowledge and action in ways that are meaningful to stakeholders in their local realities. Here, knowledge and action are unified by means of the boundary objects deemed appropriate by local stakeholders and relevant to their local circumstances. This empirical research has enabled participants in the North West to take “talk to action”, the theme of a recent forum emanating from this study and held in the North West.

Finally, in this chapter, I build on the concepts introduced through the literature in Chapter Two, and discuss the findings and implications of Chapters Four and Five. Through a series of Venn diagrams, I illustrate the main interface dynamics raised in the earlier chapters in several contexts and discuss their importance in relation to planning child and youth health services. I propose a conceptual framework that highlights these interface dynamics toward collectively informing, integrating, and melding research and planning practices. Some concluding remarks are then offered.

Discussion

The quote at the beginning of this chapter refers to Plato’s Cave, an allegory by which Socrates addresses the relationship between appearance, reality, and knowledge as summarized by Morgan (1997, pp. 215-216). Morgan uses this allegory as a metaphor for organizations as psychic prisons in which people can become confined by processes that lead to very powerful,
but not necessarily appropriate, thoughts and actions. This metaphor is particularly apt in the context of how to address the challenges posed by multiple stakeholders’ perceptions of the health system, their local realities, and the relationships involved in knowledge boundaries and related boundary objects. The journey described in this thesis is akin to my journey out of and back into this metaphorical cave, as I seek to describe the many issues I face when I question the appearance of the health system, explore a new complex reality, explain this appearance and reality in terms of knowledge boundaries and boundary objects, and suggest means to move towards new ways of knowing and acting collectively.

Current approaches to planning and reforming health services and systems in BC have failed to adequately address key local issues facing people living and working in rural and remote environments. This is not surprising given the highly complex nature of the health system, the stakeholder relationships, the many factors that contribute to health status, and the unrelenting challenges facing those attempting to improve system function (Saunders & Wanke, 1996). Historically, collaborative efforts have largely failed to produce meaningful results. As the data have demonstrated, the general sentiment is much talk, little action.

**Weaving Together the Conceptual Strands**

I have introduced many concepts throughout the course of this thesis some of which, on the surface, may not appear connected. To demonstrate the relationships, particularly those raised in the context of the literature reviewed in Chapter Two and the findings presented in Chapters Four and Five, I now shift to a graphic representation of these concepts by introducing a series of Venn diagrams (Figures 19 – 29). Through these, I portray the conjuncture (a combining or joining together) of, and interfaces generated by, the concepts raised in the course of this thesis. There is a loose hierarchical relationship among the concepts, moving counterclockwise from circles (a) – (d) within each Venn diagram. However, this depiction does
not imply a hierarchical relationship between the figures. These increasingly dynamic boundary interfaces reflect, in approximate terms, the three conceptual categories introduced in Chapter Four. The dynamics created by, at, and between these interfaces (or boundaries) give rise to the analytical concept of boundary objects, as discussed previously.

As will have been appreciated during earlier reading of the findings chapters, there are considerable variations in boundaries and boundary objects raised by stakeholder participants over the course of this study. In keeping with the sub-title of this thesis, my goal centred on finding common ground. I do this using Venn diagrams. These graphically depict a number of interrelated concepts that build upon those raised and discussed in Chapters Four and Five, and portray the notion of common ground at the core of each diagram.

Through the sequential introduction and discussion of the Venn diagrams, I construct a substantive theory as the basis for an integrative framework (shown in Figure 29). While this sequential approach is necessary for introductory and explanatory purposes, the relationships between the concepts are not linear. Rather, the theory is constructed, integrated, and explained holistically through the interplay of these concepts. This approach respects and takes into account the many variations of boundaries and boundary objects as raised through the multiple perspectives of the participants. These are developed as interrelated concepts through constructivist grounded theory analyses and development of the core categories as discussed earlier.

Before proceeding, it is necessary to review two concepts: substantive theory and double-loop learning. These constitute an approach to how we learn, especially in complex environments such as the health system. These two concepts will help us to understand the progression through the Venn diagrams toward the development of the conceptual model, and
help us to question our underlying, often hidden, mental models that may impede our ability to learn and act in collaborative environments.

**Towards a Substantive Theory for Participatory Planning**

A substantive theory (as opposed to a formal theory) in relation to grounded theory is distinguished primarily in terms of what it is developed for (Glaser, 1978, p. 144; Glaser & Strauss, 1967, p. 32). For example, substantive theory is developed for an empirical area such as health services. Formal theory is developed for a formal or conceptual area such as authority and power. In the view of Glaser (1978, p. 142), substantive theory “fits the real world, works in predictions and explanations, is relevant to the people concerned and is readily modifiable.” Dey (1999, p. 211) further characterizes substantive theory as having “holistic power” which “considers variables in terms of how they unite, intersect, or otherwise relate within the context as a whole.” More generally, from the perspective of Strauss & Corbin (1998, p. 25), “theorizing [emphasis in original] is the act of constructing…from data an explanatory scheme that systematically integrates various concepts through statements of relationships….It enables users to explain and predict events, thereby providing guides to action.” Similarly, Strauss & Corbin (1994) contend that grounded theory is designed to deal with multiple conceptual relationships (conceptual density) and find processes and patterns of activity. As this theory is developed as the basis for the framework, the relationships and patterns arising from the data through the constructivist grounded theory method should be apparent in the Venn diagrams.

**Towards Double-loop Learning**

How we learn is important. Two kinds of learning are single-loop and double-loop (Morgan, 1997; Stacey, 1992). Single-loop learning occurs when we solve simple problems using existing mental models, make assumptions, and use problem-solving techniques without questioning why and what we are doing. Thus, we learn from our actions and adjust as
necessary. Conversely, in double-loop learning we question the appropriateness of our mental models, assumptions, and techniques. Our learning results from exploring different perspectives and frameworks. We are cautioned by Stacey (1992) to ensure that double-loop learning occurs in complex, open-ended situations in which there are obscure cause-and-effect relationships. This is particularly relevant in circumstances entailing high levels of innovation, such as health services planning which are characteristically non-linear, dynamic, diverse, uncertain, and complex. Stacey (1992) also reinforces the following point about learning as a collective activity:

Learning in open-ended situations has to be a group process [emphasis added], not a task carried out by an individual expert or visionary....Group interaction, not analytical thinking ability, determines whether managers attend to open-ended issues, what issues they attend to, and what conclusions they reach. Part of an effective double-loop learning process therefore involves continual examination of the ways [emphasis added] in which a group is interacting. (p. 112)

As I proceed through these relationships arising at boundary interfaces, the necessity of creating appropriate conditions for both substantive theory development and double-loop learning become increasingly evident. This necessarily includes an emphasis on collective action rather than separate, individual efforts. The holistic power of substantive theory, as described earlier, emanates from the systematic interactions of relationships between variables (such as those illustrated by the components of the following Venn diagrams).

The Boundary Interfaces

Perceptivity about the Health System

As discussed in Chapter Four, perceptivity in the context of this study concerns three general areas: (a) how the provincial health system is conceptualized, (b) how issues in health services planning are approached, and (c) how to specifically address day-to-day practical issues.
In the following set of five Venn diagrams, I portray several inter-relationships that contribute to
the complexity of the health system, emphasizing the need for a collective conceptualization.
Here, it is important to avoid the trap of fragmentary thinking when holistic thinking is
necessary. Further, this emphasizes the need for all stakeholders to address their own, and each
other’s, local relevance in terms of locdud realities, as discussed earlier. This suggests a need to
move beyond the tendency of some researchers and decision-makers to collect and become
mired and muddled in more data. Rather, relevant data plus meaning created through local
stories, experiences, reflections, values, and situational wisdom together reflect a multi-
perspective reality that is more closely aligned with the real-world. This honours and is highly
relevant to the local environment. Examples of boundary objects as raised by study participants,
and identified through my analysis of the qualitative data, are included in the discussion of each
Venn diagram.

First, I suggest how to conceptualize the health system, which includes Figures 18 – 22.
Figure 18 depicts the interfaces associated with (a) a zone of agreement and certainty (i.e.,
relatively simple), moving towards zone (d) typified by high levels of uncertainty and
disagreement (i.e., chaordic—chaos and order).
This figure adapts and builds upon a characterization by Stacey (1996, as cited in Zimmerman, Lindberg, & Plsek, 1998) and Zimmerman, Lindberg, & Plsek (1998) who relate the need to use a method appropriate to the level of certainty and agreement in a CAS (such as an organization) in order to resolve an issue. I outline these basic concepts, incorporating boundary and boundary object concepts as discussed in Chapter Five, as follows.

- High agreement and high certainty, (a), is typical of stable situations where repository data can be effectively used and where relatively simple, repetitive solutions are appropriate (comparable to boundary objects associated with syntactic knowledge boundaries where accurate data leads to enough knowledge to make appropriate decisions). Here, knowledge is transferred. Participants raised, for example, Statistics Canada, Canadian Institute of Health Information, and the Northern Health website as typical syntactic level boundary objects.
• In the complicated area, (b), the importance of negotiation, judgement, and compromise are evident in decision-making (comparable to boundary objects associated with semantic knowledge boundaries where interpretation and communication are critical). Here, knowledge is translated. Participants raised, for example, the Public Health Act, the Health Transfer Agreement, and health policies and standards as typical semantic level boundary objects.

• In the complex area, (c), or “edge of chaos” as it is also known, traditional approaches do not work very well. Rather, approaches need to reflect a break from common practice and infuse creativity and innovation. This is comparable to boundary objects associated with pragmatic knowledge boundaries, where the dynamics inherent in complex environments demand that the stakeholders resolve their differences and work towards a practical solution. Here, knowledge is transformed. Participants raised, for example, the population health model, the Health Authority redesign plan, business plans, and the population-based funding formula as typical pragmatic level boundary objects.

• Stacey suggests a further area—anarchy (massive disorder)—where the situation reflects a high level of disagreement and uncertainty. Typically, this area should be avoided. However, in the day-to-day reality of life, including health services planning and delivery, what ought to be embraced when there is a high level of disagreement and uncertainty is the chaordic area, (d), a term coined in the mid-1990s by Hock (1996, n.p.). This refers to “any self-organizing, adaptive, nonlinear complex system.” A chaordic state contains both chaos and order, representing what Stacey (1992) characterizes as “bounded instability” with hidden patterns and conflict, and which is inherently unpredictable and sensitive to small changes. Stacey (1992) asserts that it is important to manage and take action at this order-chaos boundary. Typical phronetic level boundary
objects raised by participants in this area include public forums, provincial planning tables, turf wars, and public participation processes.

This diagram shows the interfaces created by such boundaries in the health system in terms of CAS and suggests that the chaordic process in the core area is a boundary object, reflecting the properties of self-organization, adaptiveness, non-linearity, and complexity. Even environmental factors such as unpredictable weather conditions in the North West, for example, contribute to the manifestation of these properties.

Figure 19 illustrates the interrelationships of data, information, knowledge, and wisdom. Clarke & Rollo (2001) describe this as a hierarchical relationship including, in their model, *insight* between the levels of knowledge and wisdom, as depicted in Figure 17 in Chapter Five. This intermediary level is conceptually similar to knowledge, by definition, and I exclude it here only for diagrammatic convenience.
To review, the knowledge management framework developed by Clarke & Rollo distinguishes these levels as follows: data—facts without context or judgment; information—data with relevance; knowledge—information with insights; and, wisdom—the best use of knowledge. It is this situational wisdom towards which we strive, but not necessarily alone. Situational wisdom is akin to the concept of phronesis as discussed earlier and is intimately tied to collective knowledge and action. Greenwood & Levin (2005) emphasize the inherently collective nature of knowledge, socially constructed by people who work together to develop and share knowledge. Likewise, Capra (1996), in the context of systems thinking, suggests that knowledge is a network. In particular, he presents scientific knowledge as a network, which incorporates concepts and models; however, the notion that one part, level, or scientific discipline is any more fundamental than another is rejected. Rather, the relationships and patterns are primary considerations in systems (holistic, contextual) thinking. This is reinforced by
participatory research methods, which democratically engage in the co-generation of group knowledge (Greenwood & Levin, 1998, 2005; Phelps & Hase, 2002). In this context, participants raised a number of phronetic level boundary objects, including taking a strength-based approach to planning services, a social planning council, and family focus groups.

In Figures 20 and 21, I show the interfaces between disciplines and between sectors, respectively. Bammer (2003) and Rosenfield (1992) distinguish between the terms multidisciplinarity, interdisciplinarity, and transdisciplinarity. Multidisciplinarity refers to working on a common issue from a discipline-specific basis. Interdisciplinarity addresses a common issue from a joint, but discipline-specific basis. Transdisciplinarity draws from specific disciplinary theories and concepts, but uses a shared conceptual framework to address a common issue in a more coherent way. Van Manen (2001, p. 850) further characterizes transdisciplinarity as a “new epistemology...that...is more context sensitive [as opposed to ‘scholarship sensitive’], eclectic, transient [as opposed to ‘systematic’], and inventive than traditional...interdisciplinary and cross-disciplinary research practices and methodologies.” In an organization vein, Ashburner (2001) believes that the strength and future of organization behavior lies in transdisciplinarity. I suggest here that, in suitable circumstances in health services research and planning, more attention must be focused on the core—transdisciplinarity. A number of phronetic level boundary objects became evident in the course of this study, including participatory research methodologies, taking a community development approach, and engaging in community consultative processes.
These situations enable the creation of the conditions to share conceptual frameworks necessary to develop new forms of collective knowing and acting. The reckless use of language here is noteworthy. In many cases, where the concept of transdisciplinarity is sought, the terms multidisciplinary, interdisciplinary, and cross-disciplinary are used with little thought, resulting in the unnecessary perpetuation of confusion surrounding these terms in the literature and in practice. However, it is equally important to recognize the place that a disciplinary focus plays in research and in the application of knowledge in settings that may not require a transdisciplinary setting. This also applies to the discussion on sectorality and culturality.

The foregoing considerations generally also apply to sectorality. For the purposes of this discussion, I refer to these in health services as different sectors within and between different Ministries, such as health, education, child and family development, justice, recreation, and
federal/provincial jurisdictions. I propose here to move toward a shared conceptual model to address transsectorality. This is similar to the notion of transdisciplinarity and focuses on creating the necessary enabling conditions to develop new forms of collective knowing and action, beyond that possible from only individual sectoral perspectives. Types of phronetic level boundary objects that were raised by study participants include an inter-governmental joint management table, child and youth mental health teams, and interagency coordination.

**Figure 21. Transsectorality: The Interfaces of Sectorality, Multisectorality, and Intersectorality.**

Figure 22 is similar to the interfaces outlined in Figures 20 and 21 and portrays transculturality. While I appreciate that there are a number of different cultures and ethnic groups in the North West, the principal relationships in this study are concerned mainly with the interfaces between Aboriginals and non-Aboriginals. Many of the issues related to culture are discussed in Chapter Four and won't be repeated here. Of importance is the need to enable the
creation of a shared conceptual framework that transects different cultures. The notion of transculturality focuses on engaging in a shared conceptual model with a view to identifying and addressing a common issue. This is difficult in practice, mainly because different worldviews have created tensions, even conflict, as evident in the data generated by this study and as I reviewed earlier in this chapter. Types of phronetic level boundary objects raised by participants include community briding events for Aboriginals and non-Aboriginals, feasts, multicultural festivals, and workshops that explore Aboriginal ways regarding children. Cultural sensitivity was identified as a significant priority regarding challenges to co-operation during a follow-up forum on “Integrating Child, Youth, and Family Services in the North West” (North West Working Group, 2005), which included many Aboriginal participants who were able to reinforce concerns around this issue in a collaborative planning milieu. This includes ensuring the use of research tools that are culturally sensitive and appropriate so as to minimize the risk of emotional harm to participants (Fletcher, 2003).
Emotivity Generated by the Health System

As I emphasized in Chapter Four, the data demonstrate a strong emotive undercurrent that pervaded responses in all stakeholder groups in this study. Attention to emotional reactions, and how we learn through such responses, are more important than has been acknowledged in public decision-making and in the planning literature (Forester, 1999). Here, as Forester (p. 80) argues, “practice leads theory, in planning and public decision-making, by light-years.” He specifically refers to telling stories and presenting sketches as important to public deliberation and as ways to learn about what is “burning” someone, thus allowing others to learn – both about the emotion and its context. As I discussed in Chapter Four, these are examples of boundary objects that exemplify praxis under phronetic knowledge boundary conditions.
The next set of three interfaces (Figures 23 – 25) collectively reflect a visible emotivity generated by the health system that, unsurprisingly, is captured in the context of knowledge boundaries and in their respective boundary objects as discussed in Chapter Five.

Figure 23 illustrates the knowledge boundaries introduced earlier—syntactic, semantic, pragmatic, and phronetic. By way of review of the Carlile (2004) model, at the syntactic (information-processing) boundary level, knowledge is simply transferred between a sender and receiver, relying predominantly on a common lexicon or syntax. The next level is the semantic boundary where increasing novelty creates a lack of clarity resulting in interpretive differences and communication problems between stakeholders. The third level identified in the Carlile framework is the pragmatic (transformation or political) boundary when novelty requires stakeholders to resolve their different interests to create common interests. As an expansion of the Carlile model, and as developed from the data in this study, I characterize the phronetic boundary level as fluid, real-time, participatory, and collaborative actions in locally-situated, multi-stakeholder settings. This stretches beyond the transformation of knowledge at the pragmatic boundary level. At this level, knowledge and action are unified, meaningful, and relevant to local stakeholders in their real-world circumstances. What is “burning” someone is made public and others can learn and respond accordingly. Typical phronetic level boundary objects elicited from the participants during the course of the study include those referenced in the other Venn diagrams. In the present context, these are further exemplified by peoples’ stories, kitchen table discussions, listserves, and bulletin boards on community issues.
In Figure 24, I display the three main boundary interfaces involved in two contexts: in the context of knowledge linkage and exchange (popularly articulated as transfer, translate, and transform, although current discourse tends to blur these terms as KT); and, in terms of how knowledge is shared and assessed across boundaries (Carlile, 2004). Transitioning in this context refers to changing from one place or condition to another (Concise Oxford Dictionary, 1995). With respect to place, as I discussed in Chapter Two, this is relevant in terms of acknowledging and changing the meaning afforded to place when new knowledge is introduced to address increasing novelty characteristic of chaordic environments, as discussed in relation to Figure 18, and in terms of wisdom in relation to Figure 19. Again, phronetic level boundary objects advanced by participants include public forums, provincial planning tables, public participation
processes, and taking a strength-based approach to planning services. Holding retreats and community development and consultation processes are further examples.

Figure 24. Transitioning at Knowledge Boundaries: The Interfaces of Transferring, Translating, and Transforming Knowledge.

In Chapter Two, I noted that explicit attention to people, process, and partnerships is essential to achieving the goal of KT. Failing this, even the basic tenets of KT cannot be appropriately addressed. The interfaces between determining what works (research) and doing what works (practice) highlights not only the critical role of KT, but the role of the health services research methods used as a means (boundary object) to transect the research-practice boundary. I elaborate upon this further in Figure 25 in the context of participatory forums, such as CBPR. CIHR (2002) emphasizes the importance of relationships in KT based on trust between knowledge creators and knowledge users. As I discussed in other sections, this process is complex, time-consuming, and resource intensive. However, the alternative (which is the status
quo for the most part) may be even more costly in terms of repeating the same mistakes and not learning from them (i.e., the significance of double-loop learning).

Figure 25 demonstrates the interfaces between types of boundary objects that I introduced in Chapter Five. From the Carlile (2004), Star (1989), and Star & Griesemer (1989) literature, we are reminded that boundary objects are elusive and can be variously described as things, concepts, methods, entities, and models.

**Figure 25. The Interfaces of Boundary Objects: Repositories, Acts/Policies/Standards, Models/Maps/Plans/Projects, and Participatory Forums.**

Typical repositories are medical libraries and health services administrative databases, which aid in representing knowledge at the boundary interfaces. Semantic boundary objects, such as health services acts, policies, and standards provide a means for stakeholders to describe and address their certainties and uncertainties and learn from the problems they are facing. Pragmatic boundary objects, such as service delivery models, maps of health services
jurisdictions, health services plans and projects, assist stakeholders to apply their respective knowledge toward transforming knowledge (changing old knowledge) in use at the boundary. Finally, as I found in this study, the boundary objects most relevant to phronetic boundaries are best described in terms of praxis—continual iterations between theory and practice, and between collective knowing and acting. Participatory forums in locally-situated, multi-stakeholder, knowledge boundary-crossing settings are critical to the success of melding collective knowledge and action. Many of these forums are advanced in the discussion of other Venn diagrams earlier in this chapter.

**Inclusivity in the Health System**

In Chapter Four, I discussed inclusivity, which centres mainly on the concept of community and the importance of creating a sense of community in which local participation and input in the planning process is respectfully and appropriately sought, heard, and used. Creating the conditions by which this genuine engagement can occur is paramount to success. Addressing real-world, practical issues from the perspective of honoring particularity (as opposed to generality), as determined by local needs, substantively contributes to furthering the notion of inclusivity.

The final set of three interfaces (Figures 26 – 28) collectively reflects inclusivity in the health system. In Figure 26, I portray the central role that place plays in the interfaces between the province as a whole, the North, and the North West.
The sense of place, even in one area like health services, is generally weak at the provincial level and comparatively stronger at the local community level. In Chapter Two, I suggested that the concept of place is critical to locality and community. By way of reflection on this point, Casey (2003, p. 2247) characterizes this as "the praxis of place"—an "intimate dialectic"—in a "place-world" (p. 2245). As Joseph & Phillips (1984) remind us, locality is where detailed planning needs to make sense of the broader objectives. This is the boundary interface where supply meets demand. Similarly, Kearns & Gesler (1998) reinforce that health policy cannot be displaced from community, and community cannot be displaced from local territory. Again, in the context of knowledge, Davies, Day, & Williamson (2004) emphasize the importance of place, among other things, when knowledge is formed.

Participants raised a number of examples at the phronetic boundary level. These include a local community-based Health Watch Committee, town meetings, community consultation
processes, and the role of organizational development change agents and health service navigators who facilitate and coordinate access to services for clients, especially those who are marginalized. Place is a boundary object. Like many boundary objects, place “is both physical and spiritual, concrete and imagined, real and symbolic....Place is as much who [emphasis in original] we are, and how we relate to our environment, as where [emphasis in original] we are” (Inter Pares, 2003, p.1). Thus, “the rupture of place” (Inter Pares, 2003) strongly influences power, tradition, demands, and constraints leading, often, to alienation. In many ways, the effect of health system reform has been a rupture of place and the emotivity generated by such disruptions. I found that the data were highly suggestive of the impact of such action. Thus, respecting the essence of community, particularly at the local level where it is often most keenly felt, is important to discourse involving change in the health system, including health services planning.

Figure 27 shows the interfaces between individuals in the health system, the departments/divisions/centres in which they conduct research or perform work, and the organizations that employ or retain them. These interfaces suggest a need for inter-organizational networks. As management and organizational scholars such as Chisholm30 (1998) accurately predicted in the 1990s, inter-organizational networks31 are rapidly becoming the preferred organizational form to meet the complex demands facing organizations. This applies to both service delivery and research initiatives, increasingly including how research-funding agencies are starting to organize their research programs (Dault, Lomas, & Barer, 2004; Gagnon &

30 It is with a great deal of sadness that I acknowledge the sudden passing of Dr. Rupert Chisholm in April, 2004 while running, an activity he practiced on a regular basis, in Gettysburg, PA. Rupert has contributed so much to the theory and practice of network organizations and he will be sadly missed. I take renewed heed to the words he penned in my copy of his text on October 29, 2002. “Let’s continue to build a better world via helping develop networks.” I hope that in some small way I can help to build a better world.
31 Chisholm (1998, p. xxi) defines a network as “a set of autonomous organizations that come together to reach goals that none of them can reach separately.” Chisholm notes that this reflects a number of environmental conditions faced by organizations—increasingly complex issues, growing organizational interdependence, and accelerated change.
Menard, 2001; MSFHR, 2005a, 2005b). A number of examples of networks were described earlier.

**Figure 27. Inter-organizational Networks: The Interfaces of Individuals, Departments/Divisions/Centres, and Organizations.**

Unsurprisingly, network proponents such as Chisholm (1998, 2004, p. 95) attest to the need to:

- conceptualize the system in order to understand the inherent complexity and resultant ambiguity
- engage in systems level thinking in order to conceptualize and collaborate around “complex metaproblems”
- respect voluntary belongingness to, and non-hierarchy of, the network
- develop a “shared understanding of a problem area”, and
- perform functions basic to the regulation, appreciation, and on-going professional development of the network.
Finally, action research (particularly the search conference method) is seen as integral to network development (Chisholm, 1998, 2001). Again, the search conference exemplifies a type of phronetic level boundary object that is characterized by public participation, participatory research, and community development as raised by participants during the course of this study. In terms of linkage to community and community development, networks have a role to play in both structural and processual terms. For example, Gilchrist (2000) suggests that an awareness of community derives from people being engaged in complex relationships and interactions such as that experienced during network development. In this way, inter-organizational network development for health services delivery and research creates the additional significant benefit of creating a sense of community.

Figure 28 demonstrates the sequence of qualitative methods that I used in this study, including semi-structured interviews, focus groups, and a search conference.
These methods are described in detail in Chapter Three and won't be repeated here, other than to emphasize the central role of collaborative action—a boundary object, and both a process (means) and a product (outcome) of this participatory research approach. Again, this means moving toward, and focusing on, collective action. As noted earlier, this sequential qualitative methods approach was authenticated well before I completed this study in the North West. This entailed a number of study participants engaging in locally-based planning. Following from the search conference this led, later in the year, to a highly successful forum on integrating child, youth, and family services which was held in Terrace. The theme and commitment was to take “Talk to Action”, including voluntary public commitments by the participants to take further action. This forum and its success demonstrate the value in using this kind of approach and that
collaborative knowing and action is possible and can be successful. As one of the participants in a findings session noted:

[In fact, if I were a manager who could make some differences in Northern Health, I would plan that…researchers, practitioners, and the policy-makers had to spend time together on a regular basis…. So, if you actually require people to work along the shared vision they would have to make the time…. Someone, some entity, needs to say this is a priority. (Policy-maker, Findings Session)]

Towards a Conceptual Planning Framework

Figure 29 is a conceptual framework in which I incorporate the elements of the initial three conceptual categories introduced in Chapter Four, the two core conceptual categories as discussed in Chapter Five, and the boundary interfaces discussed in this Chapter. Columns (a) – (c) refer to the contents of each of the circles in the preceding Venn diagrams. Column (d), the core, depicts the resultant interfaces of all three circles, including boundary objects created by, and most relevant to, the interface dynamics in each diagram. Recall that in leddu circumstances, it is the core toward which we should progress as a priority consideration in order to move from knowing things to doing things.
Figure 29. A Conceptual Framework to Guide and Unify Participatory Research and Planning in Health Services.

<table>
<thead>
<tr>
<th>Relationship to emergent conceptual categories</th>
<th>(a)</th>
<th>(b)</th>
<th>(c)</th>
<th>(d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceptivity about Health System</td>
<td>Simple Data</td>
<td>Complicated Knowledge</td>
<td>Complex Insight</td>
<td>Chaordic Wisdom</td>
</tr>
<tr>
<td></td>
<td>Disciplinarity</td>
<td>Multidisciplinarity</td>
<td>Interdisciplinarity</td>
<td>Transdisciplinarity</td>
</tr>
<tr>
<td></td>
<td>Sectorality</td>
<td>Multisectorality</td>
<td>Intersectorality</td>
<td>Transsectorality</td>
</tr>
<tr>
<td></td>
<td>Culturality</td>
<td>Multiculturality</td>
<td>Interculturality</td>
<td>Transculturality</td>
</tr>
<tr>
<td>Emotivity Generated by Health System</td>
<td>Syntactic Transferring</td>
<td>Semantic Translating</td>
<td>Pragmatic Transitioning</td>
<td>Phronetic Participatory</td>
</tr>
<tr>
<td></td>
<td>Repositories</td>
<td>Acts, Policies, Standards</td>
<td>Models, Maps, Plans, Projects</td>
<td>Forums</td>
</tr>
<tr>
<td>Inclusivity in Health System</td>
<td>Province Interviews</td>
<td>North Individuls</td>
<td>North West Organizations</td>
<td>Place Networks</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Depts/Divisions/Centres</td>
<td>Search Conference</td>
<td>Collective Action</td>
</tr>
</tbody>
</table>

As one advances across the framework from (a) to (d) a number of increasing dynamics are illustrated. I arrived at these by examining the general characteristics of the Venn diagrams, and incorporating suggestions put forward by study participants during the findings sessions:
- systems orientation
- personal meaning
- communication
- collaboration
- process
- novelty
- sensitivity
- multiplexity
- locally relevant action
- fluidity
- real-world situations
- context
- energy
- enlightenment
- egalitarianism
- progress
- public accountability

Similarly, progressing from left to right in Figure 29 demonstrates movement, transitioning from separate knowing to collective action. It is beyond the scope of this thesis to discuss in greater detail the original Aristotelian works that gave rise to these concepts. However, for anyone interested in exploring the background to the concepts raised here, the translated works of Aristotle (specifically, The Nicomachean Ethics\textsuperscript{32}) are available.

Flyvbjerg (2001, 2003, 2004) revitalizes three Aristotelian intellectual virtues—episteme, techne, and phronesis, which are summarized as follows. Episteme is largely concerned with knowing \textit{why}. This includes universal scientific knowledge, but is independent of context. It aligns somewhat with the tenets of positivism. In contemporary language, this is approximately equivalent to epistemology. Greenwood & Levin (2005) describe episteme as theory and

\textsuperscript{32} See, for example, Book VI at http://classics.mit.edu/Aristotle/nicomachean.html
contemplative knowing. Techne is oriented to knowing *how*. This is best described as pragmatic, concrete, and context-dependent knowledge, such as a craft or art, with the goal to apply the knowledge and skills to produce something practical. In contemporary language, terms such as technical and technology reflect this concept. While techne practitioners are collaborative and involve multiple stakeholders, they are characteristically professional experts who “privilege their own knowledge over that of the local stakeholders”; consequently, they “do things ‘for’, not ‘with’ the local stakeholders” (Greenwood & Levin, 2005, p. 51). Phronesis embraces action, focusing on the variability of specific cases (particularity) and with close attention to, and reflection on, values—a conscious praxis. There is no equivalent contemporary term. This term has faded away over time; however, it relates closely to the notion of prudence and situational wisdom. Of these three intellectual virtues, phronesis is considered to be the most important from an Aristotelian perspective because it may be best able to ensure the ethics of science and technology (Flyvbjerg, 2004). Phronesis is value-focused and moves from collective knowing to collective action. Greenwood & Levin describe phronesis as:

[t]he design of action through collaborative knowledge construction with the legitimate stakeholders in a problematic situation....The sources of phronesis [emphasis in original] are collaborative arenas for knowledge development in which the professional researcher’s knowledge is combined with the local knowledge of the stakeholders in defining the problem to be addressed. Together, they design and implement the research that needs to be done to understand the problem. They then design the actions to improve the situation together, and they evaluate the adequacy of what was done. If they are not satisfied, they cycle through the process again until the results are satisfactory to all parties. (p. 51)
Flyvbjerg (2003, 2004) uses the concepts and principles embraced by phronesis to inform planning and organizational research. Flyvbjerg (2004) has developed methodological guidelines for phronetic planning research. These include: prioritizing values; analyzing the centrality of power; anchoring in reality; attending to “little things”; focusing on practice over discourse; being dependent on case-studies and contexts; narrating history; analyzing planning actors, their practices, and the structures in which they function; and, dialoguing between multiple stakeholders. In particular, explicit attention to power is central to this kind of planning. Interestingly, however, Aristotle did not explicitly consider power in phronesis; other than Flyvbjerg, neither have other scholars (Flyvbjerg, 2004).

I did not specifically set out to engage in phronetic planning research in this study, nor are the phronetic planning research methodological guidelines summarized above meant to be imperatives. Nonetheless, I am struck by the similarities between this approach and my own study. With the emergence of boundaries and boundary objects from the data in this study and the convergence toward knowledge boundaries and related boundary objects in the context of planning for child and youth health services in North West BC, there is considerable overlap with the notion of phronetic planning research. This study may represent an uncommonly empirical perspective in this regard.

Through this framework, I have suggested an approach to planning and a means to identify, understand, and act upon the issues facing stakeholders involved in child and youth health services planning. While the theory and framework are developed from findings emerging from the qualitative data generated during the course of this research in North West BC, the process and framework should be transferable to other geographical areas, population groups, and health service planning milieus. I now suggest a number of implications of these findings,
including: future research, child and youth health services research and planning, interorganizational child and youth health networks, and stakeholders involved in these processes.

**Implications for Future Research**

New research in this area revives the old idea of consilience, first raised over a century and a half ago in the context of philosophy and inductive sciences (Whewell, 1840 as cited by Wilson, 1998). I raise it here in the context of the integrative framework that brings together a number of boundary interfaces and the boundary objects that transect them. Similar to the observations of Bohm (1980) and Capra (1996) as discussed earlier, Wilson (1998, p. 41) recognizes that “[t]he ongoing fragmentation of knowledge and the resulting chaos in philosophy are not reflections of the real world but artifacts of scholarship.” He proposes consilience as a promise—the key to unification—“a ‘jumping together’ of knowledge as a result of the linking of facts and fact-based theory across disciplines to create a common groundwork of explanation.” In terms of phronesis and praxis, the promise is that “[o]nly fluency across the boundaries [emphasis added] will provide a clear view of the world as it really is.”

Again, we are reminded of the need to pay explicit attention to the boundaries in the health system. As I suggested in Chapter Two in the context of CAS, participatory research, health care geography, and knowledge translation, and as the data in this study have suggested in Chapters Four and Five, boundaries need to be central, not marginal, to the work of health services research, planning, and service delivery. In this context, Hernes & Paulsen (2003, p. 6) purport that “individuals may be considered to be almost perpetually in ‘liminal’ situations where they both move between boundaries and carry the boundaries with them.” The boundary interfaces and conceptual framework developed in this Chapter will assist in this awareness-building and, more importantly, assist in actual planning processes. This suggests both the need

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33 The Concise Oxford Dictionary, 9th Ed. (1995) defines liminal as “occupying a position on, or on both sides of, a boundary or threshold.”
for stakeholder awareness of boundaries and boundary objects, and a capacity to incorporate
liminality in future research endeavours.

Earlier studies of boundaries have raised implications for future research on the types of
boundaries that face stakeholders and what this means to people and organizations (Carlile,
2004). In this study, I have empirically demonstrated many boundaries in the context of child
and youth health services and introduced their importance to several stakeholder groups. Further
categorization and refinement of these boundaries and the implications for the public, clinicians,
managers, and policy-makers are required in terms of awareness-building, education and
training, and relevance to the issues being faced. As Paulsen & Hernes (2003) point out, the
concept of boundaries has been derived more from a theoretical perspective than from reality.
This study has inductively and empirically derived the concept of boundaries in child and youth
health services. Further research is required to demonstrate the potential for broader application
of the concept in other jurisdictions and with other population groups. Heracleous (2004) calls
for further empirical research using a grounded, inductive approach, such as used in this study.
Paradoxically, how to bring boundaries (often perceived as marginal) to the centre of attention
will require a concerted research effort.

Similarly, earlier studies of boundary objects suggest a need to expand their classification
(Carlile, 2002; Star, 1989). I have suggested such an expanded classification in the context of
child and youth health services through, for example, the introduction of boundary objects
relevant to phronetic boundaries. Further classification of the types of boundary objects and their
relevance to particular types of health services and other planning environments, and under what
conditions are also topics for future empirical research. It would be helpful to examine
implications for stakeholders involved in planning health services in other geographical
jurisdictions and with other population groups, particularly in circumstances that involve a high degree of collaborative efforts to address complexity, uncertainty, and novelty.

This is also an appropriate point to share a few thoughts about what I would do differently if I were to do another similar study. Overall, the research design, methodology, and methods were appropriate and fit well with the purpose of, and questions posed by, this study. In future research, I would explore ways to expedite the ethics and research review processes that spanned several institutional jurisdictions as I discussed in Chapter Three. Thus, scoping out the requirements for simultaneous, as opposed to sequential, multi-jurisdictional ethics and research review processes could save considerable time and energy. However, part of this protraction was due to my own learning process as a graduate student.

I did give serious consideration to forming a North West Community Advisory Committee to help guide the PAR approach but, in collaboration with my supervisor, ultimately decided against it. This was mainly because I had a comparatively large thesis committee (seven members from three universities) and to collaborate and co-ordinate on the conduct of the research could have proved too onerous. In future research, however, I would reconsider this as an additional means to ensure that the notion of locality and its interconnectedness to the broader health system, for example, the NHA, BCMOHS, and BCMCFD is ensured. This was achieved in the study, but the relationship with the broader system was dependent on a relatively few number of participants.

With respect to data gathering, I chose to only audiotape the interviews, focus groups, and the search conference. For the future, I would seriously contemplate using video and audio recording. As I described in Chapter Four, emotivity generated by the health system was very significant. Capturing the emotive content visually may assist in data analysis and help to develop further insights in this area, particularly in terms of how the stakeholders interacted with
each other during the focus groups and search conference, and how this may have changed over
time as a sense of community and an increasing level of trust was generated.

With respect to the search conference and the results it produced through this
collaborative arena, I would make even greater efforts to increase the number of participants,
attempt to equalize the numbers in each of the stakeholder groups, and try to ensure greater
attendance by Aboriginal participants. I did make a concerted effort to address these points and,
given the geographical challenges, availabilities, and real-world circumstances facing all of the
participants, I am satisfied with the level of participation. Perhaps extending the preparatory
timeframe would have helped but, even then, there would have been no guarantee of increased
attendance or more balanced stakeholder groups, particularly by the senior management and
policy-makers. Additionally, increased “high-level” participation would have, perhaps,
symbolized a higher level of commitment to the importance of addressing child and youth health
services in the North West. Participants tend to notice who is and who is not present and surmise
why.

Finally, given the volume of qualitative data generated during the course of the study, use
of data analysis software as a tool to assist in the organization and management of the data would
be helpful in future research. On the other hand, computerized data analysis does not replace the
thinking and work required of the researcher.

**Implications for Child and Youth Health Services Research and Planning**

Health services research is inching towards a purposive and appropriate intersection with
health services planning and decision-making. This is occurring in the context of concerted efforts
to recognize and bridge theory and practice and researchers and decision-makers (CHSRF,
1999). Still, a CAS perspective is largely missing. As Pang, Sadana, Hanney, Bhutta, Hyder, &
Simon (2003, p. 815) recently contend, “[h]ealth research is too often a fragmented, competitive,
highly specialized, sectoral activity where researchers within scientific disciplines often work in isolation from other disciplines.”

Child health services research can specifically enhance research capacity in the areas of childhood transitions to adulthood (Forrest, Simpson, & Clancy, 1997). Indeed, a subfield of child health services research has emerged to address the substantive differences between health care needs of children and adults, including development, dependence, epidemiological and demographic profiles, and disparities in services and outcomes (Gidwani, Sobo, Seid, & Kurtin, 2003). CBPR is a form of applied health services research. In the context of children, such research requires close collaboration between researchers, providers, and users (Kurtin, 2003). Linking knowledge and action is paramount (Kurtin, 2003).

On the one hand, evidence supports a democratic, participatory approach to solving health services and related issues; on the other, day-to-day practice often runs counter. Views expressed from the municipal government and health authority (McCallum, O’Connor, & Butler-Jones, 2003) further support this dissonance: coalition-building should align with political processes, listen to the community, go to where the power is in the community, and recognize that communities have the right answers. In other words, ask the right questions of the right people and you will most likely get the right answers. But, this often does not happen in practice. So, we are left with the nagging challenge of how to go about identifying and engaging the key stakeholders who can facilitate action. As the concept and principles of KT raised in Chapter Two become better understood in the context of boundaries and boundary objects, this could provide an effective means to facilitate the multiplexity of interactions necessary to ensure meaningful dialogue between all stakeholders involved in the planning process.

Reviewing how prominent scientists in the 1800s, such as Louis Pasteur and John Snow succeeded in their research endeavours provides further lessons. Pasteur, for example, not only
conceived of the new science of microbiology, but also enabled practice by mobilizing key stakeholders, including farmers, laboratory workers, clinicians, and politicians (Birdsell, Atkinson-Grosjean, & Landry, 2002). Similarly, John Snow worked closely with neighborhood and health officials to remove London’s Broad Street water pump handle, thus halting the spread of cholera. These highly collaborative, practical, local, and real-world approaches reinforce the concept of phronesis—collective action through collective knowledge, as described earlier. In child and youth health services, this means actively engaging all of the key stakeholders, including the public (parents, youth, and children, where practicable), clinicians, managers, and policy-makers, throughout the entire research and practice processes. The sharing of formative thinking processes early in the research help to build the requisite relationships upon which to build trust and initiate the planned strategies for change. The boundary and boundary object framework proposed in the context of research and local, community-based action puts a strong emphasis on local participation. This is where the day-to-day realities of child and youth health service delivery are confronted, best understood, and have the greatest chance of unifying the research / action continuum. Doing this will bolster democratic principles, strengthen the particularity of local communities, reorient stakeholder perspectives, and create the conditions necessary for collective action in real-world settings.

In the context of child and youth health services, this challenge is even more difficult. For example, Simpson (2004) draws attention to the extensive literature internationally for over two decades that fails to include a focus on child health issues. Such issues are critical, in her view, to determine “what works” and how to get the key stakeholders to “do [emphasis added] what works” (Simpson, 2004, p. 126). This gap between research and practice—discovering what works and doing what works—suggests not only the critical role of KT, but the critical role of health services research methods as a means to bridge the theory/practice divide. I highlighted this in Chapter Two. As Dennis (2003) urges, child health services research, in addition to
developing strong community relationships, must engage policy-makers and providers, and pay particular attention to the critical interdependencies between these stakeholders. These and other interdependencies in the context of evidence can be addressed through the lens of CAS, including the need for genuine engagement of consumers in this process (Lindstrom, 2003).

**Implications for Inter-organizational Child and Youth Health Networks**

There is a need for further research to better understand the structure and process of networks, their developmental trajectory, and their impact on health outcomes. Despite the interest and activity in this area, an evidentiary void persists. If inter-organizational networks are, as Chisholm (2004) purports, the organizational form best able to deal with the complexities of 21st century health services, then attention to best-practices for the development of these networks is critical. Certainly, such structures capture the intent of integrated services toward which health reform continues to strive.

Networks, in particular inter-organizational networks, are emerging as important organizational forms (see for example, Birdsell & Matthias, 2003; CHSRF, 2005b; Chisholm, 1996, 1998, 2004; Dolinski, 2005; Hill, 2002; Lindstrom, 2000; Tagliaventi & Mattarelli, 2006; Tung, 2002). Networks are necessary to reach goals and address complex issues that are beyond the capability of single organizations working independently (Chisholm, 1998), and to capture the value-based emphasis of phronesis:

Networks have the capacity of enabling individuals, groups, and organizations to develop and put into practice a new set of post-industrial beliefs and values—beliefs that emphasize interconnection, holism, pluralism, and cooperation. These beliefs are highly congruent with the self-regulatory, collaborative nature of interorganizational networks. (p. 228)
The development of effective networks in health promises to improve care, share information, and maintain high standards; however, based on a recent review of 16 successful health networks in Canada, this has been characterized as "almost a matter of good luck" (Change Foundation, 2004, p. 4). Similarly, the CHSRF (2005, p. 1) suggests that "something more like faith than evidence is driving these new inter-organizational structures." This concern is causing organizations such as CHSRF to concentrate more on people, as opposed to organizations, with a view to improve the exchange of informal knowledge.

Others, such as CYHNC have taken on the challenge of determining what it is about networks that make them work. As I raised in Chapter Two, CYHNC is a "network of networks" formed in 2001. I was privileged, and continue, to play a major role in its inception and development at the national level. My contributions at this national scale are directly related to my study in the North West in terms of a multiple stakeholder participatory strategy of inquiry and the need to include rural contexts. As a network, CYHNC continues to grapple with how to best organize and develop given the dearth of evaluative research in this area (CYHNC, 2005, p. 1). A major evaluative research question is currently being addressed through a number of potential research funding opportunities: "Are inter-organizational networks an effective and efficient means to address the child and youth health service delivery issues faced by member organizations?" (CYHNC, 2005, p. 4).

There are many research implications for network planning and development incorporating a boundary and boundary object framework. Networks as "bundles of boundaries" (source unknown) represent multiple intersections of stakeholders' worlds. In this context, it is critical to determine what are the boundaries at work and what are the boundary objects (the things, processes, concepts, that traverse such boundaries). As I suggested in the context of the boundary/boundary object framework in Chapter Five, it is important to identify and match the
correct boundary object with the correct boundary. This type of approach necessitates earlier and more applied education and training for people involved in network development. This includes an acknowledgment of the value of participatory approaches to planning in spite of the additional time, energy, and resources this takes. Such an approach necessarily engages local communities in the context of the broader health system. It will help us to find common ground—the same goal as a search conference, which is one of a repertoire of participatory methods that can be used as an appropriate boundary object in the context of planning child and youth health service delivery inter-organizational networks. As is often the case, wisdom flows easily from those closest to the issues. I highlight here the words of a parent whose insight is worth heeding as we continue to plan and develop more integrated, networked services for children and youth:

> Everybody has their own policies, their own thoughts, on the way things should be, instead of finding a common ground that they'll agree on. They're so busy trying to make it their way. The health community runs things their way. School board does things their way. And the parents all work individually, instead of as a group. So, I think they need to start by all working together. (Parent)

**Implications for Stakeholders**

Participatory research approaches, including health services research, continue to gain credibility in health care settings. This reinforces the need to create opportunities to incorporate participatory planning methods and tools that can assist in overcoming stubborn obstacles to collaboration as outlined earlier. This raises the question of who participates.

In terms of which stakeholders participate and which don’t, Thomas-Slayter (1995, p. 10) observes “ultimately it is the professional planners who determine levels of people’s participation.” This problem of who determines participation is germane to a successful multi-stakeholder planning process. Professional planners are not common-place in the BC health environment, particularly at the Health Authority (HA), regional, and community levels. In their stead, political decision-makers (which, for the purposes of this study, includes health authority
board members, civic leaders, and others who influence health policy) and health executives (for example, administrators, directors, and managers) largely assume this planning role. This often occurs in the absence of professional training in the theory and practice of health services planning and policy-making. Nelson & Wright (1995) warn that participatory approaches must be backed by an institutional commitment to participation—more than what is stated in their documents. They raise several possibilities, including: shifting power to constituents; shifting power in organizations to close the gap between participatory rhetoric and actual behaviour; and, closing the gap between rhetoric and practice in organizations.

Planning health services for children and youth poses additional challenges. Beyond meeting the typical health service delivery needs of the general adult population, several requirements unique to children and youth must be addressed. These include, for example: recognition of the child/family unit; sensitivity to voice (including that of children and youth) and advocacy; time-sensitive biological and cognitive developmental imperatives; issues around life-course transitions; availability of family practitioners, pediatric generalists, specialties, and sub-specialties, nursing, therapy, psychological, child life, numerous diagnostic and therapeutic paramedical personnel, and other professional human resources; and, highly technical and typically centralized tertiary/quaternary services. Balancing competing needs with resource availability (human, technical, physical, and fiscal) presents a number of challenges, especially in rural and remote areas of the province such as the North West. Combined with the lingering ripple effects of former New Era restructuring and hospital role changes and downsizing, including pediatric beds and related resources, this presents challenges beyond the purview and expertise of any single perspective. Participatory forums acknowledge and embrace collective action through the means that I discussed earlier in this chapter. Such planning and decision-making should honour the role that local communities and stakeholders play in practical solutions to these problems.
This need is exemplified by the follow-up actions to the study’s search conference as referenced earlier. Specifically, the November, 2005 forum – “Integrating Child, Youth and Family Services in the North West” – was organized by several local and distant study participants as a direct result of the search conference. (See Appendix H). This local action initiative highlights the attention paid to addressing child, youth, and family planning issues and priorities. These are directly related to my study in the North West. The salient actions were described earlier in Chapter Three in the context of qualitative authenticity criteria.

However, “many healthcare decisions are based principally on...opinion-based decision-making; little attention has been given or is paid to evidence derived from research” (Gray, 1997). Nearly 10 years ago, but still relevant today, The Final Report of the National Forum on Health (1997) described the gaps and underuse of such evidence. This Report underscores the importance of the role of communities in health, recognizing the critical role that local communities play in problem identification, leadership, and action. This is especially true for child health and presents a unique opportunity to understand and develop new and exciting insights into how to best address these shortfalls. For child health services research and planning the issues are complex, as I described earlier. There are unique issues concerning the Northern BC local rural and remote health agenda context. This includes, for example, modeling rural systems and communities with health as a central pillar, toward sustainable human-environmental relationships (Troughton, 1999). Addressing place is also key to understanding how to go about this, as I stressed in Chapter Two. The impact of participatory methods on practice creates tension between principle (including political) and expediency (Cornwall, 1996). This is especially relevant in the current political climate in this province, which seems to favor financial results over due process. Finally, health planning and policy generally, and for child health services specifically, requires special consideration of process and genuine engagement in a climate of uncertainty with, and distrust of, institutionalized power structures. This is especially
relevant with respect to Aboriginal issues. Unsurprisingly, the residential school debacle and
land claims issues have cause irreparable damage to, and distrust of, the relationship between
Aboriginal people and government. The framework that I have proposed can serve to raise
awareness of the complexity of the health system and the kinds of processes that can be engaged
to work collectively toward action in a way that respects all stakeholders.

The findings sessions afforded me the opportunity to share what participants had told me
during the data gathering stages and provided a means to explore ways to solve some pressing
issues such as how to go about planning integrated child and youth health services in the North
West. The Venn diagrams and resultant conceptual framework resonated well with the study
participants. During these sessions, participants frequently raised the question of how the
conceptual framework could be used to address day-to-day practical issues. I responded in two
ways. First, I shared my commitment to creating a ‘thin’ version of this thesis which could be
used in the North West as a planning framework for implementation during planning processes
in circumstances that require this kind of multiplexity of approach. This would be written with
less emphasis on academia and more on practice. Second, I emphasized the critical importance of
thinking about how health services planning should be approached in order to respect the
principles of Icddu in the context of the broader health system. Such an application requires the
inculcation of a different way of thinking about and framing problems, such as raised in Chapter
Two and illustrated through the perspectives of participants in Chapter Four. As a policy-maker
pointed out during one of the findings sessions, there is a risk of this conceptual framework
being adopted in totality, thus setting up a possible risk of failure because users may try to do too
much but only be able to achieve a marginal benefit. This caution supports the need for a thin
version framework which could be introduced as part of HA and organizational strategic change
management initiatives. Further study is required in order to determine how best to introduce
these concepts in practice settings. In other cases, this comprehensive approach may not be
Concluding Remarks

I have explored through this study an approach to planning child and youth health services in North West BC, emphasizing a multiple stakeholder, community-based participatory research and planning process. I have approached the research problem, used a unique sequence of qualitative methods to gather qualitative data in the conduct of the research and, through the use of an inductive method of data analysis (constructivist grounded theory), recognized the emergence of three major conceptual categories: perceptivity about the health system, emotivity generated by the health system, and inclusivity in the health system. Through the identification of a number of dyadic relationships, I wove a common thread. Two core conceptual categories emerged from the data—boundaries and boundary objects. I further developed these in the context of an existing framework of knowledge boundaries and boundary objects, and substantively contributed to that framework. I introduced three knowledge boundary levels: syntactic, semantic, and pragmatic, based mainly on earlier empirical research by Carlile. However, this earlier research did not identify a fourth level, which I have termed phronetic, and which emerged from the data in this study in the context of a public sector industry (health). From the data generated in this study, I suggested that the characteristics of boundary objects at this phronetic level are fluid, real-time participatory, and collaborative in locally-situated, multi-stakeholder, boundary-crossing settings. These boundary objects unify collective knowledge and action in ways meaningful to stakeholders and relevant to their local circumstances.

Through this study I have illustrated several interface dynamics which together constitute a conceptual framework towards collectively informing, integrating, and unifying research and planning practices demonstrating ways to approach planning for health services for children and
youth in North West BC. This approach and resultant framework may also be of assistance in planning complex health service issues in other population groups and geographical jurisdictions.

As I reflect on the journeys introduced in Chapter One—intellectual, technical, geographical, and liminal—I believe that we (i.e., me, as researcher, and the study participants) have been able to bridge the boundary (often a barrier) between rhetoric and reality. This was possible because of many sincere stakeholders, including the public, clinicians, managers, and policy-makers, who were willing to be involved in, and dedicated a lot of time to, this study. They were genuinely engaged and contributed so much to the study. Collectively, we moved beyond the rhetoric of participatory planning in health services in BC, demonstrating how it can be accomplished with a genuine honoring of, and emphasis on, local nuances in the context of the broader health system. This has reinforced for me the essential role that participatory research (PR) has in planning health services. I have experienced and, hopefully, contributed to several key characteristics of this approach: genuine participation by multiple stakeholders; the conduct of rigorous health services research; relevant on-the-ground action; transformative learning, both by me as the researcher and by participants; and a sincere effort to reduce any perceived or real power differentials at so many levels.
References


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Appendices
Appendix B

Sampling Criteria for Public/Service Recipient group
(Parent/legal guardian/child or youth)

N=10 (approx.)

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<thead>
<tr>
<th>Category</th>
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<td>Acute injury with hospitalization (including result of violence, crime)</td>
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</tr>
<tr>
<td>Acute medical with hospitalization</td>
<td>2</td>
</tr>
<tr>
<td>Special needs/chronic medical (with or without hospitalization)</td>
<td>2</td>
</tr>
<tr>
<td>Mental health/behavioural (with or without hospitalization)</td>
<td>2</td>
</tr>
<tr>
<td>Tertiary care at BC Children’s or Sunny Hill (with or without hospitalization)</td>
<td>2</td>
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Additional criteria (as part of the above N=10)

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<tr>
<td>Male/Female</td>
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<tr>
<td>Ethnicity – Aboriginal/Caucasian</td>
<td>3/7 or 4/6</td>
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<tr>
<td>Age – Preschool/Primary &amp; Middle schools/Secondary school</td>
<td>3/10; 4/10; 3/10</td>
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(Note: If possible, I would prefer to interview the youth subjects in the Secondary school group rather than their parents, providing there is parental/legal guardian consent.)

Version: October 9, 2003
Appendix C

5) BC Ministry of Children and Family Development through the Human Early Learning Partnership.
There is no known actual or potential conflict of interest between the researchers and the funding sources.

Study Procedures:
You are being invited to participate in 3 separate components of this study – an interview, a focus group, and a participatory planning conference. First, an interview will last for approximately 90 minutes which will consist of a series of questions about your perceptions of, experiences with, and views about the health system and child and youth health services in the North West. The session will be audiotaped.

Second, the focus group will last for approximately 2 hours to explore in more depth the results of the interviews. The session will be audiotaped.

Third, you are being invited to participate in a participatory planning conference over 1½ to 2 days to expand upon the previous interviews and focus group results. This will also include the sharing of your historical views, developing a common vision for the future, co-creating action plans to reach the goals, prioritizing actions, and linking planning to action. The sessions will be audiotaped.

Confidentiality:
All information (identifiable data) obtained during this study will be treated confidentially. All identification will be removed from the transcripts created from the interviews, focus groups, and the participatory planning conference. You will not be identified by name in any reports of the completed study; however, in the event that you prefer to have your comments attributed to you, your review and approval of your comments will be requested prior to publication of any reports of the completed study. Confidential information (identifiable data) will not be collected nor exchanged via email. Only the research investigators and research assistants will have access to the audiotapes and transcripts now and in the future. The audiotapes and transcripts will be kept in a locked filing cabinet in a locked office. The electronic transcribed data will be kept in a password-protected computer.

Only limited confidentiality can be offered in focus groups and in the participatory planning conference. All participants will be encouraged to refrain from disclosing the contents of the discussion outside of the focus groups and participatory planning conference; however, we cannot control what other participants do with the information discussed.

Remuneration/Compensation:
You will be paid the following at the completion of each session:
Appendix D

Questions to Guide the Semi-structured Interviews

1. **How are you involved with the health system in the North West?**
   *Prompt: With health services for children and youth in the North West?*
   *Prompt: In the Northern Health Authority?*
   *Prompt: In the province?*

2. **We hear and read a lot about the health system. What does the term “health system” mean to you?**
   *Prompt: In the North West?*
   *Prompt: In the Northern Health Authority?*
   *Prompt: In the province?*

3. **What are your views on health services for children and youth in the North West?**
   *Prompt: What are your views on how these services are planned?*
   *Prompt: What is your understanding of how this planning activity works?*
   *Prompt: In the past, how have you participated in the planning of these health services?*
   *Prompt: How did your participation make a difference?*
   *Prompt: How are you participating in this planning activity now?*
   *Prompt: How is your participation making a difference?*

4. **What facts, figures, and information do you think would help improve health services for children and youth in the North West?**
   *Prompt: To identify what the needs are?*
   *Prompt: To increase your understanding of the needs?*
   *Prompt: To guide the planning of health services?*
   *Prompt: To guide children, youth and families who access and utilize the health services?*
   *Prompt: To guide clinical service providers who make decisions about the health care of children and youth?*
   *Prompt: To guide managerial decision-makers who make decisions about organizing and operating health services?*
   *Prompt: To guide policy decision-makers who make decisions about health policy, future directions, and major changes in the health system?*
   *How would you like to see these facts, figures, and information presented and made available?*
   *Prompt: To whom?*

5. **What are your thoughts on the best way to go about improving health services for children and youth in the North West?**
   *Prompt: In the Northern Health Authority?*
   *Prompt: In the province?*
Appendix D

6. If this "best way" was adopted, do you think it would help people in the following groups? If so, how?:
   - children, youth and families who access and utilize the health services?
   - clinical service providers who make decisions about the health care of children and youth?
   - the managerial decision-makers who make decisions about organizing and operating health services?
   - the policy decision-makers who make decisions about health policy, future directions, and major changes in the health system?
   - others?

7. The term "community" is used a lot in everyday communication. What does the term "community" mean to you?
   Prompt: In the North West?
   Prompt: In the Northern Health Authority?
   Prompt: In the Province?
   Prompt: Have you experienced a sense of community in relation to health services for children and youth? How?

8. What are your views on how the geography of the North West affects the planning and implementation of health services for children and youth in the North West? What are your views on how the geography affects the utilization of these health services? (For this question, geography includes such things as: mountains, water, weather, distance, transportation, where people live, and the location of health services).
   Prompt: In the Northern Health Authority?
   Prompt: In the Province?

9. Are there any other important topics or problems that you think should be addressed in relation to health services for children and youth in the North West?
   Prompt: In the Northern Health Authority?
   Prompt: In the Province?
Appendix E

Questions to Guide the Focus Groups

1. How are you involved with the health system in the North West?

2. We hear and read a lot about the health system. What does the term “health system” mean to you?
   Prompt: Include idea of lines, interfaces, edges, borders, boundaries (barriers and relationships/exchange) and what happens there.

3. What are your views on health services for children and youth in the North West?
   Prompt: What are your views on how these services are planned? Include idea of lines, interfaces, edges, borders, boundaries and what happens there.

4. What facts, figures, and information do you think would help improve health services for children and youth in the North West?
   Prompt: To guide the planning of health services? Include idea of lines, interfaces, edges, borders, boundaries and what happens there.

5. What are your thoughts on the best way to go about improving health services for children and youth in the North West?
   Prompt: Include idea of lines, interfaces, edges, borders, boundaries and what happens there.

6. The term “community” is used a lot in everyday communication. What does the term “community” mean to you in the context of health services for children and youth?
   Prompt: Include idea of lines, interfaces, edges, borders, boundaries and what happens there.

7. What are your views on how the geography of the North West affects the planning and implementation of health services for children and youth in the North West? What are your views on how the geography affects the utilization of these health services? (For this question, geography includes such things as: mountains, water, weather, distance, transportation, where people live, and the location of health services).
   Prompt: Include idea of lines, interfaces, edges, borders, boundaries and what happens there.

8. Are there any other important topics or problems that you think should be addressed in relation to health services for children and youth in the North West?
   Prompt: Include idea of lines, interfaces, edges, borders, boundaries and what happens there.
Appendix F

SEARCH CONFERENCE – AGENDA
Tuesday April 19th and Wednesday April 20th 2005
Health Unit – Auditorium (main floor)
3412 Kalum Street, Terrace, B.C.
*All sessions will be audiotaped

"...an excellent means of planning large-scale systems change in real time, and it generates excitement, energy, and purposeful behavior." (Emery & Purser, 1996:4)

This 2-day search conference (participatory planning conference) brings together 25-30 participants as "co-researchers" (family members; managers; clinicians; policy-makers). This conference is the final component in a sequence of three data gathering methods for the North West Research Project (42 semi-structured interviews and 4 focus groups have been completed to date). The overall project explores how to identify child and youth health service needs, and how to guide the development and utilization of health services in the North West Health Service Delivery Area. The results of this study, including this conference, are expected to lead to more effective multi-stakeholder, community-based approaches to planning and developing better integrated services for children, youth and their families.

Through a combination of plenary and small group dialogues, the goals of this planning conference are to:

- refine and expand upon the findings emerging from the previously conducted semi-structured interviews and focus groups
- co-create a shared history and the current reality of child and youth health services in the North West
- co-create an ideal future for child and youth health services in the North West and prioritize realistically attainable goals
- co-create action ideas and strategies to realistically attain prioritized goals
- co-create action teams to follow-up on, and be responsible for, prioritized ideas, strategies and goals.

**Day 1 – Tuesday, April 19th**

0900 – 0920: Welcome – Ron Lindstrom
Opening Prayer – Isabelle McKee, Elder, Kitselas Band
Overview of conference, logistics, and expectations for Day 1

0920 – 0945: Introductions by all participants

0945 – 1000: The North West Research Project and findings to date
Appendix F

STAGE 1 – RECALLING THE PAST AND APPRECIATING THE PRESENT

1000 – 1130: Collectively create a shared history and current reality of child and youth health services in North West, including the identification of significant environmental trends. Includes key events/milestones at the global, local, and personal level. This will be achieved by 4 small groups of mixed participants (ie, family members; clinicians; managers; policy-makers).
Includes refreshments (provided)

1130 – 1200: Small groups report back to large group; create collective “mind-map”

1200 – 1245: LUNCH


STAGE 2 – LIVING THE FUTURE

1330 – 1500: Collectively create an ideal future for child and youth health services in the North West, say, by 2010. This will include a recognition of a probable future... if no action is taken. This will be achieved by 4 small groups of mixed participants

1500 – 1530: Small groups report back to large group
Includes refreshments (provided)

STAGE 3 – MOVING INTO ACTION

1530 – 1700: Collectively identify action ideas and strategies to attain desired future. This will be achieved by 4 small groups of mixed participants

1700 – 1730: Initially prioritize action ideas and strategies. This will be achieved individually in large group setting

1730 – 1745: Summary of Day 1 – Ron Lindstrom
Appendix F

Day 2 – Wednesday, April 20th

0830 – 0845: Welcome back; questions and clarification; and expectations for Day 2 – Ron Lindstrom

STAGE 4 – PRIORITIZING IDEAS

0845 – 0900: Review initial priorities and categories

0900 – 1030: Collectively (re)prioritize and (re)categorize the action ideas and strategies in large group

1030 – 1045: Refreshment break (provided)

1045 – 1145: Review, finalize, and group the prioritized action ideas

1145 – 1230: LUNCH

STAGE 5 – ACCOMPLISHING CHANGE THROUGH VOLUNTEER ACTION TEAMS

1230 – 1300: Create action teams to follow-up on, and be responsible for, prioritized strategies and goals

1300 – 1515: Planning session for action teams to develop planning framework, integrate with group goals, and agree on time-line
Includes refreshments (provided)

1515 – 1545: Action teams report back to large group

1545 – 1600: Summary of Day 2 and wrap-up of conference – Ron Lindstrom
Closing Prayer – Isabelle McKee, Elder, Kitselas Band

Prepared by: R. Lindstrom
April 15, 2005
Appendix G2

North West BC
2003/04 MH not served by formal system 0 - 19 yrs

km
# Certificate of Approval

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<th>Department</th>
<th>Number</th>
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<td>Armstrong, R.W.</td>
<td>Paediatrics</td>
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**Institution(s) Where Research Will Be Carried Out**
- UBC Campus

**CO-Investigators**
- Lindstrom, R.R., Medicine

**Sponsoring Agencies**
- Canadian Institutes of Health Research

**Title:**
- A System and Rural Community-Based Approach to Planning Child Health Services in BC

**Approval Date:**
- Aug 13, 2003

**Term (Years):**
- 1

**Documents Included in This Approval:**
- August 6, 2003, Contact letter;
- July 11, 2003, Consent forms / Questionnaires

**Certification:**

The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

---

*Approval of the Behavioural Research Ethics Board by one of the following:*
  - Dr. James Frankish, Chair,
  - Dr. Cay Holbrook, Associate Chair,
  - Dr. Susan Rowley, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures.
Certificate of Approval

PRINCIPAL INVESTIGATOR
Armstrong, R.W.

DEPARTMENT
Paediatrics

NUMBER
B03-0426

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT
UBC Campus

CO-INVESTIGATORS:
Lindstrom, Ron, Medicine

SPONSORING AGENCIES
Human Early Learning Partnership (HELP)

TITLE:
A System and Rural Community-Based Approach to Planning Child Health Services in BC

APPROVAL DATE
03-08-13

TERM (YEARS)
1

AMENDMENT:
Oct. 9, 2003, Consent form / New funding source

AMENDMENT APPROVED:
OCT 23 2003

CERTIFICATION:
The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval of the Behavioural Research Ethics Board by one of the following:
Dr. James Frankish, Chair,
Dr. Cay Holbrook, Associate Chair,
Dr. Susan Rowley, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures.
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**INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT**  
Children's & Women's Health Centre, UBC Campus,

**CO-INVESTIGATORS:**  
Lindstrom, Ron, Medicine

**SPONSORING AGENCIES**  
Canadian Institutes of Health Research

**TITLE:**  
A Systems and Rural Community-Based Approach to Planning Child Health Services in BC

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**CERTIFICATION:**  
The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

( )

Approval of the Behavioural Research Ethics Board by one of the following:  
Dr. James Frankish, Chair,  
Dr. Cay Holbrook, Associate Chair,  
Dr. Susan Rowley, Associate Chair  
Dr. Anita Hubley, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures.
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**INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT**

Children's & Women's Health Centre, UBC Campus,

**CO-INVESTIGATORS:**

Lindstrom, Ron, Medicine

**SPONSORING AGENCIES**

Human Early Learning Partnership (HELP)

**TITLE:**

A Systems and Rural Community-Based Approach to Planning Child Health Services in BC

**APPROVAL DATE**

July 2, 2004

**TERM (YEARS)**

1

**DOCUMENTS INCLUDED IN THIS APPROVAL:**


**CERTIFICATION:**

The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

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- Dr. Cay Holbrook, Associate Chair,
- Dr. Susan Rowley, Associate Chair
- Dr. Anita Hubley, Associate Chair

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Certificate of Approval

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<td>B04-0478</td>
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**Institution(s) Where Research Will Be Carried Out**
Children's & Women's Health Centre, UBC Campus,

**Co-Investigators:**
Lindstrom, Ron, Medicine

**Sponsoring Agencies**
University of British Columbia

**Title:**
A Systems and Rural Community-Based Approach to Planning Child Health Services in BC

**Approval Date**
JUL 2, 2004
**Term (Years)**
1

**Documents Included in This Approval:**

The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval of the Behavioural Research Ethics Board by one of the following:
Dr. James Frankish, Chair,
Dr. Cay Holbrook, Associate Chair,
Dr. Susan Rowley, Associate Chair
Dr. Anita Hubley, Associate Chair

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**INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT**

- UBC Campus

**CO-INVESTIGATORS:**

- Lindstrom, Ron, Medicine

**SPONSORING AGENCIES**

- Canadian Institutes of Health Research

**TITLE:**

A System and Rural Community-Based Approach to Planning Child Health Services in BC

**APPROVAL DATE:**

- 04-07-08 (04/07/2008)

**TERM (YEARS):**

- 1

**AMENDMENT:**

- Oct. 4, 2004, Reimbursement method

**CERTIFICATION:**

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Institution(s) where research will be carried out:
- UBC Campus

Co-investigators:
- Lindstrom, Ron, Medicine

Sponsoring Agencies:
- Human Early Learning Partnership (HELP)

Title:
A System and Rural Community-Based Approach to Planning Child Health Services in BC

Approval Date: 04-07-08

Term (Years): 1

Amendment: Oct. 4, 2004, Reimbursement method

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**CO-INVESTIGATORS:**

Lindstrom, Ron, Medicine

**SPONSORING AGENCIES**

Faculty of Medicine/Dean's Office Summer Student Research Pg

**TITLE:**

A System and Rural Community-Based Approach to Planning Child Health Services in BC

**APPROVAL DATE:**

04-07-08 (yr/mo/day)

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Children's & Women's Health Centre, UBC Campus,

**Co-Investigators:**

Lindstrom, Ron, Medicine

**Sponsoring Agencies:**

Canadian Institutes of Health Research

**Title:**

A Systems and Rural Community-Based Approach to Planning Child Health Services in BC

**Approval Date:** 04-07-28

**Term (Years):** 1

**Amendment:** April 11, 2005, Access to Data

**Amendment Approved:** APR 20 2005

**Certification:**

The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

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Appendix I

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Co-Investigators:

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Title:
A System and Rural Community-Based Approach to Planning Child Health Services in BC

Approval Date: 05-07-08 (yr/mo/day)  
Term (Years): 1  
Amendment: Feb. 22, 2006, Time / Reimbursement / Procedures  
Amendment Approved: FEB 23 2006

Certification:

The request for continuing review of an amendment to the above-named project has been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approved on behalf of the Behavioural Research Ethics Board
by one of the following:

Dr. Peter Suedfeld, Chair,
Dr. Susan Rowley, Associate Chair
Dr. Jim Rupert, Associate Chair
Dr. Arminee Kazanjian, Associate Chair

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**CO-INVESTIGATORS**

Lindstrom, Ron, Medicine

**SPONSORING AGENCIES**

Human Early Learning Partnership (HELP)

**TITLE**

A System and Rural Community-Based Approach to Planning Child Health Services in BC

**APPROVAL DATE**

05-07-08 (yr/mo/day)

**TERM (YEARS)**

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**AMENDMENT**

Feb. 22, 2006, Time / Reimbursement / Procedures

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