Steps in the Right Direction

Connecting & Collaborating in Early Intervention Therapy with Aboriginal Families & Communities in British Columbia

by Alison Gerlach for

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Steps in the Right Direction has been developed for occupational therapists (O.T.), physiotherapists (P.T.) and speech language pathologists (S.L.P.) who provide early intervention therapy services to Aboriginal children, families and communities in B.C. It is hoped that the information in this guide will support interdisciplinary therapy professionals in designing and delivering early intervention programs in Aboriginal communities that are meaningful, effective and culturally safe. This information is also relevant to other early intervention disciplines, such as infant development programs (I.D.P.) and supported child development programs (S.C.D.P.).

Steps in the Right Direction is based on the following beliefs:

- Historical and sociopolitical issues influence therapist-client relationships, early intervention therapy program access and efficacy.
- Early intervention therapy programs in Aboriginal communities must be developed in collaboration with the community.
- A strengths-based lens of children, family members and communities as a whole builds trust and is more effective than a deficit-lens.
- Partnerships between Aboriginal people and therapy professionals need to be based on mutual respect, equality and trust.
- Traditional early intervention practices and methods of service delivery need to be adapted to meet the authentic needs of Aboriginal families and communities.
- Reflective thinking is an essential practice whenever non-Aboriginal health care professionals provide services to Aboriginal clients.

Steps in the Right Direction introduces ideas and concepts that are to date significantly lacking in early intervention therapy literature. Research from a broad range of international, interdisciplinary literature, the author’s own clinical experiences, and anecdotal evidence provide the foundation for “Steps in the Right Direction” in early intervention therapy practice with Aboriginal families and communities in B.C. The anecdotal evidence was gathered from interdisciplinary therapy professionals and Aboriginal child and health care service providers from across B.C. through telephone/email interviews, focus groups, and from workshop participants at the B.C. Aboriginal Child Care Society 8th Annual Provincial Training Conference.

It is hoped that when early intervention therapists, and other professionals, are reading this guide that they use the opportunity to take “Time to Reflect” on their own personal and professional values, beliefs and practices, and consider how these influence their clinical reasoning and early intervention practice with Aboriginal clients and communities.
**CULTURAL SAFETY**

AN INDIGENOUS WORLDVIEW OF CULTURE IN HEALTH CARE

“To really learn about Indigenous communities is to learn about oneself… An authentic listening to the cultural ‘Other’ should produce more than a fascination with the exotic: it should provoke an awakening to the cultural ‘Self’” (1)

The concept of “cultural safety” originated in New Zealand in response to the poor health status of the Maori people and “their insistence that service delivery change profoundly” (2). The rationale for developing cultural safety was that the significant health anomalies experienced by the Maori were a direct outcome of 152 years of suppression by a dominant non-Maori group and chronic cycles of poverty, which were misconstrued by others as being synonymous with Maori culture (3,4). Ramsden, who is recognized as the architect of cultural safety, contends that an understanding of the devastating impact of colonization, as experienced by the Maori, provides an historical context for clinical encounters with non-Maori health professionals and avoids “perpetuating common stereotypes, such as irresponsible and non-compliant” (4). Cultural safety recognizes the need for health care providers to be educated on how to provide their services in different social, economic and cultural contexts.

A “cultural sensitivity” approach was considered inadequate in addressing these issues (3). The focus in cultural sensitivity is on understanding the health beliefs, values and practices of different ethnic groups. Within a cultural safety framework, this is extended to include an examination and understanding of the “power inequities, individual and institutional discrimination, and the dynamics of health care relations” (2).

In cultural safety terms, “culture” is defined in its broadest sense and “safety” is defined in relation to the responsibility of health professionals to protect their clients from anything which may risk or endanger their health and well-being (2). Unlike cultural sensitivity, a cultural safety model is founded on the conviction that historical, economic and social contexts influence health and are embedded in culture (5,6).

**Culture**

A “simple invocation of a return to culture” is not enough (7)

How “culture” is understood by health professionals can influence their health care encounters and clinical reasoning. In healthcare literature, culture has been presented as comprising the beliefs, practices, and values of particular ethnic groups (8). Although descriptions of cultural characteristics and practices can be useful to healthcare practitioners and researchers, they can also reinforce stereotypes and simplistic views of particular ethnocultural groups as outsiders, as different, and as “Other.” These culturalist discourses also view issues of access, compliance and poor health status as stemming from cultural characteristics that conflict with mainstream, routine healthcare practices (9). Narrow conceptualizations of culture can, paradoxically, reinforce the stereotyping of people who belong to particular ethnocultural groups – in this case Aboriginal people, and overlook the broader structural, economic, and historical contexts that shape social and health problems such as poverty and intergenerational trauma (10). Browne and Smye emphasize that “while understanding the culture of the client is a crucial dimension of competent health care, it is only one aspect of the complex nexus in which people's experiences are located” (9).
“We cannot presume an unchanged, single or uniform ‘Aboriginal’ culture... as culture can never be reduced to a single variable in a contemporary world of urban Native artists, traditionalists, or poverty-weary young mothers. At the same time though, we must remain cognizant of the very real cultural and social barriers that may exist between First Nations, Inuit and Metis individuals and health-service providers in communities and urban centres. It is only in this way that we will understand and be able to effectively reduce both the inequities and the disparities of health” (7).

Cultural safety has the potential to direct health professionals’ clinical reasoning and cultural discourse into a new and different direction. By shifting the focus off of a narrow perspective of culture as the potential source of a problem, cultural safety promotes questioning and better understanding of the historically entrenched root causes of health and illness as experienced in contemporary Canadian society by many Aboriginal people (9). Cultural safety is therefore not about “cultural practices”; rather it involves the recognition of the social, economic and political position of certain groups within society, such as the Maori in New Zealand or Aboriginal people in Canada (9).

### Cultural Risk

In cultural safety, the patients/clients are the only ones who decide whether they feel safe with their health care; it provides them the power to comment on care and to be involved in changes. Culturally unsafe practice is defined as “any actions which diminish, demean or disempower the cultural identity and well-being of an individual” (2). Cultural safety addresses health professionals’ attitudes towards their clients and how these are knowingly or unknowingly communicated and risk influencing access to the health service. It therefore addresses the quality of health care that may be both experienced and accessed (2, 11).

Principles of cultural safety can be applied to all cultures (11). Nursing scholars in Canada believe that cultural safety has been instrumental in shifting the gaze onto the “culture of health care” and in showing how practices, policies, and research approaches can themselves create marginalizing conditions and inequities (12). A failure to understand health care through a cultural safety lens risks perpetuating negative stereotypes of indigenous peoples (12, 13). Cultural safety therefore brings the power held by health educators, students and providers into the forefront and aims to transfer “power from providers to consumers” (9). Partnerships within this model aim to rebalance the distribution of power. This challenges not only the notions of the inherent power of knowledge and status afforded a health professional but also the historical power that their ethnicity may represent for Aboriginal people (9).

Within a cultural safety perspective is a profound attitudinal shift in terms of understanding how colonial power and dominance have historically forced Aboriginal communities to change and adapt to a Western worldview. Cultural safety therefore reminds all health care providers that it is incumbent on them to reflect upon the ways in which current policies, research and practices may recreate the traumas inflicted upon Aboriginal people (9).
Time to Reflect...

Partnership and participation are two principles which are embedded in cultural safety. Participation aims to rebalance the “distribution of knowledge” so that indigenous and Western knowledge of health are valued as equals\(^a\). It is important for you to reflect on where you are located within Canadian society; only then can you begin to develop equitable relationships in which not only are differences acknowledged, but in which power, biases and privilege are not perpetuated.

Reflect on your position within all segments of Canadian society and consider if/how you occupy a position(s) of power and privilege:

• Are you aware of how this influences the comparisons that you make about “Others?”
• Are you aware of how this influences your relationship with Aboriginal people?

Adapted from Ramsden \(^a\)
To understand any human action, including a family’s decisions, early intervention therapy professionals must develop their awareness of the social history and present reality as experienced by the individual, family and community (18).

The Royal Commission on Aboriginal Peoples (19) stated that most Canadians’ knowledge of Aboriginal life and history is based on limited curriculum in the public school system and biased media coverage, in which they are frequently represented as “noble environmentalists, angry warriors or pitiful victims. A full picture of their humanity is simply not available in the media” (19). The information contained in this section of the guide is a starting point for expanding early intervention therapists’ understanding of Aboriginal people in B.C. and Canada.

### Terminology

**Aboriginal people**

This term refers collectively to the indigenous inhabitants of Canada including First Nations, Metis, and Inuit peoples. The term “First Nation” replaces the term “Indian” and “Inuit” replaces the term “Eskimo” (20).

**Indian people**

This term is “considered derogatory and insensitive in the Canadian context” (7). The federal government continues to categorize Aboriginal people in Canada based on the Indian Act of 1876. People are known as “status Indians” or “registered Indians” and are assigned a number that is registered by the Department of Indian Affairs at birth. The term “non-status Indian” applies to people who may be considered as “Indian” according to ethnic criteria but are not entitled to/have chosen not be registered under the Indian Act. “Treaty Indians” belong to a First Nation that has signed a treaty with the Canadian government. In B.C., most First Nations did not sign treaties. The first modern treaty in B.C. was with the Nisga’a Nation in 2000, which negotiated jurisdiction over a range of community services including health and education (21).

**First Nations**

This term appeared in the 1970’s to replace the word “Indian.” Although the term is widely used, no legal definition of it exists. Many First Nations people like to be known by the name of their nation, such as the Nisga’a, or by their language.
The Aboriginal population in Canada was estimated at 500,000 at the time of first contact with European settlers; this plunged to 102,000 by the time of the 1871 census due to the introduction of infectious diseases by the Europeans (20). In 2001, just over 1.3 million people in Canada identified themselves with an Aboriginal group or reported themselves as a Registered or Treaty Indian or a member of an Indian Band or First Nation, representing 4.4% of the total population.

There are 595 Indian Bands in Canada each recognized by the Federal government as an administrative unit. Several bands will occupy a distinct territory and have their own unique customs, language and dialect (22). There is no common language, belief system, religion, or social structure but great diversity influenced by age and geographical location (23). The Aboriginal population in B.C. is geographically dispersed. “About one-third live in Greater Vancouver, Victoria or the Fraser Valley. Another third live in the Thompson, Okanagan, Kootenays and Central/Upper Vancouver Island regions, while almost one-third live in the northern areas of the province” (21).

In the second half of the 20th century, Aboriginal peoples’ living standards have improved. However, there continues to be significant disparities in key health outcomes, such as mortality rates and the prevalence of certain diseases, when compared to the rest of Canadian society (20). The complex process of colonial policies and practices has resulted in profound social and cultural disruption in Aboriginal communities, the appropriation and exploitation of traditional lands and resources, marginalization from the wage economy and forced economic dependence of many Aboriginal people on the nation-state (9, 24). Life expectancy is lower; illness is more common; fewer children graduate from high school; unemployment is higher; and housing is more likely to be inadequate with poor water and sanitation systems (25).

Language is frequently cited as the means by which culture is transmitted and preserved (22). Prior to contact, Aboriginal languages flourished with an estimated 450 distinct Aboriginal languages and dialects in Canada. B.C has the greatest diversity in Aboriginal languages of all the provinces and territories. Today Aboriginal languages are being revitalized in many communities, but remain among the most endangered in the world; the 2001 census showed a decrease in Aboriginal languages as a mother tongue (26). “In the last 100 years alone, at least 10 of Canada's Aboriginal languages have become extinct. There are now about 50 to 70 Indigenous languages still spoken in Canada. Only three of these languages (Cree, Inuktitut and Ojibway) are expected to remain and flourish in Aboriginal communities because they have a sufficient population base” (27). These statistics reflect the continuing devastating effect that assimilation has had on the Aboriginal peoples’ pride in, and knowledge of their traditional languages and dialects.

“Early childhood is a critical time for positive identity formation. The opportunity to learn one’s heritage language clearly contributes to healthy cultural identity formation” (27)

Today, Aboriginal children are the fastest growing segment of the national population, representing 5.6% of all children in Canada (26). Modern Aboriginal communities are regaining their strength and hope, and much of the effort is focused on the well-being of their children (28). The language goals that “Aboriginal parents set for their children vary across a wide spectrum: some want their young children exposed to bilingual and bicultural experiences; some want their toddlers to develop a solid grounding in their Aboriginal mother tongue exclusively before learning English or French as a second language in primary school or even later; others want their children to develop English first and foremost” (28).
Steps in the Right Direction

Bill C-34; First Nations Jurisdiction over Education in B.C.: On July 5, 2006 representatives of First Nations and the federal and provincial governments signed a set of framework agreements recognizing the rights of First Nations communities to make decisions about the education of their learners from K-12. Jurisdiction can now rest with the First Nation (Chief and Council) to develop a vision and guidelines for its education system. First Nations languages can be recognized as a second language credit, and the development of culturally relevant learning environments is enhanced. Further information is available at www.fnesc.bc

Language Revitalization & Early Child Development

In our daycare and preschool in Tsaxana, Gold River, B.C. an Elder comes in twice a week to teach the children our language (Nuu-chah-nulth) in a group setting. The staff are all from Mowachaht/Muchalaht Agnes George Preschool/Daycare and speak Nuu-cha-nulth to various degrees. On a daily basis our language is incorporated through out the daily routines and on a continual basis all the time; if the adults know the word they use our language first and then English. There are pictures of animals, trees and flowers labeled with our language all over the room. Our children also learn songs and dances from this traditional area and there is traditional music playing throughout the day. The parents and grandparents feel a great sense of pride that our children are learning our language on a daily basis.

(Aboriginal I.D.P. Consultant)

Education has been called “the key that unlocks the future” and an important determinant of mental and physical well-being. On most outcome measures, Aboriginal students do more poorly than other students. A focus on academic learning, a research base, clear goals and objectives, cultural relevancy, and strong family and community involvement are some of the attributes of effective programs of schools and districts that have had the best academic outcomes for Aboriginal students.

“We can now succeed without having to change who we are.”

Regaining Strength

Over the past ten years daycare personnel, community health nurses, I.D.P and S.C.D.P. consultants and early intervention therapists have collaborated together in the Aboriginal community of Mount Currie. In that time, the community has seen many changes that have benefited the children and families of the Lil’wat Nation: The building of a health and daycare center and the training of community members in early childhood education; the development of a team of therapists to support children with special needs and their families and to mentor early childhood staff. An integrated and community-based early intervention team is the result of a positive and equitable partnership and is well-integrated with health and early childhood programs.

(Early intervention team)
Time to Reflect ....

What do you know about the Aboriginal community in which you are providing early intervention therapy services? Use these questions as a starting point to guide your learning:

• How can you learn more about the Aboriginal people and communities in which you are providing early intervention therapy services?
• What is the name of the First Nation people(s) and their language(s)?
• Is there a language revitalization/immersion program?
• How is the traditional language used in homes and child care settings?
• What are some of the traditional activities that are valued by the community?
• Where is their traditional territory?
• Where is the Band Office and who is the Band Administrator?
• Who is responsible for managing child/health care?
• What are some of the challenges and successes within the community that influence health, and the health of their young children?

AN HISTORICAL & COLONIAL CONTEXT

Understanding of health issues for Aboriginal people frequently fails to incorporate an historical perspective (31)

Socio-historical challenges to family life need to be recognized in the development and delivery of child care services and supports in Aboriginal communities (32). Furthermore, non-Aboriginal health professionals need to be cognizant of the historical power that their ethnicity may represent for Aboriginal people (5,6). This chapter therefore provides a brief overview of historical and sociopolitical contexts in order to better understand the past and present experiences of Aboriginal people in Canada. More in depth reading and reflection are necessary to fully understand the influences of history on Aboriginal peoples’ current health status, as well as their access to and relationships with health care professionals.

Colonialism

The process of political, social, economic, and cultural domination of a territory and its people by a foreign power for an extended time. It involves the creation of ideological formulations around race and skin color, which positions the colonizers at a higher evolutionary level than the colonized. Colonialism remains an everyday staple for Aboriginal people in current Canadian society (24,33).
Key Historical Events

1755-1830: Benevolent Protection
In 1755, the British government established an Indian Department and appointed a superintendent of Indian Affairs. The Royal Proclamation of 1763 focused on the benevolent protection of Aboriginal people by the colonizing Europeans and provided a legal foundation for British Indian policy.

1830-1867: Assimilation
In 1837, a British government committee developed “a new set of policies based on a worldwide view of Britain’s imperial and civilizing role” aimed at “inducing the Indians to change their present ways for more civilized Habits of Life.” The governing colonial power perceived it as a “burden to support a race of indigent people” and contended that “true civilization and Christianity are inseparable: the former has never been found, but as a fruit of the latter.

1867-1950: The Indian Act
The Indian Act of 1876 and its subsequent amendments provided successive governments over several centuries with the legal power to enforce cultural assimilation, which included the enforcement of reserve land and removal of children from their families to be “Christianized” in residential schools. Resistance from Aboriginal people resulted in more amendments to the Act with the result of further decreasing the power, autonomy and self-determination of Aboriginal people in their every day lives. In 1894, the Act provided a legal means for Aboriginal children to be removed from their parents and placed in residential schools. When this proved insufficient, the policy was further strengthened in 1920 when children who did not attend residential school were classified as delinquent and their parents subject to criminal penalties.

A defining event for Aboriginal people in their history following European contact is the catastrophic decline in their population. Some studies suggest that by 1890 there was a devastating 90% decline in the population of Aboriginal people on the northwestern coast. The Spanish flu epidemic of 1918 resulted not only in mass graves but in a cultural disruption in traditional practices related to death and burial.

In the mid-1940’s, high rates of infant and adult mortality compared to the rest of B.C. were attributed to environmental and nutritional factors, as well as lack of access to prompt medical care and the devastating hardships of reserve and residential school life. Not until 400 hundred years after European contact did the birth rate start to exceed the death rate in Aboriginal communities in B.C.

1951-Present
The revised Indian Act of 1951 focused on practical ways of integrating services for Aboriginal people with those of the mainstream Canadian society and its primary objective remained assimilation. By the mid-1900’s the survival of Aboriginal history and culture was challenged at several levels by colonization; not only forced assimilation through the missionaries and residential school system but also by devastating rates of mortality linked directly to the living conditions on reserve land.

In 1969 the government announced the intention to absolve its responsibility for Aboriginal governance and repeal the Indian Act, deferring responsibility to the provinces: “Indians would become Canadians, differing from other Canadians only in ethnic origin, not in law.” This was completely rejected by Aboriginal people and finally withdrawn in 1973. Events at this time did signal the potential recognition of internal decolonialization and the independent self-government of Aboriginal peoples. These included recognition in discussions related to the Canadian Constitution; introduction of practical measures for recognizing and promoting self-governance; settlement of outstanding land disputes throughout Canada (except in B.C. due to provincial opposition); and challenges to the definition of “Indian” in the Indian Act under the Charter of Rights and Freedoms as it was found to be discriminatory based on gender.

Steps in the Right Direction
Although the Indian Act continues to provide the legislative authority for the federal government's control over Aboriginal people (24, 30), “Aboriginal communities are beginning to have more governance over the programs and services they receive. Genuine decision-making power and a collective sense of control over a community’s destiny are key to economic and social development” (21).

Resource:
“Canada’s First Nations: A History of Founding Peoples from Earliest Times” by Olive Dickason is the first history text written by an Aboriginal author in Canada in which the author has tried to reverse the perspective of the standard history. It has become a standard and accepted text in history classes across the country and includes the first consistently accurate portrayals, in a sound academic work, of Indigenous people in history.

The Residential School System

“To understand where First Nations people are coming from, you must educate yourselves about one thing: residential schools. It isn’t nice, but it’s crucial to realizing how we got from a balanced, holistic, spiritual, respect-everything, wind-in-your-hair type of people to the people we are today. I always say, ‘we didn’t wake up one morning and decide to be drunks and drug addicts’ ...

I strongly recommend that you understand this point of view before knocking on the door of a First Nations client.” (34)

Residential schools from the late 1800’s to the early 1970’s were utilized by the Canadian government and 25 different religious orders to assimilate Aboriginal people into the dominant society; denying children the use of their traditional language, customs, diet and lifestyle. Children as young as three were forcibly taken from their families and tribal way of life and indoctrinated into a system based on British industrial schools (35). The speaking of any Native language was forbidden and punished by corporal punishment; thus the very base of culture was attacked. The intention was to “civilize the Natives by Christianizing them and by transforming the children into good, English-speaking, and law-abiding Canadians” (36, 37, 38). This practice was legalized through the Indian Act of 1894. By 1932, there were over 17,000 Aboriginal children in residential schools across Canada (24).

The residential school “taught us that we were dirty Indians ...
we were raised to be ashamed of being native,
we were raised to be ashamed of our identity” (39)

There were many documented reports of Aboriginal family members speaking out about the diseases that killed their children while attending the residential schools, which served as breeding grounds for tuberculosis, smallpox, scarlet fever, meningitis and chicken pox (24). In 1907, an investigation by the Department of Indian Affairs found “a scandalous procession of Indian children to school and onto the cemetery” (24). However, Aboriginal and non-Aboriginal scholars have highlighted how residential schooling had some positive outcomes: For some Aboriginal women, it advanced their position in the community as they learned English which increased their employment opportunities in local non-Aboriginal communities (40). While it is not uncommon to hear some former students speak about the positive experience in these institutions, these stories are overshadowed by disclosures of abuse, criminal convictions of perpetrators, and the findings of various studies, such as the Royal Commission on Aboriginal Peoples (55), which tell of the tragic legacy that the residential school system has left with many former students.
In addition to allegations of physical and sexual abuse, which are found in 90% of the legal claims, there are also allegations relating to such things as cultural loss, breach of treaty, loss of educational opportunity, forcible confinement, and poor conditions at the schools. It is estimated there are 80,000 people alive today who attended residential schools.

Most residential schools ceased to operate by the mid-1970s; the last federally-run residential school in B.C. closed in 1996. Not until 2000 did the Law Commission of Canada make a public apology and acknowledge that the Aboriginal community suffered particular harm by denying them the value and benefit of their language, their culture, and their families.

**Ongoing Intergenerational Impact**

“We had to learn to love ... I know our parents loved us but they just didn’t know how to show it” (39)

Aboriginal people have shown remarkable resiliency and strength in response to historical and contemporary practices of oppression and assimilation. However, some child welfare experts believe that all Aboriginal people are affected in some way by the residential school system and the resulting multigenerational breakdown in family life, regardless of whether or not they attended these schools (37). Safe and responsive health care for Aboriginal people is predicated on understanding the intergenerational impact of residential schools on health access and the relationship between Aboriginal people and non-Aboriginal health care providers (41).

“Intergenerational or multi-generational trauma happens when the effects of trauma are not resolved in one generation. When trauma is ignored and there is no support for dealing with it, the trauma will be passed from one generation to the next. Children who learn that sexual abuse is ‘normal’, and who have never dealt with the feelings that come from this, may inflict physical and sexual abuse on their own children. The unhealthy ways of behaving that people use to protect themselves can be passed on to children, without them even knowing they are doing so. This is the legacy of physical and sexual abuse in residential schools” (42).

“I didn’t know what to do, usually it was your grandmother who helped you a lot, that’s kind of gone, when they take the grandparents away from the grandchildren, that’s the kind of thing you lose”  
(A mother describing when her first child was born (39))

Children were disciplined to be ashamed of their culture, language, and ethnicity and lost their sense of identity and the experience of caring parenting (37). As adults they “now find themselves enduring a sense of inferiority and struggling as parents” (38). For women, the denial of being a mother or grandmother had major repercussions for later generations, including the loss of traditional child-rearing practices, language and cultural traditions, and the infliction of sexual, physical and psychological abuse.

Aboriginal parents and Aboriginal Speech Language Pathologists in a study by Ball and Lewis (28) pointed out that residential schooling has resulted in parents facing unique challenges. For some, these experiences have resulted in limited parenting skills, such as not knowing how to play with their children, not seeing value in providing books or other pre-literacy materials in the home, overly permissive or authoritarian parenting styles, and feelings of inadequacy that left them fearful or intimidated by schools, teachers, and professionals.
Multigenerational effects of the residential school experience include (42):

- Loss of traditional parenting skills, sometimes for generations.
- Self-medication: abusing drugs and alcohol to dull the emotional pain.
- Feelings of guilt, shame, and low self-esteem.
- Anger and distrust of government and non-Aboriginal people.
- Internalized oppression and political instability.
- Sexual and emotional dysfunctions (don't talk, don't trust, don't feel).
- Depression, hopelessness, and suicide. (Aboriginal youth suicide rate is 8 times the nation rate).
- Physical illness that is stress and trauma related.
- Family violence.
- High incarceration rates; many Aboriginal inmates are affected by F.A.S.D.

Time to Reflect ….

It is important to learn and reflect on the history of power differentials that exist on a national and local level in relation to Aboriginal people.

- How are the Aboriginal communities in your region represented in the local media and viewed by members of your society?

When collaborating with Aboriginal families and communities, you need to understand and respect the intergenerational effects of the residential school system that continue to influence the daily lives of individuals and families in the communities in which you practice.

- How does the residential school system continue to influence:
  - The health and well-being of individuals and the community as a whole?
  - Your relationship with members of the community?
  - The amount of time you need to spend building trust?
  - The way that people access health care services?
  - The way that people view the education system?
Resources:
To fully understand the devastating historical and modern day effects of the residential school system, readers are directed to the many personal stories available in print and online:

Internet Resources:
Digital Narratives of Survivors’ Stories
“Where are the children? Healing the Legacy of the Residential Schools”
www.wherearethechildren.ca
“This web site gives voice to the untold stories of so many Aboriginal boys and girls who attended residential schools in Canada from 1831 to the 1990’s. By doing so, may it bring healing to those whose experiences have left them behind, as well as begin to introduce a sense of understanding for all Aboriginal and non-Aboriginal peoples.”
“Hidden from History: The Canadian Holocaust”
www.hiddenfromhistory.org
Digital narratives of survivors’ testimonies of “crimes against humanity” in residential schools.

Video Resource:
“Mission School Syndrome”
This documentary examines the practice of sending Aboriginal children away to mission schools. Several adult Aboriginal Canadians who were sent to these schools as children look back and reflect on its dramatic impact. This video shows the complexity of residential schools in terms of the “benefits” (some people say that it helped them learn about Christianity and they are grateful for that), and the long term damage from abuse that was experienced by many.
By familiarizing themselves with the historical roots of education in Aboriginal communities, viewers will gain an understanding of the devastating effects the mission schools had on family lives.

Books:
“Behind Closed Doors: Stories from the Kamloops Indian Residential School” (Jack Agnes)
“No Time To Say Goodbye” (Sylvia Olsen)
“Shingwauk’s Vision : A History of Native Residential Schools” (J. R. Miller)
HEALTH & HEALING

Changes identified by Aboriginal people regarding the way health and healing are promoted focus on the pervasive effects of chronic poverty on health; the importance of balance and harmony in all aspects of life; the need for autonomy in solving health and social problems; and the need to return to traditional healing practices (20).

Prior to European contact, Aboriginal people were thought to have lived healthy, relatively disease free lives (24), and some Elders continue to view the current poor health of their people in relation to historical epidemics of infectious diseases and the negative impact of Euro-Canadian dominance (24). It is now recognized that “mainstream health care, as it has evolved in relation to Aboriginal communities, has been shaped by a century of internal colonial politics that has effectively marginalized Aboriginal people from the dominant systems of care” (43). There is a consistent and significant disparity in health status between Aboriginal people and the overall Canadian population, which has been related to poverty, poor housing, and unemployment (44).

In an Aboriginal Peoples Survey of 1991, 9.7% of Aboriginal children under the age of 15 were reported as having a chronic health condition as compared to 3.9% in the general population. Similarly, 5.1% of First Nations children in the same age group were reported as having a mental handicap, a learning disability, and/or a behavioral or emotional condition, as compared to 2.2% in the general population (26). Aboriginal children are associated with the highest reported rate of fetal alcohol spectrum disorder in Canada (45). The association is real but also serves as an example of “public health surveillance” which O’Neil contends “inadvertently constructs such communities as sick and disorganized” (45).

“Aboriginal people do not want pity or handouts. They want recognition that these (health) problems are largely the result of loss of their lands and resources, the destruction of their economies and social institutions, and the denial of their nationhood. They seek a range of remedies for these injustices, but most of all, they seek control of their lives” (39).

A literature review (40) on the health of Aboriginal children and youth in Canada highlighted the importance of health care professionals understanding an Aboriginal worldview of health but also cautioned that “while there are cultural differences in how health is understood, there are also social and historical factors that are impinging upon any sense of health and well-being that cannot be remedied with a simple invocation of a return to culture” (39). A “disproportionate burden of illness is linked to Aboriginal people’s economic and social conditions as well as a history of oppression and marginalization” (44).

Extensive and graphic representation of the enormous disparity in health outcomes between Aboriginal people and mainstream Euro-Canadian society during the early 20th century failed to show the human experience of losing a child or family member or any association between health outcomes and the devastating hardships of reserve and residential school life, decreasing access to land and resources, and increasing oppression (24). Deficit and sterile health stereotypes of Aboriginal people as genetically inferior and predisposed to being sick reflected the dominant society’s view of Aboriginal health to the extent that this unchallenged worldview formed the basis for health policies (24).
Illness has historically been used as a way for the government to exert their control over where Aboriginal people could live; “they could be relocated to new communities where health services, sanitary facilities and permanent housing might be provided” (20). The centralization of T.B. hospitals in the south resulted in prolonged physical and cultural isolation of the Inuit, just as the centralization of primary health care clinics next to trading posts and missions promoted the sedentarization of previously nomadic people (33,47). “To this day, for many Aboriginal peoples, there is a lingering fear of institutions that can be traced directly back to the insensitive treatment of those with tuberculosis” (7).

“Inequities in health and social indicators cannot be glossed over as lifestyle, behavioral or cultural issues – rather, they are manifestations of the complex interplay of historical, socioeconomic and political conditions that influence health status and access to equitable health care” (9).

Socio-political policies responsible for the dispossession of Aboriginal lands, economic dependency, and loss of autonomy are recognized by Aboriginal people as having a pervasive influence on their continuing health issues (30). Even today established relations of power, authority, and paternalism continue to shape health-care policies and practices concerning Aboriginal peoples (7,10,24,47).

“To know the community, family, and child, one must have knowledge of the powerful societal forces affecting their lives” (18).

Infant mortality rates, which are generally considered to be a powerful indicator of socioeconomic conditions and health care services, are more than double the national average for Aboriginal infants (9). Poverty, relative isolation, unemployment, and inadequate housing all contribute to family disruption. Aboriginal children are more than seven times as likely as non-Aboriginal children to be placed in government care. Preliminary research in one region of B.C. suggests that as many as 60% of children in care province-wide may be Aboriginal (21). Colonizing images that portrayed Aboriginal women as irresponsible and incompetent contributed to the “inferiorization of Aboriginal motherhood” and fuelled the wide-spread practice in the 1960’s and 1970’s of placing Aboriginal children in non-Aboriginal foster homes (40). More recently, public awareness campaigns portraying fetal alcohol spectrum disorder as a primarily Aboriginal health problem have been criticized by some for perpetuating the public and professional perception of Aboriginal women as negligent and uncaring (45).

The “Sixties Scoop”

Historically, high infant and childhood mortality rates were blamed on their non-Christian Aboriginal mothers (24). Referred to as the “sixties scoop” thousands of Aboriginal children were deemed to be in need of protection from their mothers. The social construction of Aboriginal women as negligent and irresponsible was instrumental in contributing to the “inferiorization” of Aboriginal motherhood (40). Today, research continues to show that perceptions of Aboriginal women as negligent mothers persist and influence how women are treated at the front-lines of health care (40).
Evidence suggests that self-determination and local governance in Aboriginal communities is related in important ways to improved health outcomes (47). In a 2002 public opinion poll, 63% of Aboriginal respondents identified the loss of land and culture as significant contributors to poorer health status (48). One study found that Aboriginal communities in B.C. that have more community control over schools, health, and other services have much lower youth suicide rates than other communities (48).

Cowichan Teachings

The following teachings were adopted by an Elders Council in Cowichan Tribes in 1995:

1. Each person is important
2. Honour the Elders
3. Everything in nature is part of our family – we are all relatives
4. Live in harmony with nature
5. Take care of the earth and take only what you need
6. Be positive
7. Take care of your health
8. Enjoy today
9. Share what you have
10. Be truthful in all you do and say
11. Do the best you can do, be the best you can be
12. Learn from one another
13. Respect the rights of one another
14. Respect your leaders and their decisions
15. Respect your neighbours
16. Respect women, the giver of life
17. Respect the sacredness of children

Shared by Diana Elliott, Provincial Aboriginal Advisor I.D.P. who uses these teachings to guide her decision-making and practice.

The Cultural Nature of Health

“All health professionals practice in a cultural world, a ‘culture of biomedicine’ which strongly influences health care decisions and clinical reasoning. This culture offers powerful assumptions about the characteristics of good health care practice that shape the behavior of practitioners; their definitions about the nature of their work; and their communication and interactions with colleagues, consumers, and the consumer’s families” (49).

“People of all cultures have beliefs about health that are culturally anchored and that influence how illness is experienced, understood and treated” (50). Early intervention therapy is grounded in a Western biomedical model of health. This model emphasizes objective information, the use of diagnostic categories that focus on problems and deficits (51,52) and has been criticized for narrowly addressing diverse social
and cultural concerns and needs (49). “While some service providers have adopted the ideals of cultural sensitivity, their services may continue to reflect western values and individualistic views of health” (50).

The meaning of “health” for many Aboriginal people “does not translate across the boundary of care in a typical biomedically based health-care system” (7). While members of mainstream Canadian society turn to health professionals, Aboriginal people may turn to Elders, community members, or traditional healers. Aboriginal people have expressed a need to reclaim their cultural heritage and to reconnect with their traditional spiritual and natural healing practices (53,54). According to Statistics Canada, (26) Aboriginal children who live on a reserve in B.C. are more likely to be seen by a traditional healer than Aboriginal children who are integrated into mainstream society. Some families may use Western medicine only as a second opinion (55) and some may chose to combine mainstream Western health care with traditional healing practices, depending on their beliefs and financial resources (56). It is important to note that “a family's cultural identity does not always dictate how the family will respond to a health crisis” (57).

However, in a study of Native American Navajo children with autism, cultural beliefs and definitions of disability did have a pervasive effect on the family's adaptation to the long term care of their children, even when some families consciously chose to access mainstream health services (51).

Traditional healing approaches usually involve a collective approach, which contrasts with the one on one approach of professional and client that is familiar in a Western model (54). Thus traditionally, relatives and community members play important roles in the healing process; “bringing together many forces to best utilize the powers that promote health” (54). This interdependency is in contrast to the Western emphasis on autonomy and independence which are common therapeutic goals in early intervention.

Within an Aboriginal worldview “health is understood as a complex inter-relationship between physical, mental/intellectual, spiritual and emotional factors. Such elements are not arranged in a hierarchy of human needs but as equally important and necessary components of being healthy. Well-being flows from maintaining balance and harmony between all areas and with nature” (48).

An interconnectedness of physical, mental, emotional, and spiritual needs is not paralleled in mainstream Western health practices which views and treats these areas of life separately, including separate beliefs, practices, and specialists. Separating the healing of the body, healing of the mind and healing of the spirit results in some Aboriginal people experiencing dissatisfaction with the Western health care system (58). Based on a collaborative research project with three First Nations in B.C., Ball noted that: “the many aspects of a child's body, mind and spirit are seen as intertwined and requiring nurturing, guidance, and respect. This view permeates community decisions about what child care and development programs should entail- namely, a proactive, developmental approach to the whole child that included nutrition, preventative health, socialization, education and Aboriginal language and culture” (59).

Cultural traditions are said to provide families with stability, comfort, guidance, and a means of coping (51). In many Aboriginal cultures, children are seen as gifts from the Creator and considered to have a special purpose and spirit. If a child is born with an obvious birth defect, he/she may be accorded special status (60). Acceptance of “natural and unnatural events is representative of the belief that these events occur as part of the natural order of life and that one must learn to live with life and accept what comes, both the good and the bad” (60). This belief is also “closely tied to the capacity to view others as inherently worthy” (60); a child with a disability is not viewed as deficient but as someone able to be part of the community in their own way (55,56). Families may therefore “be less anxious to seek rehabilitation to eliminate traits which they do not perceive as a problem” (62).

A family's view of disability may be intertwined with religious or spiritual beliefs, and parents who have a child born with a disability may turn to their cultural resources to find out why the disability occurred (56).
Beliefs about causation will have a significant influence on a family's adaptation to having a child with a disability and their decision to seek services. Spiritual beliefs help to interpret life and incorporate ideas of multiple causality of illness and misfortune.

A 2002 Aboriginal Health Forum proposed a health system based on the following vision:

- A paradigm shift from an illness-based model to one that is population-based and stresses prevention and individual decision-making and responsibility for health.
- A holistic framework where health services are interconnected with social services, education, housing, economic development, justice/policing and other community services.
- Local governance and Aboriginal involvement in all aspects of the health system, from design and implementation to administration and evaluation.
- Decisions regarding services and traditional medicine to be determined by community needs and preferences.
- Long-range planning supported by stable, long-term financing.

Time to Reflect ....

“As an individual you have your own definition of health. This definition ‘operates’ in your daily life and work regardless of the extent to which you are aware of it.”

- What is your working definition of health and how does it shape how you engage with clients?
- How is health meaningfully defined and experienced by your clients? Do you enquire into what health means to them?
- Are you aware of what happens when your working definition of health differs from that of your clients?
- How do you know you are in fact promoting the health of your clients as perceived and experienced from their perspective?
CONNECTING & COLLABORATING

In order to achieve effective prevention and early intervention in rural and northern communities in Canada “community involvement and participation at all stages of the design, planning, implementation, operation and evaluation of services must become the norm” (64).

B.C. is a diverse, multicultural society in which there are large populations of people who have alternative worldviews towards family, child rearing and health. However, early intervention therapy is grounded in a traditional western approach towards child development and health. The following information, while focused on Aboriginal people, may be applicable to other diverse families and communities.

In a national survey of S.L.P.s who had experience with young Aboriginal children “79% perceived an urgent need for an altogether different approach to serving Aboriginal children, compared to serving children of dominant cultural groups (e.g. European ancestry). There was general consensus among the respondents that an “expert” service orientation is ineffective. Family and community-driven practice that is consultative and collaborative is more culturally appropriate than professionally driven approaches. S.L.P.s strongly emphasized the importance of working with Elders, community governing bodies, parents and other trusted service providers, and being responsive to expressed values and wishes. In their experience, these people can offer feedback about tools, methods and messages that are likely to be accepted and effective in various families or community groups” (28). In this section of the guide, key principles of a community development approach in working with Aboriginal families and communities are highlighted.

Trust

“The legacy of mistrust is transmitted intergenerationally” (62)

Aboriginal people have identified trust and respect with individual health care providers and institutions as key components of accessing health services (6,21,39,61). An unspoken hierarchy in which family and community members locate a health professional in the position of “expert” challenges the family-centred idea of equality in collaboration (66). The nature of this relationship has a significant impact on health care access and the delivery of equitable and effective services (10). Building trust is particularly challenging in an outreach model of service delivery, or where there is infrequent or inconsistent contact. Trust may take a long time to develop and is promoted when community members see the early intervention therapy professional in the community consistently over a prolonged period of time. Further strategies for developing trust and communication include:

- Initiating and developing a relationship with the Band Administrator and key community members involved in the management of child health care programs.
- Initiating and developing relationships with community members who provide or are interested in child development and care (see Community Connections).
- Planning and delivering flexible and adaptable early intervention therapy services in collaboration with community members.
- Participating in existing community programs for children (see Community Integration).
- Being a consistent presence in the community.
- Participating in community events and activities.
- Recognizing and focusing on the strengths of a child, family and community (see Strengths Based Approach).
- Being friendly, informal and using “plain language” in all written and verbal communications (see Empowering through Knowledge).
‘Being Present’

I visit the preschool in the village once a month for 1-2 hours to play and observe all the children. I join in with their Native language circle time and sometimes leave a few sheets with play ideas but really most of the time I just show up to play. Among the group of children, two are on my caseload but I play with all of them. Sometimes I worry that it’s a waste of my time, but I have lots of support from my Executive Director to keep doing what I am doing. During one visit to the preschool, I informally talked about fine motor development and how proximal stability is crucial to develop fine motor skills. I wondered if I was listened to as I did not get much reaction. On a following visit, I saw children using big rolling paint brushes on big sheets on the floor and tables. I said, “Wow, this looks like a fun activity!” The teacher said to me: “Well yes, this is to work on the shoulder stuff you talked about.” Then I realized not only was I listened to but they took the information and created an activity with it. This taught me how important it is to just spend time being together so that we get to know each other. (O.T.)

Finding Common Ground

I always try and make time to spend some time in the staff room and have a cup of coffee and a social chat with whoever is there. I think it’s really important to make some time for people to get to know me in a social way. We often find common things to talk about and I have learned that laughing together is a great way of building positive relationships. (O.T.)

I leave my ego at the door. I’m there as a person first and an S.L.P. second. I also think it is important to dress casually and not too ‘professional’, so for example, I take a backpack instead of a briefcase. (S.L.P.)

I think it’s sometimes hard for people to relate to me as a health professional ... I share stories about my family, my own kids and I think it helps if they can see I’m also a mom and a wife and not just another white health professional (O.T.).

Fears about Child Protection

There is a lot of fear amongst the families about having a therapist come to their home. They are very hesitant and worry that if their house is messy that the therapist will report them. (Aboriginal I.D.P. Consultant)

One mom told me that she was really fearful of the S.L.P. and I doing a home visit because she was worried about child protection issues. We thought we had a really good and trusting relationship with this mom and had known her for several years at the time that she told us this. It was really shocking for us as we had never considered that we would be viewed in relation to child protection. (O.T.)
Strengths Based Approach

“Strengths represent potential pathways to wellness” (50)

A biomedical model and many early intervention practices traditionally employ a “deficit lens” in which children are categorized with a diagnostic label and their abilities and disabilities compared to “typical” children their age. This approach can be useful for specific purposes such as seeking funding. However in Aboriginal communities this approach may inadvertently risk perpetuating a colonial legacy of Aboriginal people being judged and labeled by others, who represent the dominant society.

Inherent within a community development approach is a focus on strengths. Individual and collective strengths are found in “the activities, places, people, values, beliefs and traditions that are working well in the life of the individual and/or community” (50). Early intervention therapists entering a community for the first time need to identify the strengths of a community, the strengths of an Aboriginal worldview towards family, health, and child rearing, as well as the strengths, wellness and competence of individual families and children. Existing programs, services and key community members are also sources of community strengths. All need to be highlighted and integrated throughout the therapy process.

Community Connections

Research by Ball and Lewis (28) highlights the importance of early intervention therapy professionals seeking out knowledge about the local culture, community structures and circumstances, including community development goals for their children. Making community connections is the theme of a publication written for Aboriginal consumers interested in learning more about early intervention therapy programs: Aboriginal child health/care service providers are encouraged to take a lead in connecting with therapists and collaborating on how therapy services are delivered so that they are respectful and responsive to local historical, cultural and contemporary needs and strengths in relation to raising healthy children (67). It is also important to be aware of and honour the customs of the community by finding out about these from a community partner.

Focusing on Strengths

I had this school in Cowichan refer a 5 year boy to our program as his hygiene was very poor. Staff were complaining that his clothes were always dirty, and he was always late. So they referred him to Aboriginal I.D.P. and I went to meet the principal and they voiced their complaints. I responded by saying, “Wow, that mom has got four other kids and she still gets him to school every day.” His school attendance was perfect. From that day on that school principal understood the need to focus on the strengths and from there we could work on the other things. To me this was teaching that school about talking about the strengths of a family and then going from there. They really started to minimize their judgments. (Aboriginal I.D.P. Consultant)
Honouring Customs

I have found on Central Vancouver Island that some Aboriginal people may be uncomfortable with shaking hands. Some Coast Salish people talk about how they believe they are giving part of their spirit away when they shake hands so they are reluctant to handshake or may give a very light handshake which may be misinterpreted. Coast Salish people may be more comfortable and willing to hug a person they have seen more than once or have some regard for rather than shake hands, which may make some non-Aboriginal people feel uncomfortable. I also see a difference in the way Aboriginal people in traditional circles introduce themselves in formal situations; saying who they are descended from, their First Nation name if they have one, a few words in their traditional language if known, and/or showing respect for the First Nation Territory they are visiting by thanking them for allowing their presence on their territory. (S.L.P. & member of the interior Salish Skuppah Band, Lytton, B.C.)

Respecting Community Self-Determination

I always make a point of emailing the school principal and the director of the daycare program to remind them of the timing of my visit and to ask them for advice on which families or children they think it is important for me to follow up with or to meet. When I arrive I also always pop into their offices to touch base and confirm what I am doing. (O.T.)

We have a community-based early intervention team which is co-ordinated and chaired by a member of the community. We invite the community’s health director to attend meetings when we need advice on writing proposals or advocating for funding.

We (therapists) all really respect that we cannot make these kinds of decisions without input and guidance from these key members. (Early intervention team)

When entering an Aboriginal community any preconceived ideas and attempts to control the process will hinder efforts. Let the process flow naturally and at its own pace, as flexibility in service planning and delivery is important. It is also essential to recognize that the Aboriginal people are in charge and to follow the lines of authority. Planning and delivering early intervention therapy services need to be carried out with the permission and direction of the key decision makers in the community. Follow the lines of authority and show respect by recognizing the autonomy and rights of an Aboriginal community. Seeking approval for how/when/where early intervention therapy services are provided demonstrates a respect for Aboriginal self-determination.

Early intervention therapy professionals need to identify key individuals in a community with whom they may develop working partnerships in the delivery of early intervention programs. Such a partnership is based on mutual trust, promotes mutual respect and capacity building, and is developed over time with community partners such as:

- A resourceful Elder or younger person who is willing to share their knowledge and provide support.
- An interested person who is involved in community child care.
- An interested person who is involved in a Head Start program.
- A health care provider who is a member of the community.
- A community health care representative (C.H.R.)
- An Aboriginal I.D.P. consultant.
- An Aboriginal S.C.D.P. consultant.
Community Integration

Integration and communication between everyone in a community who is involved in providing services for children are essential. One way of achieving this is to locate health professionals in the same building as child care programs as these act as a springboard for staff referrals and increase access to early intervention therapy services which would otherwise be socially and or physically inaccessible. This concept of “hook and hub” in early childcare and development as proposed in Ball's research (32) highlights the success of integrating early intervention therapy services into existing community programs.

“High quality, family-centred child care programs ...can clearly be a ‘hook’ to draw parents as well as young children into new circles of social support and safety, as well as a ‘hub’ for cultural learning, role modeling, parent education, and services for those with special needs” (32). This approach is also conducive with a cultural safety approach in that it provides a safer environment in which families can access early intervention therapists.

A key worker model in which there is a single point of contact with a family may also be less overwhelming for family members. The key worker helps co-ordinate care/services, provides information (general & child specific), advocates for family and child, and acts as a link to other professionals who are involved in an early intervention program.

Connecting through Community Programs

We join in with the play groups and a healthy baby group run by the Aboriginal I.D.P. Consultant. We give the Consultant some ideas and she helps with following up on our recommendations and also uses the ideas in the play groups. (Outreach P.T.)

I have been to all of the preschools and daycares. When a specific child in the preschool is referred, I talk to the lead teacher and ask how I can fit into their centre. (S.L.P.)

At an Aboriginal preschool, I was asked to come in and give the staff ideas as to how they could use the materials they already had to meet their children's fine motor needs. (O.T.)

We partnered with the daycare to develop a small evening workshop with dinner for families that focused on issues identified by the daycare staff. (Early intervention team)

Overcoming Barriers

Once a month we have an S.L.P. join our playgroup. She screens all the children on our caseload and then sees some children individually. We provide childcare for the other children so that the parent(s) can focus on their visit with the S.L.P. It is very difficult for families to get to us so we provide transportation. If a child is seeing the S.L.P. we might arrange a home visit that week to remind the family to come or leave a reminder note, or just phone the day before. These children would not be receiving S.L.P. services unless we provided this program and transportation. (Aboriginal I.D.P. Consultant)
Remote Aboriginal Communities

In order for a family to get to the nearest child development centre they would have to catch a plane/boat to the nearest logging road and then travel on the logging road for 2 1/2 hrs to the main highway and then drive 3 hrs to Campbell River. Many families don’t have a car, and if they do have a car they can’t afford to make such a long journey. So children who need early intervention are not receiving it because of the distance. I have tried to get an S.L.P. to come up with me but have had no luck and am not sure whose responsibility it is to provide therapy services to these remote communities. I go to each community once a month and it would be ideal if an S.L.P. could come with me; she could give us advice on certain children, and she could teach us about some basic speech and language enrichment strategies. (Aboriginal I.D.P. Consultant)

Community Enrichment

Typically child-specific early intervention therapy services can be designed and delivered, in collaboration with community-based key decision makers and caregivers, in such a way that they contribute towards enriching the development of all children.

Celebrating Children

For the past few years the health centre has been successful in receiving funding from ‘Putting Children First’ to hold a health fair focused on healthy child development and to promote better relationships with the different child health professionals. The community health nurses, dental hygienist, early intervention therapists and the child care service providers from the daycare are all involved. Last year the team participated alongside family members in different traditional activities, such as storytelling, dancing and beadwork. Displays and information were available to let family members know about different aspects of child development, and what services were offered in the community. The fair ended with a dinner for everyone. It was really well attended and was a positive way to bring families and health professionals together. (Early intervention team.)

Sharing & Respecting Knowledge

Aboriginal caregivers and those who make decisions in Aboriginal communities regarding programs for children need to be given clear information about the different early intervention therapy services to help ensure that specialist services offered to Aboriginal families and communities are culturally appropriate and effective. Early intervention therapy professionals are a resource of information and need to consider how this information can not only be shared but more importantly sustained within a community. “Non-helpful practices include telling the adults what to do, … telling the adults you’ll show them what to do, giving written handouts, or inviting the community to a lecture or presentation. It is not helpful to assume that you know what to do and by virtue of your knowledge you have the right to tell Aboriginal people how to communicate with, teach, or raise their children” (28).

Therapists also need to be cognizant that early intervention is founded on a Western, biomedical model of health and disability. It is important to respect that these are cultural in nature and may not be shared by clients who have an Aboriginal heritage. By learning about Aboriginal views on health and healing from local community members, therapists can respect this knowledge and begin to understand how it may influence some family member’s perspectives towards traditional health care practices.
Steps in the Right Direction

“Families have been expected to assimilate to the cultural imperatives of the early interventionist by adopting their mode of communication with children and adapting to the recommended therapeutic style of play and interaction. The new paradigm requires that early interventionists learn to adapt to the culture and aspirations of the families with whom they work.” (69)

There is currently a significant lack of research and literature to guide the delivery of effective, meaningful and culturally safe early intervention therapy with Aboriginal children and families in Canada. While the literature on early intervention with culturally-diverse families is relevant and is used in this section of the guide, it does not adequately address all of the questions that arise in providing early intervention therapy programs with Aboriginal families and children. Anecdotal evidence from interdisciplinary early intervention therapists and Aboriginal I.D.P. and S.C.D.P. Consultants from across B.C. is therefore used to highlight steps in the right direction.

Aboriginal families, just like all families, cannot be considered a homogenous group and are influenced by many factors aside from culture. For example, a family’s socio-economic status and level of education are associated with differences in parenting behaviors, attitudes and home environment (69) and may be more influential than culture (70). Child rearing in Aboriginal families also continues to be significantly influenced by the intergenerational impact of the residential school system (38).

Traditionally in many Aboriginal communities, children are cared for and nurtured as part of an interdependent extended family structure (74) whose wants and needs may over-ride those of individual members (65). Extended family and community members may be involved in child-rearing “in spheres of activity that, in Euro-Canadian society are parental” (37). Different extended family members may also take on different roles; first cousins may be thought of as siblings, and the responsibility of child rearing may be extended to include active involvement from aunts, uncles and grandparents (72,73). When working with diverse families, therapists “need to be able to step outside Western assumptions about family structures, living situations, housing requirements and gender roles” (74). Within this interconnected framework, siblings and extended family members may be viewed as strength within the therapy process.

Respecting Grandparents
I find that grandparents are often parenting their own children and their grandchildren. Sometimes they have custody of a grandchild but still are able to maintain a strong link with the child’s parents. When a grandparent brings a child to see me I ask them to tell me about the responsibilities in their life, such as raising their grandchildren. I often ask grandparents questions that I would usually ask a parent. (S.L.P.)

Respecting Elders
I was recently at a meeting and a young person said, “We have an Elder here and she would like to lead a prayer.” I think it is important for therapists to know how important and responsible a role Elders play in the community. (S.L.P.)
Time to Reflect ....
Many health care professionals' beliefs and knowledge of parenting are unconsciously based on their own personal childhood and parenting experiences (75).

- List four words that come to your mind when you think of the word “family.”
- List three defining features of your family.
- What are two things you learned in your own family of origin that shape how you think of families?
- How might your personal view of family shape your early intervention therapy practice?

Based on work by Doane & Varcoe (6)

Referral

A complex referral process, especially one dependent on paperwork, risks decreasing access to health services for Aboriginal families, including early intervention therapy. Co-location of services and a single point of entry are important characteristics of an integrated approach (76). Access to services may be increased by making community connections and by being a known face prior to a referral. It can also be helpful to complete a referral form with the family during an initial meeting, so that they know who the therapist is and have the opportunity to gain more information about early intervention therapy.

Connecting with Families

It can be hard to develop rapport with some families as we are not in the community very often. I have worked with I.D.P. and Aboriginal I.D.P. Consultants who have a really good rapport with their families. They have helped to co-ordinate referrals and consents for children that needed to be seen; they also set up a meeting time and place. (Outreach P.T.)

I consistently take part in a drop-in play group, where lunch is provided. I get to know families and they get to know me. I find that this really helps when I come to see them on a one to one basis later on if they get referred. I think it really helps to spend more time building relationships before I start asking questions. (S.L.P.)

In our community we have developed our own intake, consent and referral process so that it includes Aboriginal S.C.D.P. and early intervention therapy. It is a ‘one stop shop’ for our families where I complete the intake form with them for our Aboriginal S.C.D Program and gain written consent for our therapists to see their child if helpful in the future. (Aboriginal S.C.D.P. Consultant).
There may be differences between an early intervention therapist’s view of a child and how that child is seen by his/her family and caregivers. Does the family agree with the reason for referral or are they simply complying with the recommendations of other professionals? Asking the family: “If we all work together for three months, and at the end of that time you tell us that the program has been successful, what will your child be doing compared to right now?” can help them and the early intervention therapist define concrete, measurable and meaningful outcomes. Each session can begin with a reminder of the focus of intervention.

The ethical principle of confidentiality is challenging in some small communities in which there are extensive family networks. Therapists must ensure that a child’s parents or guardians list all the family members and child care service providers that they wish to be included on a consent form. This may include Aboriginal I.D.P., grandparents, older siblings, cousins etc. This needs to be accompanied by a clear explanation that information about the child will only be shared with those people listed on the consent form.

**Time to Reflect …..**

When collaborating with Aboriginal families and communities, consider how can you make your referral process more user-friendly and improve access to your programs:

- Can the referral process be integrated into existing referral systems for community programs (such as a daycare or I.D.P.)?
- Does the family understand what early intervention therapy means for their child?
- Does the family understand why their child has been referred for early intervention therapy?
- Does the family agree with the reason for referral?
- Which family & community caregivers/members need to be included on consent forms?

**Initial Meeting**

It is important for early intervention therapy professionals to examine their own motives in planning and delivering their services. Paternalism, benevolence, or an expert model will likely negatively influence the development of trusting relationships. It also takes time for people to feel comfortable and trusting enough to talk about the real issues. When “opportunities to listen arise unexpectedly one must take the time and make the most of that opportunity”. Existing community programs (e.g., drop-in mom and tots or playgroup, daycare, Mother Goose program) provide an opportunity for families and caregivers to get to know you over time. It is important to be as informal as possible: “be who you are, be ‘human’, do not play a ‘role’ because people sense insincerity and role playing”.

It is also important to explore who will be involved in the therapy intervention process with each family. Recognize the importance of extended family and be prepared to involve siblings, cousins or grandparents. Vacca and Feinburg suggest the following dialogue: “Do you want other family members to be present for the appointments?” or “Who are the family members you think can attend the sessions? Do you want me to give them information and ideas about the sessions if you are not there?”

Some Aboriginal people traditionally do not adhere to strict schedules or time frames. Meetings may not start on time and may not end until everyone has had a chance to add their comments. It may be helpful to have a discussion about scheduling appointments: “Sometimes you may have other things that you need to do when our appointment is scheduled. How should we handle this? Can you call me? or “Should I call the day before or the day of the appointment as a reminder? How early in the day may I call you?”

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Steps in the Right Direction
Involving Extended Family

When I am meeting a family, especially for the first time, I make sure that it is clear that any family member is welcome to come to the appointment. I have just seen a child with a young single mom, who came to see me with her boyfriend. The child’s grandmother had a strong caring role and came too. I think it is important to give plenty of time so that the family does not feel like they are being rushed, and I make sure to ask them for their perspective. We have a lot of Haida and Nisga’a who live here and I think it is important to know where they are coming from. (S.L.P.)

Flexible Scheduling

I think that it is a good idea to stagger our visits so that not all of the therapists go on the same day. I also schedule visits on different days of the week so that I can spend time in different playgroups. Being flexible with my timing helps to meet the community’s needs. (Outreach P.T.)

It Takes Time

It takes a lot of time to establish a friendship and rapport. We need to set aside a lot of extra time to just talk about social things and get to know caregivers, or else we are not going to be trusted enough to be effective. We also participate regularly in the health care fair which helps to show that we are approachable. We have also developed strong relationships with key people in the Band and try to maintain that contact quite regularly... It does take a long time to build relationships, and in the past people in the community have given up on our services when there were a lot of staff changes in the early intervention therapy team. (Early Intervention Team)

On/Off Reserve

I do not feel that there is a difference in etiquette when it comes to on and off reserve. First Nations people are very transient, and we like to move and travel from community to community. We take our values, morals and traditions with us wherever we go. (Aboriginal Early Childhood Development Consultant)

Time to Reflect ....

It is important to consider what you can do to prepare a foundation for building trust and make connecting easier when meeting an Aboriginal family for the first time:

• Who in the community can help you to make a connection with the family?
• Who can help you decide on the best place to meet with the family so that they feel most comfortable?
• Who can be present during an initial visit so that the family feels more comfortable talking about their child and family?
• Has the parent(s)/primary caregiver(s) been invited to bring family members and other caregivers to the meeting?
• Is there adequate time scheduled so that the family does not feel rushed?
• What is the family’s preference for future appointments?
• What is the best way and time to contact the family?
• Does the family want to be reminded the day before/the day of an appointment
Screening & Evaluation

“The very concept of ‘testing’ and ranking the developmental levels of children ... is offensive to many Aboriginal parents. Assessment may be viewed as discordant with cultural values involving appreciating each child for who they are, accepting differences, and waiting until children are older before making attributions about them” (28).

Cultural bias is often most evident in the evaluation process. Instruments that have been designed for use with children who are part of the dominant culture are not always appropriate for children with other life experiences (77). This process also risks unintentionally increasing the distance between Aboriginal family members and health care professionals, as it may symbolize and recreate the legacy of being judged and labeled by members of the dominant society.

Furthermore, “family members who themselves have experienced procedures that labeled them in any way are often fearful of repeating these painful experiences, both for themselves and for their children ... such feelings can lead to a lack of responsiveness to intervention or hostility toward the service provider” (69). The value in assigning a diagnostic label to a child and categorizing a child as special needs is founded in a biomedical approach and may not be perceived as ‘helpful’ by some Aboriginal families; “ideas like disabled children ... don’t come from us. They are not Aboriginal ideas. They come from white people, and from cities. We don’t like to box people up and separate them” (32).

Assessments must be selected with care as developmental norms and expectations for Aboriginal children may differ from the North American population on which the assessments have been normed and developed. In addition, Aboriginal children may not have had the opportunity to practice behaviors that are reflected in a test or they have not been expected to perform at those levels (77).

Strengths-Based

I have an 18 month old infant at the daycare who can point to his facial features when asked in our language. I feel there is a key component that is missed when our children are tested by various agencies with tests that do not include our cultural ways of learning and speaking. They do not recognize if our children can speak our language. Difficulties with English are seen as a deficit and not as an accomplishment for our children. I think that speech and language testing and scoring should have some flexibility to include our language and reflect our ways of life in a positive way.

( Aboriginal I.D.P. Consultant)

Assessments must be selected with care as developmental norms and expectations for Aboriginal children may differ from the North American population on which the assessments have been normed and developed. In addition, Aboriginal children may not have had the opportunity to practice behaviors that are reflected in a test or they have not been expected to perform at those levels (77).

Fine-motor Assessment

I was involved in screening all the 4 year old children in the nursery program for fine motor skills prior to entering kindergarten. I noticed that several of the children appeared to be confused about how to hold and cut with scissors. The nursery teacher told me that lots of the children had not used scissors before. After that I really changed the way I viewed and used my assessment results. (O.T.)
In the S.L.P. profession, “language assessment tools and procedures are based on the standard English dialect. This can result in speakers of non-standard dialects being misdiagnosed as language impaired” (78). Some “First Nations parents, Elders, S.L.P.s and early childhood care givers have expressed frustration about culturally inappropriate assessments that labeled their children deviant or deficient, when it was more likely that the assessment approach, tool, or norms were culturally biased and inappropriate” (28).

**Dialectal Variations on Formal Language Tests**

I believe I am doing Aboriginal children a disservice if I recognize dialectal variations on formal language tests, then say a child is functioning within normal limits. I prefer to count non-standard grammatical forms as errors on Standard English S.L.P. tests, so that I can see how a child is functioning in relation to their peers. This does not mean, however, that I would rate the lower scores as delays. I prefer to note the dialectal variations, then rate the level of performance with Standard English as ‘mild’, ‘moderate’, or ‘severe difficulties’. By using the term ‘difficulties’ I am acknowledging a child’s challenges but not implying a learning difficulty. Traditional formal tests are not always culturally appropriate but certain tests and subtests are useful with informal qualitative analysis in documenting areas for intervention with Aboriginal students. (Aboriginal S.L.P.)

“Gather only the data necessary to begin to work with the child and family. Limit the number of forms, questions and other types of paperwork” (77). Allocate time for building trust and a relationship by “being present” with the children, their families and caregivers prior to undertaking any standardized testing, particularly if therapists are new to a community. What are the important issues for the family? These issues may or may not be represented in the “reason for referral.” What has the parent been told by others? What does the parent agree or disagree with? Become familiar with the family’s cultural background and culturally determined beliefs about family roles, disability, and intervention. A useful question is “Have you been given advice about taking care of your child that's different from the way you think families should act?” Being sensitive to cultural practices and beliefs conveys respect for the family and can help to shape the intervention approach in ways acceptable to the family (79).

**Informal Assessments**

As an experienced clinician, I don’t use standardized assessments very often out of respect for how the family may see their child. Instead I talk to the parents and/or grandparents and ask them about where their child is at and where they would like them to be. I ask the families about their concerns and also about their dreams for their child. I use developmental milestones to help guide their concerns and dreams. We then focus on lessening their concerns through early intervention. If standardized tests need to be used, I will involve the parents in the assessment by asking them questions about how their child may perform on an item or task at home. I will query their concerned looks when their child finds a test item difficult. I also provide them with detailed information about the test such as what the test is measuring, why the child has to achieve a certain number of test items (basal and ceiling), and why I give positive feedback for participating in the activity rather than for correct responses. I also try to give standardized test results to parents right away rather than waiting so that their worries or concerns can be dealt with right away. (S.L.P.)
One strategy for integrating parent/family perspectives into early intervention practice “is the use of a narrative approach, or parent storytelling, throughout intervention, as an ongoing process of parent-therapist collaboration” \(^{80}\). Techniques are “used to elicit an individual story of each parent's experience of their child with a disability. These include encouraging parents to develop visions or ‘snapshots’ of their child at present and in the future, and identifying meaningful family activities and routines through parent interviews. It is suggested that these strategies can provide therapists with entry points to the family’s story which can assist them in assessment and intervention planning” \(^{66}\). As part of an authentic and reciprocal relationship, professionals also need to “step outside their professional façade and be willing to share their own (family) stories and experiences” \(^{68}\).

**Time to Reflect....**

The evaluation process has the potential to inadvertently increase the distance between Aboriginal family members and health care professionals. What can you do to make the evaluation process meaningful and positive for an Aboriginal family?

- **Do you co-ordinate the timing of your assessment so that it allows for the people important to the family to be present?**
- **Do you ask the family where they would like you to assess their child?**
- **Does your written and verbal communication recognize and highlight a child’s and family's strengths?**
- **How/when can you share evaluation findings with family & community members so that it engages (rather than distances) them?**
- **Who can you partner with in the community when sharing assessment information?**

**What are your dreams for your child?**

I facilitate a group where families have the opportunity to learn more about play and how to interact with their children to promote language development. I ask each family member to think about and share a dream for their child as they introduce each child to the group. This allows me to learn how a family sees their child or children and is a good way to bring the group together. One parent’s dream was that their child will “dream his own ideas and achieve them”, while some other parents found it very difficult to share. An Elder who was present noted that this was a good activity for the parents because she felt that it was time for her people to dream again. For so long they had not allowed themselves to dream. (S.L.P.)
Program Planning & Intervention

“Therapists must balance their time and efforts between focusing directly on the child’s needs and addressing family member’s needs.”

Family Context: Therapy professionals need to consider a child within the context of the family as a whole. The priorities of a family may be focused on other issues/stressors which may need to be addressed before they are able to focus on early intervention therapy. An Australian study investigated the values of five urban Aboriginal parents related to parenting and child development. Maslow’s cumulative theory of motivation was used to explore how the need to survive took precedence over other considerations, such as education or day care for children, safety in relation to mainstream government services, and a strong emphasis on the value of social relationships and family involvement. “Surviving day to day was the primary focus for many Aboriginal people who experienced low socioeconomic status.” The study highlighted the need for therapists to increase their profile in advocating for “the provision of basic necessities and access to an equitable and appropriate service.”

A Hierarchy of Family-Centred Practice: All families vary in the level of involvement they choose to have in the intervention process. A hierarchical approach to family-centred intervention may serve to address the experience of some families who feel overwhelmed not only due to the needs of their child with special needs but also due to the needs of the early intervention service providers. If attendance and participation is an issue, it is important to discuss with the family their preferred “level of family-centred intervention” that meets both their child’s and their family’s needs.

Family as a Whole

I remember one mom saying “I don’t care if she’s not talking – she’s hungry and I don’t know how I’m going to feed her.” So I supported her to go to the Food Bank and in the long term I helped her with budgeting as she was running out of money every month. So once we met all those needs then finally we were able to get to her daughter’s developmental needs.

(Aboriginal I.D.P. Consultant)

Figure 1: A Hierarchy Model of Family-Centred Intervention - Adapted from Cahill.
A hierarchy of family-centred practice acknowledges that “families have different ways of understanding and participating in interventions for their children. What may be considered active participation by one group is viewed as passive by another” (77). A hierarchy reminds clinicians, particularly new graduates, that family-centred practice may look different for each family; a family's level of involvement in the therapy process will vary within and between different families. Flexible models of service delivery enable therapists to engage family members in their child's early intervention at a level which meets both their child's needs and their needs as a family. Changing family events and circumstances may influence a family's level of engagement.

**Integrating Therapy into Routine Activities:**
Inclusive early intervention in natural environments is considered current best practice (85). Home therapy programs allow family members to support early intervention in a child's natural home environment. However, unless such programs are integrated into a families typical routine, they risk failing to meet the needs of the family as a whole. The early intervention therapist needs to learn a family's typical daily routine and which family members are involved. Such information provides a greater understanding of a child's day, how the family functions as a whole, and enables the therapist to consider what opportunities exist for gradually integrating therapy. This approach can be used in any setting and promotes a holistic approach to meeting a child's and caregiver's needs throughout the day.

**Extending Family-Centred Practice**

_I need to be prepared with activities for the older children in the family and everyone needs to be included ... so I need to know who is going to be there, have activities for those ages and take some time to get the other children going - hopefully independently - so that I can then focus on the child I am working with._ (O.T.)

_I think it is important to acknowledge the role of grandparents... I recently saw a child for early intervention with her grandpa and said: “I can tell you’re concerned about your grand daughter, I appreciate you’re caring for her.” (S.L.P.)_

**Individualized Matrix**

_When we have a child in the daycare program that is receiving or needs extra support we meet as a team to develop a matrix which integrates our daycare routine with a child’s early intervention. The child care providers tell us about their typical routine activities and we talk about how therapy goals and intervention could fit into each of these activities. This matrix is then posted on the wall in the daycare, and it helps to keep everyone informed about what strategies or skills the child is working on at snack time, free play, circle time etc._

(Early Intervention Team)

**A Primary Therapist Model:** A model of intervention in which a primary therapist works with the child and family rather than expecting families to establish relationships with service providers from a variety of disciplines (69) may be easier and less threatening for the family and community. Initially gaining trust with just one health care professional may be easier for a family than developing relationships with several therapists at the same time. The primary therapist may already have a good working relationship with family members, and other therapy disciplines can provide consultation to the primary therapist who passes these suggestions on to family members and caregivers. This model “minimizes the number of people with whom a family must interact and avoids giving a family too many activities to integrate into their lives” (69).
A Community Development Approach: A community development approach to early intervention enhances cultural safety and promotes trusting and collaborative relationships. The traditional outreach model of service delivery risks cultural safety as knowledge and skills are controlled by the arrival and departure of health professionals. Integrating services with existing community programs means that therapy services can be provided in neutral locations, such as a daycare setting. Developing partnerships with a child's Aboriginal child care service provider allows knowledge to be sustained within the community.

Resident Expertise

I have developed a really good relationship with the daycare staff. One person in particular has always been interested in learning more about how to support speech and language in the daycare. Over the years, she has taken extra courses to learn more and I have provided her with strategies, materials, and information to enrich the language program in the daycare. She is a valuable resource and has become really good at identifying children that need extra help and integrating language learning opportunities into the daycare routines. As well, she really encourages other staff to do the same. Together, we have developed a language enhancement group that is making a difference for the children. (S.L.P.)

Community Partners

I work a lot with an Aboriginal I.D.P. Consultant. We do home visits together and I find the I.D.P. Consultants are often closer to the family and know their needs better than I do. I also appreciate how they orient us when we give suggestions for the family - are they too much or not enough - and how they help us with follow-up. Our A.I.D.P. Consultant is awesome - she is learning from us and we are learning a lot from her. (O.T.)

I have found that community health nurses are good partners for providing early intervention to infants. (S.L.P.)

I arrange my travel days so that I can join in with the ‘Starting Smart’ program (nutrition/playgroup) as this is a good way for people to get to know my face and to know me so that I am not just a speech pathologist. (S.L.P.)

We used to have a play group in the village where the Aboriginal I.D.P. Consultant would bring crafts and toys and each week a different therapist would join her. I will go for five weeks to do infant massage, and then we will alternate therapists. (O.T.)

Consistency

It is important to visit a community program on a regular basis so that we aren't just seen as a therapist flying in and asking more questions. We now visit every week and over time have developed an openness with staff. They watch what I am doing with the children; they see the strategies that I would like them to use and they see the successes. (S.L.P.)
Time to Reflect....
A cultural safety perspective “assumes that all health care encounters are ‘bicultural’ regardless of the number of people or the number of cultural frameworks through which messages are filtered. It is therefore important that all health professionals reflect on their own values and beliefs in every clinical encounter as one interacts with the values and beliefs of the ‘other’” (9).

• How much time do you spend talking with families about their values and practices?
• How do you identify roles and responsibilities within an extended family network in order to understand a family’s pattern of responsibility and care?

Based on work by Christensen & Hocking & Whiteford.

Intervention can be made more effective by putting time and energy into ensuring that the goals and outcomes proposed are those that are of primary importance to the family.

• Who does the family want to be involved in their child’s early intervention program?
• How does the family define “being involved”?
• How can you involve extended family members and siblings in program planning?
• What are the family’s top three concerns, worries or questions about their child?

When planning for child specific early intervention therapy services, therapists need to consider:

• What kinds of activities does the family do together in a typical day/week?
• How can therapy be integrated into some of the family’s routine activities?
• How can therapy be integrated into existing community programs (playgroups, daycare, nursery)?
• Who can you partner with to promote a community development approach to early intervention therapy?
EMPOWERING THROUGH KNOWLEDGE

Families and caregivers need early intervention therapists to provide information in a clear and easily readable format, so that this information empowers them to make informed decisions and become as involved as they are able in their child’s health and care.

The following information is aimed at achieving this goal, based on the principles of “health literacy”, and is relevant for all families. Four out of every ten people in B.C. fall in the “low-literacy range”; that is, people who can use printed materials for limited purposes such as finding a familiar word in a simple text.

Health Literacy

Health literacy is the ability to find, understand and use health information, including medical tests, healthcare brochures, consent forms and a health professional’s written and verbal instructions. Health literacy is more than the ability to read. It utilizes a mix of skills including reading, listening, analysis and decision-making. The ability to understand and absorb health information is influenced by many factors including literacy level, disability, language, emotion, stress, pain and medication. It is also influenced by how information is presented: Is there a lot of jargon? Is it respectful? Does it make incorrect assumptions about the client and their life situation? It is crucial that health professionals and educators be conscious of health literacy issues. When people do not understand health information, find it confusing or irrelevant, they are unlikely to use it.

Aboriginal Perspectives

Nineteen Aboriginal early child health/care service providers (Aboriginal I.D.P., Aboriginal S.C.D.P., Early Childhood Educators) participated in a workshop titled “Early intervention therapy reports: User friendly/culturally sensitive?” as part of the 2005 B.C. Aboriginal Child Care Society Conference. The workshop was designed to gain input from the participants on their past experiences with early intervention therapy reports. Participants commented that many phrases in reports were medical or therapy terms and were deficit oriented. They also noted that written language often served as a barrier between the family and therapist. Several Aboriginal I.D.P. consultants also provided their input through a written questionnaire on changes that they would like to see in the reporting/documentation for Aboriginal families. The findings are summarized in Appendix B.
Early Intervention Therapy Perspectives

In B.C., report writing in early intervention therapy is influenced by multiple factors including the needs of the client(s); guidelines/protocols of the child development centre/agency in which therapists are employed; discipline specific standards/guidelines from regulatory Colleges, and documentation policies developed through accreditation. As such, therapy reports are a “concrete record of what you have done; important for accountability and professional liability and ethics” (personal communications, 2005).

Six child development centres from four different health regions in B.C. agreed to participate in a telephone questionnaire as part of a survey on report writing by A. Gerlach, O.T. and B.C.A.C.C.S. in 2005. The percentage of families identified as Aboriginal represented between 15-50% of all families served by these early intervention therapy programs. A summary of these findings are presented in Appendix B.

Donaldson et al explored the perspectives of O.T.s, S.L.P.s and parents of children who received therapy services on clinical report writing in the United Kingdom. The authors concluded that “therapists should combine verbal and written reports to be more useful to parents... scores on measures and tests need to be interpreted for parents in functional ways to enhance parental understanding” (88). The authors recommend avoiding report pro formas, and individualizing each report.

Family involvement in early intervention may be increased by offering each family a choice in how they receive information from an early intervention therapist or team (69). Family-centred reporting involves communicating in a way that is most useful for the family. One evaluation/intervention reporting strategy is the use of dvd/video as a visual record of a child’s progress and intervention. Viewing this visual record together with family allows the therapist to celebrate a child’s strengths, teach the family more about early intervention therapy and provide a visual reminder of intervention strategies.

Plain Language

“Persons at all literacy levels prefer and have a better understanding of simple written materials compared with complex materials” (89).

Plain language does not mean simplifying or “dumbing down” the content; rather it is a way of clarifying written materials so that the writing style does not distract from the message. Health professionals need to use simple low-literacy materials and/or use nonwritten materials for all their clients regardless of their level of reading proficiency (89).

Visual Reporting

I was working with a little girl in daycare who was transitioning to kindergarten. I wanted to record her progress and also let her family and new caregivers know how much more independent she could be when she was given specific physical assistance and verbal cuing. I made a 35 minute DVD of her participation in daily routines at daycare. The DVD showed what it looked like when she received just the right amount of support from her Aboriginal S.C.D.P. worker and her peers. I watched the DVD with her mom and grandmother and we talked about how well she was doing in different activities of daily living. It was also an excellent way of training her new support worker in the summer program and preparing for her new teaching assistant in kindergarten. It has been a much more successful communication and educational tool than any reports I have written. (O.T.)
People with limited reading skills interpret words literally, rather than in context, read slowly, skip over unfamiliar words and tire quickly while reading. “It is important for health care providers not to assume that they can recognize patients with poor literacy skills, because most individuals with limited literacy try to hide the fact that they cannot read; “I forgot my reading glasses/I'll read this through when I get home/ I'd like to discuss this with my family first, may I take the instructions home?” (89).

Designing Effective Written Materials

“A client’s ability to read and understand written information is influenced by both its content and design. Clients also comprehend and learn best when the information presented is relevant to their lives” (90).

1. Aim for a grade 5/6 reading level*
2. Keep content clear, simple and concise
3. Avoid jargon; define medical terminology
4. Ensure relevancy by considering the information needs of the target audience
5. Use client’s questions to frame information
6. Use short sentences and one or two syllable words, with one idea to one sentence
7. Discuss important points first
8. Bullet points may be helpful
9. Use clear, obvious and bolded headings
10. Use adequate spacing between lines
11. Use at least 12P.T. font size
12. Use clearly labeled illustrations, digital photographs

[*Microsoft Word in the “spelling and grammar” function provides reading ease statistics.]
Adapted from Griffen, McKenna & Tooth (90).

Time to Reflect…..
Consider how you can empower family members and caregivers by using the principles of health literacy and plain language throughout the therapy process.

• Do you discuss with family members and caregivers their preferred method of receiving therapy information?
• Do you provide the option of visual information (photographs, video, DVD)?
• Do you avoid any use of medical or therapy jargon?
• Do you put the most critical information at the beginning of your communication?
• Do you check the grammar level of your written communication?
• Do you review written information in a draft format with family members and caregivers?
• Do you have a ‘community partner’ who can support your communication with family members and caregivers?

Resource:
National Aboriginal Health Organization at www.naho.ca for information on plain language guidelines.
APPENDIX A: ‘UNPACKING YOUR CULTURAL BACKPACK’:
THE CULTURAL NATURE OF YOUR EARLY INTERVENTION TEAM & ORGANIZATION

This is a useful tool to assess team members’ and organization leaders’ standing and commitment to gaining cultural competency. Photocopy the pages, date them and compare answers to evaluate your progress.

A = Things we do frequently
B = Things we do occasionally
C = Things we do rarely

_____ 1. Team members/organization leaders acknowledge and respect the right of an individual to his or her cultural customs, beliefs and practices.

_____ 2. Team members/organization leaders affirm that an individual's culture is an important part of the physical, emotional, intellectual, spiritual and overall well-being of that individual.

_____ 3. Team members/organization is responsive to issues of cultural diversity, and designs their materials, events and programs to be inclusive.

_____ 4. Team members/organization leaders respects the diversity and rights of the individuals they serve.

_____ 5. The mission statement explicitly recognizes cultural diversity in the community.

_____ 6. The team’s/organization's publications and promotional materials refer to services to culturally diverse people.

_____ 7. In selecting new board members, the organization considers representation from the culturally diverse community.

_____ 8. Board members, team members and organization leaders and/or key volunteers receive cultural sensitivity training.

_____ 9. Organization leaders screen books, and other media resources for negative cultural, ethnic or racial stereotypes before sharing with members of the public.

_____ 10. Team members/organization leaders avoid imposing values that may conflict or be inconsistent with cultures other than their own.

_____ 11. Team members/organization leaders understand and accept that family is defined differently by different cultures, and reflect that understanding in outreach activities.

_____ 12. Team members/organization leaders recognize that the meaning or value of medical and therapeutic interventions, parenting styles, and family relationships may vary significantly among different cultures.
13. Team members/organization leaders understand that beliefs about developmental disabilities are culturally based. They acknowledge that responses and treatment/interventions are heavily influenced by culture.

14. Team members/organization leaders respect and accept that spiritual and religious beliefs may influence a family’s reaction and approach to a child born with special needs.

15. Outreach programs use trained/certified interpreters when visiting families who do not converse comfortably in English.

16. Team members/organization leaders understand the value in using alternatives to written communication for some families, as word of mouth may be a preferred method of receiving information.

17. Team members/organization leaders understand that approaches to disciplining children are influenced by culture.

18. Team members/organization leaders understand that expectations of children for acquiring toileting, dressing, feeding and other self-help skills are culturally based, as are expectations for employment, independent living and relationships.

19. Before visiting a family, team members seek information on acceptable behaviours, courtesies, customs and expectations that are unique to families of specific cultures.

20. The team members/organization leaders educate culturally diverse organizations, religious groups and businesses about their organization and about children with special needs.

There are no right or wrong answers to these questions, however, if you frequently respond ‘C’, your team/organization may not necessarily demonstrate values and engage in practices that promote a culturally diverse and culturally competent service in your community.

(Adapted from ‘Cultural Competency: A Self-Assessment Guide for Human Service Organizations’ University of Calgary, Cultural Diversity Institute).
APPENDIX B: HEALTH LITERACY IN EARLY INTERVENTION THERAPY

Aboriginal Perspectives

A workshop ‘Early intervention therapy reports: User friendly/culturally sensitive?’ at the 2005 B.C. Aboriginal Child Care Conference was facilitated by A. Gerlach, O.T. and D. Zeidler, S.L.P. The following is a summary of the views and experiences of the 19 Aboriginal child/health care service providers who attended this workshop:

“Why do you (Aboriginal child/health care service providers) need therapy reports?”
- Planning for individual children
- Record keeping
- Statistical purposes
- Sharing with other helping professionals (with parents’ permission)
- So that the team understand the problem and everyone is on the same page

“How can you play a role in helping family members understand therapy reports?”
- Sit down with parents and go over the report – simplify and translate were necessary
- Communication book between home and school

“What wording/phrases don’t you understand/would like more information on/think family members may have difficulty with?”

Participants reviewed two examples of different styles of early intervention therapy reports and were asked to note any words/phrases that they did not understand or that they considered were not family-friendly. Participants commented that many of the phrases were medical/therapy terms and were deficit orientated. These included: ascends the stairs/milestones/imitate gross motor movements/range of motion/balance reactions/standard testing/stimulation/visual/auditory/poor sense of where her body is in space/unco-ordinated/deep pressure/transitions/motor planning difficulties/bear crawl.

Aboriginal I.D.P. Consultants provide an important connection between Aboriginal families and early intervention therapists (personal communication, 2005). The following is a summary of key points from the perspectives of four Aboriginal I.D.P. Consultants in different regions of B.C. who completed written questionnaires as part of a survey on report writing by A. Gerlach, O.T. and B.C.A.C.C.S. in 2005.

Describe some of the benefits/uses of these reports for you/the families you support?
- “Offers clear descriptions of what may be developmental challenges and great suggestions”
- “Supports our staff and families in providing care and helps us plan activities”
- “Ensure child has appropriate supports/activities to enhance his/her development in whatever area is needed”
Describe some of the challenges you/families you support experience when you receive a report on a child written by an early intervention therapist.

- “I find reports to be negative in nature – focused on identifying deficits”
- “Some reports entail a great amount of jargon”
- “Sometimes written in such a way only other professionals might understand”

Do you think these reports are sensitive to the needs of your community’s cultural and socioeconomic needs?

- “No but this will take a lot of training with people who are motivated”
- “Not always, but I notice that each therapist appears to consider individual family needs and abilities”
- “No, sometimes the reports are not read by the family due to the literacy level”
- “No, language is not sensitive to parents or children”

What would you like to see changed in how early intervention therapists communicate their evaluation findings in written reports?

- “More strengths based”
- “Simpler wording, i.e. what does gross motor etc mean?”
- “Communicating both verbally and in writing in plain language”
- “I would like to see a more sensitive, user-friendly report method. Too often parents are left feeling overwhelmed and confused”

What would you like to see changed in how early intervention therapists communicate their intervention recommendations in written reports?

- “As recommendations; words like ‘should’ place expectations”
- “How about a discussion of results with family and then discuss possible recommendations based on input from family”
- “Simple activities that don’t cost money. Home-made ideas”
- “Keep it simple and realistic; families are more likely to do things when they can be incorporated into what they are already doing”
- “I would like to see early intervention therapists be more sensitive to parents needs and sometimes literacy levels”

Early Intervention Therapy Perspectives

Feedback from six child development centres from four different health regions in B.C. that participated in a telephone questionnaire as part of a survey on report writing by A. Gerlach, O.T. and B.C.A.C.C.S. in 2005 is summarized as follows:

“Can you describe some of the key points in your program’s policies/guidelines for report writing for therapists?”

- “Our centre is moving towards a multidisciplinary team reporting system”
- “The reports are written for the explicit use of the parents and therefore language is targeted for that purpose”
- “Templates are used and the primary reader is considered to be the family. If terms such as ‘expressive language’ are used they are always followed by an explanation”
- “Aim for below grade 8 level of literacy”
- “Need to do an annual summary report which is always reviewed by the family and their consent obtained before final copy circulated”
“What can therapists do to help ensure that information in a report is respectful of a family’s culture and socioeconomic status?”

- “At the intake process ask if there is anything about your culture that we need to know/how do you prefer to receive information/who do you want this information shared with”
- “Doing a home visit is a great way to build a relationship and gain more background information”
- “Family concerns are at the beginning of a report and are the focus. Need to aim for a grade 6 level but probably the reports are at a much higher level”
- “Is it better to avoid terminology altogether or to use some with a brief explanation of what it means?”
- “If the family has a known learning disability then we review it with them orally. We are also very careful to use language at the family’s level”
- “If we are using a standardized assessment we put the scores in an appendix so that the body of the report is not too complicated”

“Is a report the best way to communicate this information?”

- “How families prefer to receive information from therapists can be asked at intake”
- “I wonder if we need to think about other ways of communicating such as using video?”
- “I think what works better is a home visit record (on a triplicate form) and limit the recommendations to two”

“What do you think is the most effective way of therapists learning more about how their evaluations and intervention plans are communicated with Aboriginal consumers?”

- “To plan a visit to go through the report with the family”
- “I.D.P. and S.C.D.P. Consultants are in a key position to help a family understand a report”
- “Provide other options beside written reports”
- “An I.D.P. consultant who used to work on the reserve used to do lots of cut and paste of pictures which works well if your recommendations can be depicted in this form”
- “Consider the learning style/needs of each family”
- “Need to be reminded about the residential school system. Need to think about the socioeconomic status of a family and how this challenges personal and professional assumptions”
- “Provide a draft copy of report and review with the family; if draft is stamped over it then more likely to get feedback”
APPENDIX C: USEFUL RESOURCES

ABORIGINAL CANADA PORTAL
An excellent Government of Canada web portal to on-line resources, contacts, information, programs and services of interest to Canadian Aboriginal people. Lists Aboriginal organizations, for example all the Friendship Centres in B.C.
Website: www.aboriginalcanada.gc.ca

ABORIGINAL HEAD START B.C.
Each Aboriginal Head Start project focuses on Aboriginal preschool children and their families with programming in each of six program component areas including culture and language, school readiness, health promotion, nutrition and family involvement.
Tel: 604-666-1356
Website: www.ahsabc.com

ABORIGINAL INFANT DEVELOPMENT PROGRAMS
An A.I.D.P. program is a family-centred, child development focused home visiting service for Aboriginal children and families in B.C. There are currently 30 programs located both on and off for children who might need extra support for healthy development and to reach their full potential. As well as home visiting, A.I.D.P. provides parenting groups and workshops, and community education workshops on child development and early and lifelong learning. A provincial office is available to support, guide, and ensure mentorship and training for A.I.D.P. staff toward quality services and programs. A Provincial Advisor and five Regional Advisors are available to ensure that all A.I.D.P. programs are supported around B.C. to facilitate local, regional, and provincial training opportunities, networking and collaboration.
Contact: Diana Elliott, Provincial Advisor for Aboriginal Infant Development Programs
Tel: 250-388-5593
Website: www.aidp.bc.ca

ABORIGINAL SUPPORTED CHILD DEVELOPMENT PROGRAMS
Aboriginal Supported Child Development offers culturally-based services for children with extra support needs and their families. Services are intended for children from birth to age 12, with some services for youth 13 to 19. Aboriginal Supported Child Development services are in varying developmental stages across the province as communities develop capacity and determine service delivery models.
Contact: Lorraine Aitken, Provincial Advisor for Supported Child Development Programs of B.C.
Tel: 250-338-4288 ext 225
Toll free: 1-866-338-4881
Website: www.scdp.bc.ca

B.C. ABORIGINAL CHILD CARE SOCIETY (B.C.ACCS)
A non-profit charitable organization serving Aboriginal early childhood programs throughout B.C. It offers training workshops, a lending library, rotating curriculum boxes, a traveling child care advisor, annual conferences and newsletters. A Pdf of this publication and ‘A Guide for Culturally-Focused Early Intervention Programs for Aboriginal Children & Families in B.C.’ are available on the website.
Tel: 604-913-9128
Website: www.acc-society.BC.ca
B.C. ABORIGINAL NETWORK ON DISABILITY SOCIETY
Provides a variety of support services and resources for Aboriginal people with disabilities, and Others associated with the disabled.
Website: www.bcands.bc.ca

B.C. ASSOCIATION OF ABORIGINAL FRIENDSHIP CENTRES
An umbrella association for 24 Friendship Centres throughout B.C. While each Centre is as unique as the community it serves, all are united in their effort to improve the quality of life of Canada’s Aboriginal people and to protect and preserve Aboriginal culture for the benefit of all Canadians. Friendship Centres are reflective of the communities they serve, controlled at the local level and, above all else, responsible to and responsive to, the people they serve. Currently home for the office of the Provincial Advisor for Aboriginal I.D.P.
Website: www.bcaafc.com

B.C. PROVINCIAL GOVERNMENT
Website: www.gov.bc.ca/arr/reports/default.html
Aboriginal Child & Family Development provides information on the B.C. Regional Aboriginal Planning Committees, Delegated Aboriginal Child and Family Service Agencies, the Aboriginal Chairs Caucus, and the Joint Aboriginal Management Committee.
Website: www.mcf.gov.bc.ca/about_us/aboriginal/index.htm

CENTRE OF EXCELLENCE FOR CHILDREN & ADOLESCENTS WITH SPECIAL NEEDS
A program sponsored by Health Canada to meet the needs of children with special needs living in remote or northern areas of Canada.
Website: www.coespecialneeds.ca

FIRST NATIONS EDUCATION STEERING COMMITTEE (FNESC)
FNESC facilitates discussion about education matters affecting First Nations in B.C. by disseminating information and soliciting input from First Nations.
Tel: 1(877)422-3672
Website: www.fnesc.ca

NATIONAL ABORIGINAL HEALTH ORGANIZATION (NAHO)
An Aboriginal-designed and controlled body committed to influencing and advancing the health and well-being of Aboriginal Peoples through carrying out knowledge-based strategies. The Journal of Aboriginal health is the only publication in the world dedicated exclusively to Aboriginal health issues in Canada. Published by NAHO, the peer-reviewed journal includes articles from leading health scholars, academics and Aboriginal community members. Subscription is available through the NAHO website.
Website: www.naho.ca