# EXPLORING AND REDEFINING HOME VISITABILITY WITH THE SCIA'NEW AND ESQUIMALT NATIONS

by

**Renée Ahmadi**

BCYC, University of Victoria, 2009

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# Abstract

This qualitative study was designed in collaboration with the Scia'new and Esquimalt Nations to learn how home and community design impacts the health and quality of life of those living with mobility challenges in their communities. The research questions were: 1) How does the presence or absence of the three structural visitability features (a zero step entry, 32 inch wide doorway and a wheelchair accessible bathroom on the main floor) impact First Nations people with disabilities, 2) What barriers and supports most impact the quality of life of those living with disabilities, 3) How does reserve community infrastructure influence individual home visitability? Methods included: a community scan to assess the layout and physical infrastructure, and photovoice, employed to provide a medium for documentation by participants and to stimulate individual interviews. The study included interviews with nine participants who identify as First Nations (four from Esquimalt and five from Scia'new) living on reserve with mobility challenges. The thematic analysis included a group check-in session, where key findings were tested and themes verified or modified. Findings indicated that emergent themes were divided into two dimensions: physical safety, including themes of home visitability, physical barriers, home maintenance, and community infrastructure; and social capital, including reciprocity of support, community relations, and Band administration. The results showed that despite the many physical and social barriers experienced by the Scia'new and Esquimalt participants, the degree of social capital strongly mitigated the negative impacts of their limitations.

*Keywords*: First Nations, visitability, Photovoice, people with disabilities, social capital

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# Chapter 1: Introduction

Despite being the subject of costly and time consuming studies and inquiries, First Nations communities remain burdened with a higher infant mortality rate and lower life expectancy; inadequate health care, high rates of substance abuse and suicide, violence, poverty, and a disproportionally high rate of incarceration (Health Canada, 2009; Kendall, 2001; Senese & Wilson, 2013). The deep social inequalities that produce many of the health disparities are related to a history of loss of lands and sovereignty, as well as cultural genocide brought about through state policies such as mandatory residential schools, foster care, inadequate educational support, job market discrimination, and the ever persistent jurisdictional complexities between federal and provincial governments (Adelson, 2005; British Columbia First Nations Leadership Council (BCFNLC), 2005; Kendall, 2001; Wilson, Rosenberg, & Abonyi, 2011). The history of failed oppressive state policies that aimed to eliminate Indigenous culture and fully assimilate the Indigenous population into the dominant western population has resulted in numerous contemporary policy complexities, jurisdictional barriers, and a fragmented uncoordinated approach to service delivery that continues to harm families and divide communities (BCFNLC, 2005; Wilson et al., 2011). The dominant historical narrative has ignored most stories of continuous Indigenous resistance, and the survival and ultimate resurgence of their culture (Kelm, 2001). Valuable actions such as the push to close residential schools were often led by families and leaders who had learned their traditional language and systems. These have been documented in letters to government demanding justice for their people (Kelm, 2001). Even with ample evidence that identifies the mistreatment of Indigenous Canadians, and the need for reconciliation (Blackburn, 2007), neither the federal or provincial governments acknowledge the impact that colonialism continues to have on the quality of life of Canada’s First Peoples (Kendall, 2001; Senese & Wilson, 2013; Wilson et al., 2011).

Momentum continues. Communities and nations have unique needs, and at times conflicting priorities. Some focus on economic development opportunities and treaties, while others seek to be separated and liberated from the Crown (TRCC, 2015). The new Liberal government campaigned on many promises related to making improvements to the quality of life for Indigenous Canadians. These promises included increased investments in education, community infrastructure, child welfare, and health care, as well as to lead a major national inquiry into the murdered and missing Indigenous women, and committing to the 94 recommendations made by the Truth and Reconciliation Commission. That these issues have become politicized and are included in public discourse shows that research that works to assess the needs and priorities of First Nations communities could help ensure that future investments into community infrastructure adequately address and respond to health and safety concerns of the most vulnerable community members.

The First Nations in British Columbia (BC hereafter) carry a disproportionate load of the province’s diseases and disability. The British Columbia Aboriginal Network on Disability Society reports that 32 percent of First Nations identify as disabled, compared to the 14 percent in the general population (BCANDS, 2012). Durst, Manuel South, and Bluechardt (2006) add that while the rates of congenital disabilities are on par with rates for non-Indigenous Canadians, “environmental and trauma related disabilities” such as injuries, accidents, violence and self-destructive behaviour, as well as illnesses like diabetes that can end in a disability account for the main difference in the higher percentage of disability reported by First Nations (p. 35). Over 50 percent of First Nations people who are 60 years and older live with a disability (BCANDS, 2012) compared to the rate of 43 percent reported by the general population of Canadians who are aged 65 and older (CCDS, 2013, p. 3). In addition, geographical barriers often force First Nations people with complex health needs or permanent disabilities to stay in unsafe or inaccessible homes and communities, or to leave their homes, communities and support networks in order to access necessary health services (BCFNLC, 2005). There is an urgent need for quality reserve housing, yet in 2013 there was an estimated shortage of over 8,500 houses on B.C. reserves, with 44 percent of existing homes in serious need of renovations (Canada Mortgage and Housing Corporation [CMHC], 2013). The immediate housing needs of families for basic shelter have taken precedence over the prioritization of appropriate housing for people with specific mobility needs. In this thesis, I will argue that improvements to the overall functional utility of a home or community by considering the needs of those living with limited mobility could dramatically improve the quality of life for families over the lifespan. To support my argument, I have organized this thesis into six chapters: Chapter One includes an introduction and a definition of terms. In Chapter Two, I present a review of the relevant literature. Chapter Three describes my methodology, Chapter Four, my findings, and Chapter Five, a discussion of my findings. In the sixth chapter, I present my conclusions and considerations for the future.

Home visitability refers to how easily a home can be entered and used by someone with restricted mobility. For a home to be considered visitable by the standards established by the Canadian Center on Disability Studies (CCDS, 2013), the home design features must include **1.)** a zero step entry at the front, side, or rear of the house, **2.)** a 32 inch wide doorway and **3.)** a wheelchair-accessible bathroom on the main floor (CCDS, 2013, p. 2). The objective of this study was to collaborate with the Scia'new and Esquimalt Nations to understand how home and community design impacts the health and quality of life of those living with mobility challenges in their communities. The study focused on the following three questions:

1. How does the presence or lack of the three structural visitability features impact people with physical disabilities?
2. What barriers and supports most impact the quality of life of those living with disabilities
3. How does a reserve community's infrastructure influence individual home visitability?

To answer the first question I collected data on the participant's home environment, and these features were the focus as each participant documented the existence, or lack, of the three visitability features inside their homes in the communities of Esquimalt (Esquimalt Nation) and Beecher Bay (Scia'new Nation). Participants answered the second question through the group sessions and photo inspired interviews where they discussed the role and quality of their social networks, and the relationship that community infrastructure had to their quality of life. To ground my study I reviewed literature on the environmental dimension of homes and communities as it relates to home visitability and community infrastructure for First Nations communities situated on Federal reserve land, specifically examining how both the Band and AANDC (Aboriginal Affairs and Northern Development Canada) administrative processes are critical factors influencing the health and well-being of participants. Due to the complexity involved with understanding the deeper social processes both anticipated and revealed through my analysis, my literature review also introduces theory to help ground these large contextual issues.

## Researcher Positioning

My interest in community based social justice topics has been strongly influenced by my own experience growing up in a settler home in Glenora, near the remote Tahltan community of Telegraph Creek in the Northwestern corner of B.C. My mother was the community nurse, so from a young age I had an insider understanding on why many people left our community to go south to meet the needs of family members with complex health issues, to have babies, or to place their elderly family members in extended care units in the larger communities of Whitehorse, Terrace, Prince Rupert, Smithers or Prince George – all between 7-14 hours’ drive away. Families whose younger members require long term specialized care must move to larger urban centers to access services, resources, and appropriate housing and infrastructure needs. The ability of mobility challenged adults to remain in their home or community depends heavily on the capacity of their family. When care needs move beyond what the family can manage, the vulnerable community member is moved to an urban care home away from family and community, where they often die, returning home only to be buried. This experience formed perspective on the relationship between community development and health for those living with specific care needs, and lead me to take a rural specialization in home support and residential care in 2000 in Dease Lake through Northern Lights College. The program was specifically created to address the needs of aging First Nations in an attempt to keep them in their homes and communities for as long as possible, through the utilization of home support services. I am biased towards keeping families and communities intact and close, as I have observed these relationships to be the crucial ingredient that brings satisfaction and quality of life in old age.

This training led me to work with people with disabilities. When I moved to Victoria, I worked as a home support worker for ten years while I completed my undergraduate degree in Child and Youth Care at the University of Victoria. I completed practicums both in a group home for youth at risk, and in a placement that focused on integrating youth with disabilities into the community through sports and recreation. For the past fourteen years I have worked for a variety of grassroots non-profit organizations on anti-poverty, harm reduction and social justice agendas on the Lekwungen Territories of the Esquimalt and Songhees Nations. This work has included legal advocacy, and also working with income assistance and disability benefits applications and tribunals. My passion for social justice, disability rights, and support for Indigenous sovereignty merges with this study, and is fueled by past front line work experience which also revealed to me the relationship between the physical and social construction of disability, and how identity is often revealed at the intersection. I recognize my own privilege, and although I grew up living under the poverty line I never was unhoused, hungry, or cold, and my family benefitted from our occupation of traditional Tahltan territory where we ate wild meat and fish, and grew an abundance of food that fed us the year round. My family expected me to get a post-secondary education after getting married. My life partner was fully supportive of my choice to work on this degree part-time at home while simultaneously having and raising our two children. My position of power as a white privileged academic researcher cannot be set aside, especially while working with Indigenous communities that continue to experience inequalities rooted in the colonization of their lands and life. Due to my position as a facilitator of this research project, I am driven to use my privilege to support the local communities in a practical way that can serve their needs. This results in added complexity by the topic and a multitude of ethical considerations, such as conflicting values within and across communities and my preferences, values, and biases. The systems and institutions are problematic, and yet while communities depend on governmental resources, and are entitled to them, some feel their liberation is tied to their resistance to the many imposed formal institutions.

Not only have my studies and past work experiences created spaces for critical thinking and challenging the status quo, but even more so have my personal relationships. Having close Indigenous friends move from an identity of Indigenous shame to one of pride that has culminated in a need to actively remove themselves from a colonized frame of reference has been intense. Four different friends of mine have felt the need to move from Lekwungen Territories of the Greater Victoria area back to their own territories, to remember the ways of their ancestors and to reoccupy their lands through the traditional ways. My friends have brought me with them in spirit, and I have seen and heard how this process has changed their lives. This has also illuminated my own privilege, and my responsibility as an occupant of unceded land, both in Tahltan and Lekwungen territories. From my position I do not claim to have decolonized my own research methods, nor have I discussed decolonization with the study participants or in any shared communication; however, because this concept has shaped me, my rationale for this study and the ultimate goal of work is to produce work that supports communities' choices around self-determination and decision-making over their own bodies, health and community development.

My passion for social justice had fueled this work, and my justice meter intersects where experiences of racism, classism, ableism, and sexism meet. I am a heterosexual white woman, mother of two young children. I do not claim to fully understand the experience of those who identify as First Nations, mobility challenged, or poverty entrenched. My own experience and identity blurs the boundaries and is complex. At times I feel I am granted an insider scoop, observing friends and activists that feel first-hand the real ways that our current socio-political structures contribute to injustice, discrimination, inequality and racism. Thus, I did not leave any of this behind through my study process, and rather, I have used my past experiences and world view to develop what I believe is a just and powerful way of doing research on home accessibility in First Nations communities. From the very beginning my approach was about listening to people, face to face over a shared meal or a cup of tea.

## Defined terms

Throughout this thesis, the following terminology will refer strictly to the definitions provided herein.

**Visitability** is a feature of basic home accessibility that includes three specific building requirements: no-step entry, accessible bathroom, and open floor design all on the same floor (CCDS, 2013).

I define a **Person with a Disability** as an individual who both self-identifies and has been identified by the Band housing administrator as having a significant physical challenge that directly impacts their mobility outside and inside their home.

**Aboriginal peoples** refers to “the indigenous inhabitants of Canada [referring] in a general manner to Inuit and to First Nations and Métis people, without regard to their separate origins and identities” (RCAP, 1996, vol. 1).

**First Nations** refers to “a relatively small group of Aboriginal people residing in a single locality and forming part of a larger Aboriginal nation or people” (RCAP, 1996, vol. 1) i.e.: status Indians living on reserve.

**Indigenous Peoples** are “those that, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing in those territories, or parts of them.” (UNDESA, 2004)

# Chapter 2: Literature Review

## Preamble

The following literature review provides an important context for my study. I begin the chapter with a section on “Colonialism and Health on Canadian Reserves,” bringing in different perspectives on the relationship between Canada’s on-going colonial relationship with Indigenous peoples and how this relationship continues to produce health disparities. This section also introduces literature that identifies the ways that Indigenous health is linked to land. Understanding the relationship between the land and Indigenous health is necessary to then comprehend how the imposed reserve system is an inherent component of the visitability assessment in both participating communities. I next focus specifically on the administration of reserve housing, showing how the Band acts as an intermediary between individual Band members and the Federal government, providing detail on the types of home tenure agreements available, and how these agreements also control opportunities for home adaptations. This discussion includes a commentary on the relationship between the First Nations and State jurisdictional processes that have contributed to the housing crisis on Canadian First Nations reservations. The section on home visitability describes how the visitability movement originated, provides specific details on the features, and makes a strong socio-economic argument for policy change. This thesis is supported by studies that focus on First Nations health inequalities, race and social policy, visitability, accessible and universal housing design, aging in place, and the ethical issues and limitation of western driven research with Indigenous communities. The major literature gap on the needs of First Nations with disabilities living on-reserve housing shows to what extent Indigenous studies have been excluded from disability discourse, and vice versa. This research topic is located at the intersection of both these exclusions.

## Colonization, Housing, and Health on Canadian Reserves

There are major health disparities between Indigenous Canadians and non-indigenous Canadians. More than 65 percent of registered First Nations who live on reserves are surviving barely above the poverty line (Health Canada, 2009). First Nations communities are growing faster than the rest of Canada. They feature a younger median age (Wilson et al., 2011), yet this growing young population bulge is underemployed, with almost half of youth leaving school prior to graduation (Adelson, 2005; Health Canada, 2009). In 2001, 976,310 Canadians reported as “Aboriginal” (Adelson, 2005). Of these, 608,850 are First Nations, of which 179,025 live in British Columbia. In “The Embodiment of Inequity: Health disparities in Aboriginal Canada,” Adelson (2005) described how the internal colonial politics and a “collective burden of a history of discriminatory practices, unjust laws and economic or political disadvantage” have led to the marginalization of Indigenous individuals who carry a disproportionate load of disease (p. S46). Adelson emphasizes how health disparities are both directly and indirectly linked to the larger cultural, political, social, and economic inequalities. She clearly differentiates between disparities (or indicators) such as lower life expectancy, and the deeply entrenched inequalities that generate the disparities, for example, poverty. Adelson argues that the Indian Act of 1876, though it formally acknowledges *Indian* (First Nations) ancestry, remains “*the* legislative authority of internal colonization” (p. S47). She clearly describes how the rates of suicide, injuries, drug and alcohol abuse, violence, and disease that First Nations experience at higher rates are symptoms of the larger structural injustices and not merely issues of the person. These inequalities take a toll. First Nations individuals are more likely to suffer from disease, become disabled, and die prematurely. Adelson references numerous scholars from diverse sectors who have shown evidence of how these issues stem from poor historical relations between Indigenous Canada and the State. She argues that knowledge is not enough without the political will to develop policy that addresses the historical injustices. Adelson makes an important contribution because she argues that health outcomes cannot improve without addressing the larger upstream determinants of health that continue to produce health disparities. Housing and infrastructure are issues that are upstream determinants and are impacted by the current colonial relationships that exist between communities and the federal government.

In "Aboriginal peoples, health and healing approaches: The effects of age and place on health," Wilson et al. (2011) explore the relationship between Canada's aggressive colonial history and the contemporary policies that impact the health and well-being of the growing population of aging Indigenous Canadians, with an emphasis on the link between *place,* or land, and health and healing. Land politics are a central part of my background literature because this issue connects how the relationship remains deeply rooted in racist ideologies that justified the displacement of Indigenous communities from traditional territories. Creating segregated communities in often marginal isolated pieces of Crown land set aside for First Nations created barriers to accessing important natural resources as well as established trade routes. This move to reserves negatively impacted health and the physical accessibility of communities by controlling the access to food and water, key infrastructure, interrupting a lifestyle in harmony with their land, imposing Eurocentric values and principles of land tenure. The authors identify an important literature gap, and conclude by considering how although the current health research focuses on the younger demographic and high profile health and social issues, it neglects to prioritize Canada's fastest growing (but proportionally small) demographic of aging Indigenous Canadians, who have inevitably become increasingly mobility challenged.

The history that founded the current relationship between First Nations and the Federal Government plays a strong role in the level of physical safety on Canadian reserves. The use of the medical model as a tool of colonization is explored in *Colonizing Bodies: Aboriginal Health and Healing in British Columbia, 1900-50*. Kelm (2001) reported that pre, and even post, contact most First Nations on Vancouver Island lived in large lineage based families in cedar plank houses during the winter which were well ventilated for smoke and keeping dried food and housed as many as the family head could afford, often ranging from 10-60. The homes could easily be disassembled when it was time to relocate in search for resources, but in the summer large families divided into smaller groups and lived in other structures covered in skins, or in the bush at hunting and fishing grounds (Kelm, 2001). Each family maintained their own fishing and hunting grounds and passed these down through generations. For this reason, the relocation to western housing on reserves located far away from logical proximity to resources created barriers to fulfilling basic needs, and also created health and safety issues, including lack of water and sanitation. Traditionally, homes were either shelters that moved with the animals and fish during the summer, or they were Long Houses which housed and gathered extended families for the long rainy season when crafting, ceremony, celebration, trading and cultural exchange took place (Kelm, 2001). The European view of the potlatch system was that it was immoral and threatening as was this kind of communal living, and it was blamed for the spread of disease. In an era when First Nations families were particularly hit with the spread of new western diseases, the influence of western health care and medicine soared (Kelm, 2001). Many of the policies which introduced residential schools were promoted to families who were told their children would be safer in the schools. Indigenous mothers were usually blamed for the spread of air-borne diseases like T.B. and bronchopneumonia in their homes, and this health crisis was used to promote the new western style housing on the reserves (Kelm, 2001). The newly built homes became the symbol of progress and cleanliness, and families who moved to western style homes were considered responsible and caring, while those who chose not to move were branded dirty, immoral and negligent (Kelm, 2001). With these newer "safer" homes, rates of disease were expected to drop off, but due to the lack of community infrastructure, access to clean water and sanitation, and impractical home design issues like poor ventilation, family members continued to die of diseases in the new homes, and at often at an even faster rate in residential schools (Kelm, 2001). This began the history of the federal government's interference – blaming Indigenous families for symptoms of inequality and poverty after it registered and segregated them onto obscure pieces of their traditional territories that were usually far from hunting, trapping and fishing grounds. The new homes were not planned to accommodate the lifestyle and family needs, but rather were provided as a tool and incentive for the colonial objective of assimilation. Adjusting to life on reserve lands in a western style home dramatically impacted the quality of life of First Nations families who had never lived in one permanent location year round (Kelm, 2001).

In "Aboriginal Urbanization and Rights in Canada," Senese and Wilson (2013) reported on the impact of urbanization on First Nations in a qualitative inquiry in Toronto, Canada. This is poignant in understanding the differences and complexities that arise for communities located in diverse geographies, such as urban areas as compared to rural communities. Senese and Wilson discuss how disconnection from traditional territories and urbanization impacts health, and show how the “destruction of Indigenous people’s ties to their land through colonial processes such as land theft and environmental dispossession” is a fundamental determinant of health (p. 219). The study revealed the on-going impacts that the colonial state of Canada continues to have on the health of Indigenous Canadians. The creation of reserve land and the legislated status of First Nation identity have resulted in the current government policy, which has operated since 1950 as though it were only responsible for on-reserve First Nations with “status” under the Indian Act (Senese & Wilson, 2013). First Nations living off reserve are no longer eligible for many benefits and services available to First Nations and are treated in this way like the general population of BC. Unfortunately, housing shortages on reserves have forced some people to move off-reserve in order to be housed, despite having to give up some benefits such as access to more affordable on-reserve housing. Senese and Wilson (2013) argue the critical role that geographies of Indigenous rights have on understanding the link between the urbanization of First Nations communities and the health inequalities of their members. Kendall (2001) considered Canada’s development pattern, and drew similar conclusions, focusing his discussion on Section 89 of the Indian Act, under which the mortgaging and leverage of reserve lands is prohibited. Without access to capital or start-up funds to become self-reliant, First Nations are encouraged to stay on the reserve without autonomy, or give up many benefits by leaving (Kendall, 2001). Finally, de Leeuw, Maurice, Holyk, Greenwood, and Adam (2012) argued that First Nations poor health can only be understood “as geographically and historically determined, linked to colonial practices, and associated with dominant symptoms of social power that spatially and socially reproduce Indigenous peoples as perpetually othered” (p.

905). On one hand, federal land reserves connect First Nations to their land and maintain close-knit communities, but the reserves also contribute to members lacking real stewardship of land, feeling isolated and socially stigmatized because of identity of being connected to colonial geographies, or land which is divided and mapped and maintained through the on-going process of colonization (de Leeuw et al., 2012). Understanding the colonial history contextualizes the practical ways in which reserve housing has evolved and is managed today through a complex administrative hierarchy. Historical events continue to impact the values and choices that inform current Band housing policies, funding, and administrative practices that control housing quality, availability, and access to opportunities for modifications and renovations for people who need it.

Gibson et al. (2011) frame housing as a structural *upstream* determinant of health. This makes sense considering the current housing crisis on First Nations reserves. The authors suggest that the uneven distribution of housing plays a key role in health inequalities, and note that to be effective, interventions must address these upstream health determinants. In a systematic review these authors set out to collect and assess evidence on factors which link housing and health under three different categories identified as having independent effects on health: area characteristics, internal housing conditions, and housing tenure (p. 175). While this article did not specifically explore reserve housing, or Indigenous peoples, it notably showed the positive impact housing *tenure* has on health. Gibson et al. (2011) make clear the link between home tenure and the control over the adaptation of one's internal housing conditions. The type of housing policy and tenure opportunities people have access to can directly create opportunities, or instead create even greater barriers, to adapting one's home to best meet their needs. In addition to providing evidence that shows that home tenure opportunities impact health, Gibson et al. (2011) show how the conditions both in the home and community all have independent health effects.

The evolution of health policy in Canada is shifting. In 2005, The First Nations Health Blueprint for British Columba was developed by the British Columbia Council of First Nations Leadership Council (BCFNLC), as a tool to help First Nations develop a health sector that can more effectively respond to the needs of the First Nations population. The BCFNLC stresses that an unacceptably disproportionate number of First Nations people identify as disabled. At 32 percent, this is twice the statistical value for all Canadians (Durst, Manuel South, & Bluechardt, 2006). The BCFNLC identifies the serious health care gap for First Nations with disabilities, and emphasizes the mitigating role that home support can have on overall quality of life by keeping community members connected to culture, family, and community. This area of literature is relevant to my second research question, which aims to better understand both the social mechanisms within support networks, and social and physical barriers which impact overall quality of life. One specific area that the BCFNLC emphasizes is the powerful role that home support, or assistance with one’s basic needs or daily living activities provided within the private home of an individual with a disability, can have in Indigenous communities.  They emphasize the impact home support options have for communities in need of a range of home care and support service options that are delivered and evaluated in a manner culturally appropriate to each community. Issues of access, fragmented service delivery, gaps, and barriers stem from the lack of an interdisciplinary approach to addressing key health determinants (BCFNLC, 2005).  The current FNIHB-funded home care program is both drastically underfunded and unreasonably complicated in reporting requirements (BCFNLC, 2005). The BCFNLC (2005) identifies how simple and flexible care and funding options for First Nations with complex care needs could potentially improve the quality of lives for families and communities by keeping valuable Elders in closer proximity to their family, culture, and lands. However, the BCFNLC (2005) does not discuss housing as a key determinant of health. This indicates the political disconnect between health care and housing in current policy development. More recently, on October 1, 2013, through the Tripartite Framework Agreement on First Nations Health Governance, Health Canada shifted its role in the planning, management and service delivery of First Nations Health Programming in British Columbia to the new First Nations Health Authority (Health Canada, 2013). Although this is a step in the right direction, I found the website only recognized conditions such as airborne pollutants, mould, and crowding, and did not make the connection between home structure on safety or social inclusiveness in communities.

## Federal jurisdiction and reserve housing

The federal department of Aboriginal Affairs and Northern Development Canada (AANDC) is mandated to support the community development of First Nations, Inuit, and Metis communities across Canada. My research topic draws upon the experiences of registered Band members with disabilities who are living on reserve in the context that issues of accessibility of home and community are public health concerns. One major issue that is impacting the availability and quality of reserve housing is the disconnection between First Nations communities and AANDC. While many communities believe that the provision of reserve housing is an inherent treaty obligation of the Crown, AANDC’s responsibility over reserve housing is ambiguous. According to the Standing Senate Committee on Aboriginal Peoples (2015), many communities, including a number of small communities in B.C., have opted out of the 1996 On-Reserve Housing Policy and are still administered under the 1960s housing subsidy program. Band councils must regularly submit proposals for between $20,000 and $40,000 to AANDC. These funds are given for specific construction projects and renovations based on priority (Standing Senate Committee on Aboriginal Peoples, 2015). Another housing program AANDC administers is through the Income Assistance program. For low income band members, AANDC provides a benefits program similar to the provincial income assistance programs, with a set amount for the shelter portion and support dependant on rent payment, family size and the maximum shelter allowance in the province (Standing Senate Committee on Aboriginal Peoples, 2015).

Chapter four of the “June 2011 Status Report of the Auditor General of Canada,” (Auditor General, 2011) provides a thorough in-depth exploration of federally-funded on-reserve programs. This is relevant to communities as the report effectively describes how Federal programs and service provision are administered to Nations at the community level, and how these translate into the real lives of Band members like the study participants. The Auditor General identified four specific areas as problematic: the lack of clarity with regards to the level of service that is being delivered, the lack of a legislated base, the lack of an appropriate funding system, and the lack of organization to support the local service delivery (Auditor General, 2011). AANDC controls much of the funding for First Nations housing, but AANDC has not defined the kind or levels of service that will be supported. The second noted limitation, the lack of a legislative base, is important. If rectified, it would clearly specify the various roles and responsibilities, would define program eligibility, and would hold AANDC accountable for adhering to specific regulations (Auditor General, 2011). The third issue, a lack of an appropriate funding system stems from a disconnect between communities and the Federal government. Both are in conflict over housing responsibility;

the Federal government argues it does not *provide* housing support on reserves, but rather that AANDC and the CMHC will *assist* First Nations to meet their on-reserve housing needs (Auditor General, 2011). In “Housing on First Nations Reserves : Challenges and Successes,” the Standing Senate Committee on Aboriginal Peoples (2015) discussed the lack of clarity around responsibility, and stated that AANDC merely claims the support or help communities get with housing is a policy decision, rather than a legislated or treaty obligation. The Aboriginal housing crisis has peaked interest in the development of improved housing policy; however, the shared jurisdiction stalls progress.

The current use of contribution agreements to fund housing programs is limited by the failure to include service standards and objectives. The way grant funding is timed restricts communities and requires in-depth annual reviews, which often result in up to six month delays. Also, while AANDC claims that First Nations must be responsible for the delivery and administration of services, the communities report that the funding is inadequate, and also that funds are wasted on the extensive reporting requirements. Many nations are small, and lack the resource capacity to adhere to the numerous reporting requirements in their agreements. These agreements prevent long term planning as only those statutory programs related to land claims are fully and continuously funded. Funds provided through contribution agreements only last one year, leaving communities unsure and insecure about the options available in the future (Auditor General, 2011). The establishment of each Nation as a separate and autonomous entity, with payment to the Nation on a per capita basis, restricts investment into social infrastructure, and prevents key long term planning, especially for small Nations. All reserve housing is administered through AANDC and CMHC. Each Nation’s Band council has unique housing policies and processes, and these are guided by general federal requirements**.** AANDC (2011) describes the options in home tenure available to First Nations living on reserves. Tenure is directly linked to the type of financial agreement that determines the who and how of living on reserve, as well as how much control a resident has over home modification if needed. Over 50 percent of First Nations operate their own housing program under the Indian Act, but the way that on-reserve housing is administered varies widely between reserves. Individual Band members can either rent Band housing, rent CMHC social housing, or own their own home (AANDC, 2011).

In *The First Nations Guide to Housing Policy,* the Assembly of First Nations (AFN) (2010) laid out a clear path to assist nations in both the strategizing and development of housing policy on reserve. The document helped me better understand key differences between the communities of Beecher Bay and Esquimalt, and to also understand the perspective of different ways of occupying homes and administrating housing policy. Each Nation in Canada develops and administers housing policy unique to the community, based on and informed by the method of land management and land tenure (AFN, 2010). First Nations also require an internal organizational system that is used to transfer, purchase, or sell land between Band members. This land may be divided and designated for a variety of different uses. The AANDC reports that around three quarters of all housing on reserves is band owned, and falls into four housing categories: individual ownership, communal, general band lands, or social housing (AANDC, 2011). Band members who can finance the construction of their own home can be granted the right to build in a designated spot at no cost to the member, but the Band keeps the land title. Therefore, the home is owned but not the land. Communal lands are used for shared buildings such as Band offices, health buildings, schools, and senior’s complexes (AFN, 2010). *General* Band lands are homes that are owned by the Band and are rented to Band members, while housing designated as *social* is managed by the Band, so through the operating subsidies given for non-profit rental housing. The social housing operates through the CMHC section 95: On-Reserve Rental Housing Program, and in 2010 had funded 25,000 rentals through subsidy (AFN, 2010). For the scope of my research it is important to understand how home tenure and land designation impact the conditions both inside the home and in the community, as these factors can be closely linked to the health and safety of community members. The health and safety of the most vulnerable disabled community members is especially relevant to my research topic.

First Nations with disabilities often have a low or fixed income, and a limited capacity to initiate and even partially fund renovations. There are a variety of programs accessed through the Band housing administrator for which Band members may be eligible (AFN, 2010). The AFN describes a few relevant housing programs: Special Needs Housing, Seniors Housing and CMHC's Residential Rehabilitative Assistive Program (RRAP). Both the seniors and social needs programs are examples of policies that the AFN (2010) suggest can help Nations prioritize vulnerable members, and ensure that they get into appropriate housing, or have their homes modified to reduce risks as quickly as possible. The CMHC RRAP program is intended to aid members to "bring an existing house up to minimum standards of health and safety and to modify housing to meet the needs of the disabled" (AFN, 2010, p. 25). The CMHC provides a Residential Rehabilitation Assistance Program for Persons with Disabilities (RRAP-D), which provides eligible low-income people with disabilities living on-reserve access to a partially forgivable loan. The maximum amount for the renovation is dependent on the zone in Canada. For Southern Canada, the maximum loan is $16,000, with up to $12,000 as potentially forgivable. The RRAP-D is limited by its ability to address the magnitude of on-reserve housing problems, both due to the inadequate funding and complex administrative barriers. Communities that run the RRAP-D program report using too much of their funding on administration, and argue that the timing of the funding allocation requires the work to be completed with timings and budgets that Band Councils argue are insufficient to meet the needs of communities (CMHC, 2003). Further, limitations around the ambiguous eligibility criteria and tight restrictions exist. Programs stipulate that any changes and costs for modifications that are found to have occurred prior to the approval of the program request are ineligible for coverage, making it difficult to respond to sudden and changing health, mobility and home care needs.

The health and safety concerns around housing quality have been recognized by the BC Ministry of Health and the World Health Organization to have a direct effect on one's overall health and quality of life (CMHC, 2013). Problems with pollutants, mildew, humidity, molds and dust contribute to asthma, allergies, immune system disorders, and chemical sensitivities. Further, inadequate homes impact physiological well-being by producing stress: this lowers the immune system, reduces privacy, impacts community relationships, produces fear around possible eviction and crime, and decreases overall social connectedness (CMHC, 2013). The WHO recognizes the health effects associated with overcrowding, tenure insecurity, high noise levels, and the lack of physical safety at home (CMHC, 2013). Incidence of fire and accidents occur most often in older poorly maintained homes. Low-income housing is most likely to have health and safety issues, and even small and inexpensive changes can greatly improve the health of residents (CMHC, 2013). Coverage from Band resources for home maintenance depends on Band housing policy, and the kind of tenure the Band member has over the home.

On Canadian reserves the lack of community infrastructure also impacts health and quality of life. CMHC (2013) reports that 41% of reserve homes did not have piped water, and 57% had no piped sewer. Of the reserve communities 60% reported inadequate garbage disposal, which is considered a major health and environmental hazard. Furthermore, 12% of on-reserve families lived with inadequate wiring and power supply, and 18% had insufficient road access. These problems result in higher risks. Only 28.5% of homes on reserves have any form of fire protection (CMHC, 2013). The rates of incidence for fire are more than double that of off-reserve homes, with the death rate by fire over ten times that of the general population (CMHC, 2013). In both the 2013 and 2006 reports, the Auditor General (2011) clearly indicated that there were dire housing shortages on reserves, and reported the need for major renovations in about 44% of the homes already built on reserves. Reserve housing stock devalues faster than off-reserve housing because of substandard building practices, poor quality building materials, inadequate maintenance, and overcrowding (Auditor General, 2011; CMHC, 2013). Substandard housing and ambiguous housing policy have presented an important background for my exploration into how both the external community features and the internal conditions of the home impact the accessibility of the home and community.

A lack of legislative responsibility from AANDC has resulted in inaction, according to the Auditor General, who recommended the development of new housing policy in collaboration between Health Canada, AANDC and the CMHC to strategically address these problems (Auditor General, 2011). In addition, reserve lands remain property of the Crown. Lenders will not grant standard loans to First Nations (Auditor General, 2011). Fortunately, AANDC does administer a loan through Ministerial Loan Guarantee Program (LGP) for housing, so that individual Band members may get bank loans to purchase, build or renovate a home (Auditor General, 2011; AFN, 2010); however, the administration of reserve housing is strongly controlled by AANDC through many complex administrative processes. As the Band Council requests and receives funding for housing projects, renovations and home maintenance they act as the intermediary between AANDC and the community members who seek to have their housing needs met. This process is vulnerable to the competing needs of communities, community members and the other projects that are prioritized, potentially leaving the most vulnerable community members in homes that are unsafe and exclude them from community participation.

One issue impacting the quality and safety of reserve housing is the lack of building standards. In March 2002, the First Nations National Building Officers Association (FNNBOA) became the first national council responsible for independent certifications of housing inspectors working in First Nations communities. The agreement between the AANDC, CMHC, and First Nations require that Nations carry out inspections at three stages in the construction process: foundation, framing, and completion (FNNBOA, 2014). A challenge of the FNNBOA report is the lack of required independent certifications by building professionals, which means that there is little assurance to the CMHC that homes are being built to the National Building Code of Canada (2014). Another challenge the FNNBOA is working to address is the overall lack of qualified trades professionals in remote areas. This burdens distant communities with costly travel expenses for the needed professionals. Ultimately, the FNNBOA (2014) reports that most builders are happier to do external quick fixes than to complete internal home work under the RRAP program, whose intent is to bring a home up to the minimum structural and health requirements.

## Home Visitability

The term visitability originated with activist Eleanor Smith, who is recognized for bringing the concept of visitable housing to North America by establishing the *Concrete Change* housing initiative (Truesdale & Steinfelt, n.d.). According to this framework, to be designated *visitable*, homes require a zero-step entry doorway, a usable accessible washroom, and open maneuverable living spaces. When all three features are on the accessible floor, they establish a minimum baseline of accessibility (Maisel, 2006; Truesdale & Steinfelt, n.d.). Truesdale and Steinfelt (n.d.) suggest that visitability requires "an affordable, sustainable and inclusive design approach for integrating basic accessibility features into all newly built homes and housing" and that visitable housing is a basic human right (p. 1). There are three principles that visitability depends on: first is that having access to three basic design features in new homes is a civil right, second is that good design can be done affordably if planned from the start, and lastly that its simplicity encourages the increased supply of visitable housing stock. Critics of visitable housing regulations fought for the rights of private property owners to be free from government interference in home construction (Maisel, 2006) yet as Truesdale and Steinfelt (n.d.) point out, other regulations guiding health and safety, such as fire, plumbing, and electricity are adhered to by builders and have been standardized. The CCDS (2013) point out additional myths that were generated by concerns of visitable housing necessarily being unattractive, constraining builders, being expensive, and limiting building sites. The CCDS (2013) has determined that the costs of visitable home design are minimal when they are planned from the beginning, with an additional cost of $200 at this stage, compared to later changes that range around $1700, depending on other factors. The topography of the land is the one factor which determines the cost of implementing visitable home features. A well planned visitable home is not designed especially for people with disabilities, but for usability over the life span for any home resident, their family and guests. The zero step entry is planned flush for attractiveness, safety, and ease (CCDS, 2013). The CCDS recommends integrating the slope of the paved path and entrance into the design of the yard and landscaping. This makes a convenient entrance for anyone: young, old, temporarily impaired, or permanently disabled.

The CCDS (2013) completed a national visitability project with a comprehensive literature review of all published work from the last fifteen years, and revealed a serious literature gap in Canada, with most research originating in Europe and the U.S.A. According to the CCDS, Canada is behind other nations with regards to the creation of user-friendly housing design for individuals with diverse needs, largely due to a lack of public education, and building or marketing incentives for home-owners and contractors (p. 2). Many individuals using wheelchairs rely on care-givers to carry them upstairs into inaccessible homes. This risky situation is the consequence of too few housing regulations, an undereducated housing industry, and the failure to build and market visitable homes to the growing aging population. The visitable housing market is indisputable (CCDS, 2013, p. 2): According to the CCDS (2013), the majority of builders and designers only consider the needs of young people, rather than home owners across their life span. As home-owners age, their own homes become less usable, resulting in an eventual incompatibility. Structural design features such as stairs, or even minimal doorsills can become impassible for individuals, and also create a riskier home where incidence of falls or other injury becomes increasingly likely. The no-step entry mitigates the risk of falls and injuries by reducing physical barriers, increasing independence, and making it possible to age in place and safely receive care (CCDS, 2013).

Margret Ward (2005), architect and inclusion advocate, works through the Australian Network for Universal Housing Design. She argues that good home design can prevent an otherwise isolating experience for seniors, and both temporarily or permanently disabled people, by improving lives and saving public health care funding by preventing injuries, and reducing the demand for institutionalized care, leaving acute care and rehabilitation centers for more appropriate patients (Ward, 2005, p. 3). Ward suggests that universal housing regulations create safer work environments for paid or unpaid caregivers of the injured or disabled, and also save costs associated with the demand for assistive equipment required for basic acts of daily life (p. 3). Hwang, Cummings, Sixsmith, and Sixsmith (2011) also demonstrate that decreasing the physical barriers in homes improved one’s overall functional independence at home, and saved resources by keeping the elderly at home longer (Hwang et al., 2011).

Rob Imrie (2004a, 2004b) has made regular contributions to research on home design and disability, and is considered an expert in the UK, a lead country in social housing and design research. He argues that the needs of disabled people are rarely featured in academic or policy debates about housing quality, and notes that this reveals the general social apathy around disability related issues (Imrie, 2004a; Zola, 1989). Imrie (2004a, 2004b) emphasizes how disability should be expected as part of life, and how a social model of disability needs to guide health research. This concept is at the core of my research topic, has influenced my own approach to life and to this study, and pushes for increased inquiry into universal housing design. Imrie and Thomas (2008) warn that disability experts are often far removed from the actual realities of the lives of the disabled. In an American example, Mace (1998) gives detailed accounts of what universal design is – features that are generally useful and helpful for anyone, anticipate future needs, are preventative, and include standard home features (p. 21). Wilson et al. (2011) add to this, emphasizing how understanding the housing needs of the aging population would not only support those living with other physical restrictions, but whole families of multiple ages over a lifetime. A better understanding of the needs of families could help policy-makers respond to the ways that social interactions are linked with health, and better mitigate the role that status, identity politics, and entrenched legal divisions within First Nations communities influence health care and overall quality of life.

Visitability features have evolved from universal design, but are not universal, rather the features strive to be made practical, affordable, and attainable (CCDS, 2013). Harrison (2004) provides a compelling critique of quality standards in housing and the meaning of *housing environments*, as opposed to a *home*. According to Harrison (2004), quality standards, such as the three visitability criteria, are inherently physical in nature, and recognize the contributions of the grass-roots experiential data produced in this area. Still, he argues that urban planners must consider the influence of social and physical factors that impact health outcomes. Harrison argues that many barriers at home cannot be solved through mere physical adaptations, and insists that these must be tested within the real socio-economic environment (Harrison, 2004). What I found most valuable from Harrison's (2004) study was his inclusion of the socio-economic and demographic factors like community autonomy and controls that influence housing decisions, access to and availability of necessary institutions, services, health services, area safety, and factors such as home tenure and composition. He also encourages researchers to carefully consider the neighbourhood rather than only a house. His critique identifies numerous environmental qualities that fall outside of the visitability assessment, but could be captured through the questions on barriers and community infrastructure.

Visitability research is political in that it is building on the foundations of an active movement working to inform the development of new and improved building standards across the country. It is even more so as it explores reserve housing. Although mainstream housing policy standards need political support, in comparison reserve housing is a highly political issue about land, rights, and Aboriginal title within both the literature and government reports. My exploration of visitability on reserves is socially complex, inherently deeply political and “from the margins” (Kirby & McKenna, 1989, p. 17). The collective history of colonial rule over Indigenous society with destructive state goals such as the assimilation of Indigenous peoples, can still be identified in current formal governing structures and state institutions. These produce jurisdictional power struggles between the federal government and the provinces, between the provinces, between and within communities. Alter, Stukel, Chong, and Henry (2011) indicate how this jurisdictional wrangling stalls policy progress. These complexities stem from intergovernmental financing relationships that lead to a polarized government and an apathetic and disengaged public (Rocher & Smith, 2002). These issues are exacerbated in Indigenous communities where funding for reserve infrastructure and homes is complex and divided across federal and provincial jurisdictions, and where policies have been founded on classist, racist, ablest, and colonial ideals.

## Summary

This literature draws on evidence from a variety of disciplines that are all essential dimensions in the exploration of home and community accessibility on reserve land. Research from the domains of public health, Indigenous health, home design, disability studies, community development, and geography have all been included with the intent of developing a holistic approach that can recognize the intersecting pathways of the socially constructed power relations of racism, classism, and ableism in this research topic. The issue of reserve land is highly political and this politicization creates barriers to access quality housing or needed modifications by community members. Also, because the participants in this study were physically impaired it was crucial to reflect on the relationship between colonization and health disparities in First Nations populations. Recognizing colonization as a process that continues to propagate current health disparities and social inequalities experienced in Indigenous communities, frames physical and social home and community barriers as an important public health issue. I then described how the lack of clarity around the roles and responsibilities of AANDC, lack of legislated support, lack of effective funding structures, and inadequate support create several administrative barriers that further impede communities. These larger structural barriers also produce administrative barriers at the community level when members' home and mobility needs change. My final section of articles reviewed critiqued work that was related to visitability or accessible home design. Beginning with the history of the visitability movement I have also included literature that identifies the value of including characteristics outside the home, such as neighborhood, social factors, and social economic factors, and access to other important resources. Understanding how the design and location of one's home and community can either improve or decrease their access to key community resources, situates home visitability in the context of First Nations communities which remain strongly impacted by colonial State administrative structures. A key finding from my literature review was that there is a serious literature gap on the needs and experiences of First Nations with disabilities living on reserves, and it is for that reason I am using theoretical constructs which guide how to access this unknown territory in a holistic way.

# Chapter 3: Methodology

## Preamble

The evidence which identifies the existence and rationale behind the major health disparities experienced by Indigenous communities has them clearly linked to Canada's colonial legacy, which is still actively experienced today through the administrative structures that control the administration of Band housing policy on reserves. The needs of the First Nations individuals living with physical limitations on reserves have not been a policy priority either for community or government. The research methodologies and methods I have employed were selected as approaches and tools to specifically hear and see the participants' experiences, and to better understand what their housing, community, and social needs are. My study plan has evolved over the past two years. It began with an invitation to volunteer as a member of the Vancouver Island Visitability Task Force (VTF), which I was invited to join in Sept 2014. My participation in the VTF and guidance from my ever-supportive graduate supervisor were essential to the completion of the study plan and its implementation. The literature aided in the development of this study by identifying the need for methodologies that would guide me ethically and practically, and also would be flexible to the priorities and needs of the participating communities. This chapter begins with my own background, values, and life experiences, which have biased my own preferences for an approach to research that ensured that the voices and experiences of the participants remained central to the process. The next section describes the theory that has influenced, guided, and helped me structure my argument and interpret the findings. After that, I include sections called research background and researcher positioning, that explain my intent, and describe the process of joining the VTF and doing this study. In the section on the research setting, I move into the details of the communities. The next two sections are about the process, where I detail the methods used to collect and analyze the data. This was the most important part of the study for me, as it ensured that my work with the communities was helpful and appropriate. Included in these sections are the three phases of the study, building relationships, theme development and forming theme hierarchies. The last section discusses the ethical concerns that were important to consider prior to the study, as well as during the process.

## Theoretical support

The exploration of First Nations housing, community infrastructure, and the availability and access to social supports brings with it the need to frame the inquiry within appropriate theoretical frameworks. To answer my research questions there are multiple dimensions to understand. The first research question asked: How does the presence or lack of the three structural visitabilty features impact people with physical disabilities? Here the analysis was at the level of the individual participant: the presence or absence of the no-step entry, open doorways, and an accessible washroom on the main floor were documented and discussed at the level of the participant as they locate themselves within their own living space. The second study question expanded on the first, asking what barriers and supports most impact the quality of life of those living with disabilities? This question focused on supports and barriers and took the inquiry beyond the home and into the extended family, and even the community level by exploring relationships and potential physical barriers that fall outside of the three visitability criteria. The final question bridged the community level to the larger social structures by including an assessment of the community infrastructure. This determined the ways that existing infrastructure, or infrastructure gaps impact the mobility of participants in their daily lives, and asked How does reserve community infrastructure influence individual home visitabilty? Capturing the experiences of local Indigenous community members with physical health challenges requires a conscious and intentional research approach that is informed by the history of the involvement of the state in Indigenous life, through land theft, politics, and all parts of culture (Jacklin & Kinoshameg, 2008). From the inception of this research, I needed to find approaches that would guide me both ethically and practically.

### *Social constructionism*

At the proposal stage I found that social constructionism both helped position my research perspective, and was familiar to me from previous work in disability studies. This approach provided an overarching theoretical lens, as it supports by the assumption that humans create meaning about their lives through their lived experience. The perspective is relevant because the experience of disability and race are social constructs that impact this research. The social constructionist approach requires the understanding and intervention at the level of social context, and not solely the treatment of the body's impairment. In the same way, I believe that the health disparities, and disproportionate number of First Nations peoples with disabilities cannot be adequately understood by ignoring the context. The value of social constructionism is its scope. For example, it motivated me to collect data not only in the context of the home, but also to recognize the wider social and community capacity to accommodate the needs of those with disabilities. For the purposes of this research I am only including analysis on the social construction of race and disability. I recognize that gender, class, and other socially constructed groups are relevant, but they are outside the scope of this inquiry. This perspective strongly supports my choice of an inductive study with large open-ended questions (Creswell, 2009). The participants who have courageously shared pictures of their private living spaces and stories to go with their pictures are speaking from their own social location that is steeped in history and in itself is the expression of their culture.

The study approach I implemented also insists that I recognize my own social position and the ways that I involve myself with my participants in the study context. As the lone interpreter of my findings, my personal interests, experience and vision have also shaped this study from start to finish. Under the social constructionist framework the emphasis is on understanding how social constructs such as policies, institutions, and built environments, as well as one's personal beliefs can either produce or minimize barriers for people living with disabilities. The social constructionist approach led me to the explorative and open-ended style of data collection, where participants literally share the significance of their *views* of their home, through one to one interviews guided by their photos. This research perspective also fits with the social construct of disability, as it assumes that people are disabled in relation to their social context. Through the development of this thesis I came across theories that helped inform my study methodology, such as postcolonial theory, and critical race analysis; however, in the end intersectionality was the most genuine fit with me and the study. All three of these theories fall under the umbrella of the social constructivist approach to research for this project. Not all of these constructs provide a complete perspective or alone are an ideal fit with my research philosophy, direction, and context, but combined they provide the theoretical backbone for my research process. Intersectionality was most effective in capturing the fluid and overlapping ways in which the study participants are socially located.

### *The Social model of disability*

My previous experience working with and for people with disabilities clearly showed me that although people all are physically impacted by diverse impairments in real ways, it is the physical and social environments in which they live that will determine the actual degree of disability that they experience. For example, someone living in a visitable apartment near to a bus route that has kneeling buses and curb cuts in the sidewalk experiences fewer barriers and greater independence than someone with the same level of impairment or condition living in a unvisitable home in a location that is not connected to accessible transit options. Illness, injury, and impairment of some sort are inevitable in life, and yet most of our world is designed and built for the needs of able bodied people. It is important to clearly differentiate between impairment and disability for this reason, for the former is the focus of the biomedical model and the latter is related to the social model of disability, and provides a major theoretical backdrop of my study topic and research questions. Barnes (2007) notes that the term "social model of disability" was coined by Oliver in 1981, and was first used to train social workers to be more responsive to the needs of people with disabilities. As such, I have used the model to develop my own understanding of the complex issues that are related to social inclusion, and the multitude of socio-economic barriers experienced by people when living with disabilities. In using this model Oliver intended adherence to three points: first that the social model intentionally takes the focus of analysis off of the individual and into the social context, second that this approach is holistic, and includes culture and the full complexity within the lived environment, and lastly that the model does not replace the value of the biomedical model for individualized interventions, but argues that alone the biomedical approach will fail to accommodate the needs of people with disabilities (Barnes, 2007).

A rationale for the creation and use of the social model framework is that it was created and promoted by people with disabilities around the world as a critical response to the inadequate and harmful policies that had been informed and justified by the biomedical model (Barnes, 2007). These international groups argued that the biggest issues they faced in their lives were related to the cultural, economic, and environmental barriers. This pushed disability rights into the human rights discourse in the 1960s, and the consumer driven action pushed the social model forward and into health policy and practices (Barnes, 2007). Pervasive beliefs rooted in societal values that favour the interests of able bodied people produced policies that did not value the lives and contributions of people with disabilities; therefore, with the new disability activism and human rights movement came the need for a new interpretation of disability (Barnes, 2007). Rather than continuing to organize themselves in groups under type of condition, or impairment, the activists united and focused on the universal phenomenon of the experience of social exclusion stemming from inequality that was linked to the environmental barriers (Barnes, 2007).

From the onset of formulating my study proposal, the questions I was interested in asking were about context; however I did not fully understand how each question would generate data at a different level of experience. It is these environmental conditions that my first and third study questions address. The social model of disability shifts the focus from the individual to the social context, and to the historical context in which the person exists, so for this reason it was a framework that was both responsive to the inequality experienced by people with disabilities, and to Indigenous peoples who experience serious environmental barriers rooted in our nation’s colonial history. This perspective holds society responsible for actions which improve the conditions that impact people with disabilities. For Indigenous communities, the medical model was a major tool of colonization. Much like how disabled people were labeled in the past as *deviant* for being impaired, many Indigenous peoples were portrayed by the Canadian state as defective, weak, and submissive, and in need of intervention (Kelm, 2001). The social model provides a rationale for stepping back and looking at the context in which First Nations with disabilities live, while it also provides an analytical framework for the interpretation and discussion of the findings.

### *Intersectionality*

The concept of intersectionality came to me as I was doing research on First Nations communities. I found myself challenged to locate specific Canadian research that linked and explored the experiences of living with disabilities and being Indigenous. Having now completed my research, I have a hunch that this is partly because there is little value in identifying as someone with a disability – this is not a concept that was used by my participants. Despite the lack of research, I needed help from a theoretical framework to guide my analysis of the physical and social dimensions of the participants’ narratives, so I could separate the barriers that were founded in experiences of physical disability from those barriers that were linked with their experiences living as First Nations, and also from those barriers that could be specifically economic. Of course all of these factors are strongly related when considered in the context of reserve housing and infrastructure, which is a topic of inequality that clearly is at the intersection of classist, racist, and ablest belief systems. Identifying the separations also made it possible to see where the intersections were. I should specify here that although I know gender and other important power relationships have impacted the communities and data, this impact was not shared universally from participants. The intersectional approach provides a concept that links the multitude of ways that oppression and discrimination are or can be experienced socially.

As a theoretical construct intersectionality provides an important framework that grasps the ways in which multiple identities interact, and lead to inequality through the social mechanisms of exclusion and subordination across society (Cho, Williams, Crenshaw, & McCall, 2013; Davis, 2008; McCall, 2005). Although the construct evolved from feminist discourse, other disciplines would benefit from this level of analysis (McCall, 2005). For example, my research on this topic rarely found articles that considered issues of race and disability. Most feminist discourse included analysis on race, but often excluded disability. Therefore, intersectionality was an important solution to this major theoretical divide. The complexity of intersectional analysis is strength, as it is in these complex intersections where the systemic inequality is deepest and most powerful. In her later paper, McCall in collaboration with other authors (Cho et al., 2013) goes into detail about the development of a new field in intersectionality and its applications. For the purpose of keeping in line with my own research objectives I will consider the dynamics of participants' identities, provided that they bring these up in a meaningful way, as an overarching scan of the multiple ways that race, class and inability act as oppressive structural categories have produced and maintained inequalities in the homes and communities of the participants.

### *Social Capital*

After completing the preliminary analysis of the data and presenting this to both communities I was up late one night working on the final stages of analysis. I was trying to distill the labels that pertained to the social themes that the participants had verified and confirmed as a group. I had heard the term social capital in my past, but initially strongly resisted the term because I worried that it might impose an external construct or values that were not intended by the participants. In the end I used the term because I was unable to think of another concept that fully conveyed the complex and interacting resources, processes, and networks within communities and because I had found some effective applications of the concept of social capital framework by and with First Nations communities. This work was produced through a partnership between the Canadian Population Health Initiative (CPHI) and the Canadian Institute for Health Information (CIHI) for First Nations to measure the level of their communities' social capital, or social assets (Mignone, 2003). For the purposes of this discussion I am only using social capital in the context of First Nations communities, and as it was described in Mignone and O'Neil (2005) as a framework to identify how socially invested communities are, and determine the role that social norms and culture play into the community members' attitude and overall participation. Of particular use is the consideration of social capital through a combination of community relationships. The first point of analysis is between community members at the micro level, called bonding. The connections between other communities in the meso level are bridging; and linkage, which links the meso to macro and assesses the relations between the communities and formal institutions. There is value in using this framework because it makes sense with regard to the themes and participant priorities, and helps answer the research questions.

For each of the three dimensions of social capital (bonding, bridging, and linkage) Mignone (2003) identifies three components of social capital: 1) Socially Invested Resources (SIR), 2) Culture, or the relations and norms around reciprocity, action, participation, and trust, and 3) Networks, or how networks are inclusive, adaptable, and diverse both inside the community, between other communities, and within formal institutions. Socially Invested Resources include five descriptors: physical, symbolic, financial, natural, and human; however, only physical, financial, and human SIRs were specifically related to my study objectives. The construct of social capital helps me understand and communicate the findings. The major theme of physical safety has already covered discussion on the physical, so further discussion will focus primarily on human and financial SIRs. The second component, culture, was surprisingly on target with the findings. The four descriptors of the culture category are: trust, norms of reciprocity, collective action, and participation. The third component of social capital, networks, can be considered inclusive, flexible, and diverse (Mignone, 2003). The value of the social capital framework is also that it shows the interconnections between the social ecology, that of the family and close knit community, the communication challenges between local nations and the community of Greater Victoria and the formal institutions like AANDC, CMHC, banks, the school district, VIHA, BC Transit, and B.C. Hydro.

For the discussion and interpretation of the study findings, the concept of social capital felt most true to what the data told me, and was most appropriate in that it fully encompassed all three of the themes in a broad way. I have added this section about social capital to provide more background on the concept, as this is a timely and growing body of literature that is being used by Indigenous communities as a tool to evaluate strengths and challenges at the inter and intra community level, as well as between nations and institutions. Although my study is small, and I have not fully applied social capital as a conceptual framework for the interpretation of the findings, the framework does support my work, and shows both its relevance and the need for additional research in this area.

To summarize, the utility of social constructivism is in its overarching value for the search for meaning. This lens led me to make the methodological and analytical choices I have, fitting with my value for collecting data in as pure a form as possible. The social model of disability drove the development of my research questions, as this model has become a natural part of my analytical style which aims to understand the lived context, but also effectively draws on expertise and work from activists with disabilities, academics, and policy makers. Intersectional analysis has been useful to unravel the complexities around reserve housing and infrastructure. The power relations that are tied to home and community opportunities are linked with our nation's on-going policies and practices that are maintained through the State's colonial relationship to Indigenous communities. Colonialism is founded on racism, and inequalities experienced intersect with classism and ableism and communities are segregated and experience significant physical, socio-economic barriers that affect their quality of life. The final construct I have introduced helps understand the similarities and differences between the participating communities, and provides a structure of analysis for the reflection on the theme of social capital. Understanding the relationships between community members, communities, and formal institutions provides insight into the factors that need to be a part of discussion of the study findings, and strongly justifies the need for further research in this area.

## Research background

Most First Nations communities, including both communities that agreed to collaborate in this study, report having been studied without benefitting from the research conducted. As Tuhiwai Smith (1999) points out, the word research connotes a harmful process, or “dirty word” to many Indigenous people whose collective memories include trauma received at the hands of western researchers working as a tool for the colonial objective (p. 1-2). The major disconnect between external study objectives and the values and needs of community members is an on-going issue that has played a large role in the historical context of this work. While some researchers in the past merely missed the mark, and produced impractical results, other research has actually been harmful to local interests (Jacklin & Kinoshameg, 2008). The meeting was an orientation for me as well. I was told how the community members felt that although they voluntarily participate in committee after committee, they are forever repeating themselves to no end. Over the decades, and in a variety of different venues, they have shared their stories and community issues as well as made numerous suggestions for a better future without ever seeing a change at the community level. Six of the nine participants, all Elders, talked about how the Band Council has changed over the years due to the erosion of the hereditary systems that would have required community accountability and following through on the suggestions of the Elders. This history influenced my choice of research methods, and made the invitation from BCANDS as well as the community interest a necessary component for a community-based study of this kind.

My study fit in with the partners, BCANDS and CCDS; however, the topic of visitability originated from CCDS. I was personally invited to do this work by BCANDS. I was invited by the BCANDS Executive Director to become a VTF member, as a student researcher, and sat as a member for one of the two years the group was active. The original participating communities were Beecher Bay, Esquimalt, and Tsawout Nations; however, during the project, the Tsawout dropped out. The visitability project ran from May 2013 to March 31, 2016. I attended monthly meetings starting in the fall of 2015, where I mostly listened and observed, collected formative knowledge that both got me into the field while I completed my course work and helped to inform the development of my thesis proposal. This task force was run as a partnership between CCDS, BCANDS, and the participating Nations of Esquimalt and Scia'new, with a few member changes over time. Task force members included a building contractor that attended while completing a large Big House[1] project on the Esquimalt reserve, a BCANDS disability case manager, an off-reserve First Nations housing expert, the visitability task force coordinator, myself, and the Band housing administrator from each reserve. This task force group was directly mandated to work with the participating communities to help raise awareness about visitable housing and move towards the development of new visitable housing policy goals that were identified by the community. The group provided both a formal and informal means for me to collect key information to situate this study, such as community characteristics, cultural preferences for food, language, and historical background. Most importantly, the two Band housing administrators took on a gatekeeper role for me, collecting a group of potential participants and later inviting them to our initial study orientation lunch. After the task force dissolved with the completion of the visitability project, the Band administrators continued to support me by helping schedule the final group session and offering to be interviewed for some general land and community information.

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[1] A Big House is a shared community ceremonial structure used by some coastal First Nations

Although both Esquimalt and Scia'new Band council were encouraged through their participation on the task force to promote the development of visitable housing building policy in each of the reserves, this was an unrealistic goal for the timeline of the task force project. Both Band councils were interested in visitable housing, but neither could implement such a policy without other internal and political changes. What was accomplished through the task force work was the overall increased awareness about the positive impact of visitable housing and community accessibility, and the community interest in future work in this area. An important achievement of the task force was the passing of a resolution that the group put forward to the B.C. Assembly of First Nation in July of 2015 titled "Support for Collaborative Knowledge Building and Action for Visitable Housing in First Nations Communities in British Columbia" (BC Assembly of First Nations, 2015).

The formal recognition of the resolution was a stepping stone to future work, with the potential for communities around BC to define and evaluate the accessibility of their communities, and integrate culturally appropriate visitability features into Band housing policy. The background work and the long term visitable housing policy goals are important and fit well with my overall study objectives. This desire to change is a required component of Photovoice method, which intends to directly change policy as a research outcome. This research context informed my methodological choices and overall research approach. Some of the ways that my methodology was customized to suit the communities can be observed in the meeting spaces, the need for my adaptability with times, dates and the ways we communicated, and the analysis process. My work has required adaptability, from a leadership role as group facilitator and hostess, to that of observer, listener, collaborator, and guest. It has also required me to be honest, take risks, and be vulnerable. While this was challenging, it also aided in mitigation of important power dynamics between myself and the participants (Denzin, Lincoln, & Smith, 2008; Russell & de Leeuw, 2012).

## Research Setting

To fully capture the home and community context in which the study participants experience their lives it is also essential to both position them geographically and describe and compare the community settings of Beecher Bay and Esquimalt. Historically, the land on Vancouver Island was some of BC`s earliest colonized and divided, and the local nations have experienced the impacts of the imposed reserve system, displacement and the effects of increased populations, and spread of the cities' urbanization (Kelm, 2001). Different stories about the arrival of settlers and the displacement of the families and communities were shared with me casually, as well as during the group meetings and interviews. Esquimalt Nation shares territory with the Songhees people – their land is the most valuable in the city, including the down town core, Beacon Hill, and the inner harbour. The current locations of the communities were not a logical or traditional site for dwellings, rather reserve land selected by the State. Applicable housing policy guides how housing decisions are made, and this is dependent on the type and availability of housing stock at any given time, and can change with Band Councils and AANDC requirements.

## Esquimalt

The Esquimalt reserve is made up of forty-four acres. Twenty-two are designated for residential use, and the other half for industrial use (Rose, personal communication, January 10, 2016). When I asked my research liaison, Band administrator Janice Rose, she informed

*Figure 1*: Esquimalt Reserve

*Source*: Google Earth (2015); Natural Resources Canada (2016)

me that the 22 acres of industrial land would require millions of dollars in toxic clean-up. This area had been used for a saw mill and was a dumping area for old machinery of all sorts, and had therefore only been cleaned up to meet the commercial use requirements. The community of Esquimalt borders an inlet from the Jaun de Fuca Straight on the Pacific Ocean to the west, across from the Inskip Islands. The community is approximately 7.5 km (or about twenty minutes) from downtown Victoria. As seen in *Figure 1,* Esquimalt reserve is divided by busy Admirals Road, which moves traffic from the Island Highway to the Canadian Pacific Naval base. Although the majority of the homes are on the water's edge, the home dwellers on the other side of Admirals need to cross the busy throughway to access the Band Smoke shop, Band Office, and BCANDS, as well as the other stores and services a short distance away. There is also a rail line that runs parallel to Admirals Road, further dividing the community. Without an alternate route other than the busy road, community members have the option of walking on the exposed shoulder of Admirals Road or on the inactive railroad track that is positioned parallel to the road. Thomas Road leads from the main section of the community up an extremely short and steep road to where it joins Admirals Road. The road through the community has large speed bumps which further limit mobility whether on foot, or with a wheelchair, scooter, or walker. The 22 acres of industrially zoned reserve land is commercially leased to a mall that surrounds the community of forty-three dwellings. Of the 304 registered Band members, 180 share these 43 homes. This leaves 124 members living in off-reserve housing (Rose, personal communication, 2016). Of the 43 on-reserve dwellings, only one of six newer townhouses built in the late 1990s is visitable (Rose, personal communication, 2016). Of the seven community members reported by the Band office to be living with physical disabilities, only one lives in appropriate housing. The other six have applied for RRAP grants; however, all have been so far denied at least once (Rose, personal communication, 2016).

**Beecher Bay**

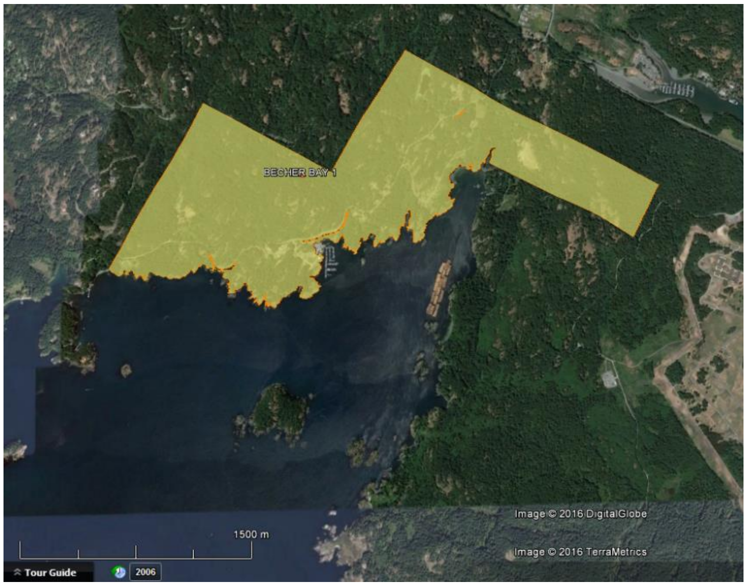

*Figure 2:* Beecher Bay Reserve 1

*Source:* Google Earth (2015); Natural Resources Canada (2016)

The community of Beecher Bay is located on the Southwestern coast of Vancouver Island. The community is approximately thirty-five kilometers from downtown Victoria, making it geographically closer to the west shore communities of Metchosin, and Langford, the closest center approximately a twenty minutes' drive away. The land is dry, steep, rocky, and covered in bush and arbutus trees, while further away from the water it becomes a thick and deep rainforest. The Scia'new First Nation has eight reserves totalling 308 hectares of land, with the main community being Beecher Bay (or Becher Bay 1 as seen in *Figure 2*) comprising 192 hectares, housed on the only part of the reserve that is zoned for residential use. The homes are all built on one 6.56 hectare parcel of land. Another 1.5 hectares is being used commercially, and includes community buildings such as the long house (another term for Big House), a day care, and the administration, health learning center, and treaty office (Preston, personal communication, January 11 2016). At present, close to where the Band office and other shared buildings are located, a large housing development project named Spirit Bay is in progress. This residential development project has been considered a positive direction by some community members as it is expected to generate jobs and may eventually bring in much needed infrastructure like more affordable hydro and a bus route, as well as resources for the community (Preston, personal communication, 2016).When I witnessed a Spirit Bay community consultation barbeque it was clear that the community is divided about this project. Some people expressed concern that the majority of the jobs related to the project go to people outside of the community, and that the benefits expected from the project will not affect the community for up to fifteen years. Beecher Bay has 248 registered Band members. Of these, 131 members, along with many additional unregistered family, live in the forty dwellings. The remaining Band members live off reserve (Preston, personal communication, 2016).

**Participants**

Having discussed the project with the VTF, the housing administrators understood my project goals, and directly approached community members in person at the Band office, as well as by phone. Janice Rose is a long term employee of the Esquimalt Nation, and is quite experienced and connected in the community. Mary Lou Preston, the administrator from Beecher Bay was equally experienced; however, she took a leave of absence during the study period that required me to connect with another short term Band employee, Koren Bear. Bear was specifically hired to help with a Scia'new housing survey, so she was quite knowledgeable about the housing situation as well as potential participants, but she did not have as much information about our project, or as much rapport with community members. Although I shared and discussed the project information letter with both Rose and Bear, I ultimately lacked control over how information would be communicated to potential participants, as I depended on others to initiate contact. I wanted the administrators to be able to know enough to briefly answer questions as to the who, what, where, when, and how of my research project if they were asked. I knew that the Esquimalt community members would have had more exposure to BCANDS and could have already known about the visitability project because BACANDS works closely with the Band, and their offices are located beside each other.

Although my research questions focus on the experiences of physical impairment in the home and community environment, I did not exclude anyone who had multiple challenges, for example a combination of physical impairment with a mental health challenge or intellectual disability. Through purposeful sampling, each Band administrator collaborated with me to collect a group of potential participants who lived in one of the two communities and who was identified as having significant mobility challenges. Participants did not need to prove a functional level of impairment or legal disability status to participate. I intentionally left this criteria of disability quite ambiguous to make room for those community members who either self-identified as mobility challenged or otherwise physically impaired, who were familiar to the Band council housing administrator. It was important that participants were not expected to prove themselves through measured functional criteria to participate. I wanted this research process to be positive and strength-based instead of deficit-based. The Band administrators found a small but diverse and interested group of participants, and helped me coordinate a recruitment and Photovoice luncheon in each community. In the end I had an ideal sample size, so I did not need to be selective, or recruit additional potential participants. The group of nine was the original sample, and no one dropped out.

The four community members who made up the Esquimalt group represented themselves and seemed familiar with the concept of visitability. They also had an idea of what to expect through the study process. Janice Rose helped set up a space to meet in the modern and visitable Esquimalt Band council meeting room. Although she was invited, she did not have time to attend the whole session. For the first Esquimalt group session we took turns talking about our backgrounds, and I spent time answering questions about who I was, and how I came to this project, as well as the plans for my future work.

In contrast, the recruitment and information session lunch went a little differently in Beecher Bay. Whereas it seemed that the Esquimalt group came prepared to sign the letter of consent and get started, the Scia'new group was in need of much more information, which was understandable considering how little they knew about the visitability project, BCANDS, or me. Koren Bear sat in on our meeting, as did a CMHC employee who happened to be in the community that day, although she only stayed for the meal. It is important to note that there is no visitable meeting space in any of the offices at Beecher Bay. We met in the most accessible office, in the Fisheries building, which still had three stairs and a tiny inaccessible washroom. Five community members came, but only two represented themselves. In retrospect, this inaccessible space totally excluded not only the people I was trying to reach, but possibly others from attending. Of the three representatives who came to get information, all ended up taking home the information, cameras, and the letters of consent. Whereas recruitment was finalized in Esquimalt and we moved on to the Photovoice training and practice portion, the Beecher Bay process needed follow up phone calls and visits to ensure that the participants were indeed interested and informed, and to ensure that they had truly consented to participating in the project. In both groups, after the information was covered and we had finished lunch, I asked for those who wanted to participate to please sign the form that we had just gone through. At the time, two participants signed; however, the three representatives could not sign, and took the forms home to review with the participants. At that time, I introduced Photovoice as a practical method of data collection. Everyone had an opportunity to ask questions. Although I set out some parameters around privacy, my main guideline was for the participants to document only what they felt was a priority, and what they were comfortable discussing with me. Everyone had my contact information on their consent letter. They each took a copy of their consent, and they were invited to contact me at any time for support or questions. From there, I did not talk to the participants until after the photography was complete as no one called me.

To respect the privacy of participants, I will use pseudonyms throughout the following sections as I begin to tie the lived experiences to real people. Age estimates are my own, as this information was not collected. In the Beecher Bay research group, Maria represented herself, but also discussed the experiences of her elderly mother-in law Amy through her perspective as Amy’s main support person. Amy lives with her elderly life partner, but only Amy’s story is included in this project. Ken is a middle aged man who experiences chronic joint pain, and who lives and cares for his severely mobility challenged partner. While Ken’s partner did not participate in the study, her experiences were included in Ken’s interview responses as they were inherently linked to his own. Betty and Carol are in their late sixties. They live with serious heart conditions as well as physical limitations. Both women live with their adult children and several grandchildren. Carol lives with eight family members, including her three adult children and their grandchildren. Her interview is the only one I conducted at a participant`s home. I was concerned this would make the interview feel more invasive; however, this was her preference. In contrast, Betty also lives with adult children and grandchildren, with a total of six under her roof. While she has limitations associated with fatigue and heart issues, she still gives care to at least three dependent family members. Another elderly woman, Ellen, talked about living with advanced rheumatoid arthritis. The Esquimalt research group consisted of Colin and Jen, a couple who were both in their late thirties or early forties and are parents to their four children. Jen also has rheumatoid arthritis, and during sporadic flare ups becomes completely immobile. Colin has a chronic bowel disease that restricts his ability to lift, walk without an aid, or manage stairs. The third participant, Sheila, is the most elderly member in this group, and is quite bent over her walker. She commutes, daily, one kilometer by foot with her walker from her home to the Band office. The final Esquimalt participant, Heather, is a middle aged woman living alone and with arthritis and heart problems that limit her mobility.

## Research Methods

### *Photovoice*

I used Photovoice as a way to provide practical methods to answer my research questions. As an approach to research, Photovoice is an ideal method that was first developed and used by Wang (2014) to provide participants in the same geographic location the means to safely share inner thoughts, feelings, and key interpretations on specific topics that were hard to see or understand, with the goal of developing strategies for change. The Photovoice process strives for participant leadership and control of data production and interpretation, and provides the potential for social action and policy change in the future. Jurkowski and Paul-Ward (2007) frame Photovoice as a useful means of addressing public health issues, especially as they fit with health promotion principles which specifically aim to address the experiences and reflect on the issues of the least visible and vulnerable populations. This method is grounded in principles of accountability, transparency, and social action, all of which are steered by emergent community needs (Allen & Hutchinson, 2009; Israel, Eng, Schulz, & Parker, 2005). An essential commitment of Photovoice is the shared but individual experiences of participants, with the interpretations of the message discussed in a group setting with policy makers present (Wang, 2014).

Photovoice techniques come from Participatory Action Research (PAR) values and provides appropriate methods for this study. The key goals encompassed within the application of Photovoice are that it 1) emphasizes the participant's experiences and validates the corresponding interpretations, 2) develops the collective knowledge of the participants through group process, and 3) provides an avenue for influencing policy change through the translation of the photographed experience (Lal et al., 2012; Sutherland & Cheng, 2009). These goals were affirmed by community stakeholders in the VTF meeting, and from letters of support from both participating nations. The Photovoice method is based on the major assumption that the study participants are experts of their lives, and that they are most qualified to do the job of finding solutions for the issues that are rooted in their lived experiences. As experts, participants have control, sharing through the interview their rationale for the content of their photography, and what it means from their unique perspectives. Through the application of this method, my participants were offered the opportunity to document, share, and interpret their experiences in the home, and link the structural environment to social networks and overall quality of life. Photovoice is grounded in both critical and feminist theory, as well as health promotion principles (Lal, Jarus, & Suto, 2012). In this study of two communities, the inclusion of Photovoice has generated holistic data from nine vastly different perspectives and social locations. One of the key benefits of Photovoice is that in the photo-led interview the participant has absolute control of the knowledge that is generated from the pictures. Although interpretation of the interview data is my sole responsibility, member checking determines the ultimate final reduction of themes from my overall thematic analysis. Sutherland and Cheng (2009) describe some important limitations of Photovoice, such as logistical challenges with ensuring the correct camera use, and the considerable time commitment from participants for the full duration of the project. These issues were dealt with through the group orientation, training and allowance for a family member to take on a role as photographer helper, and the provision of simple disposable cameras for each participant. An obvious limitation with this method is that I was unable to collect data on themes that were not documented; however, I found the group sessions effectively gleaned data that was a priority to the communities, but that may not have been captured in the interview. Castleden, Garvin and the Huu-ay-aht First Nation (2008) shared their experiences in applying Photovoice in an Indigenous community based context. Notably, they argue that since social science occurs within a loaded historical relationship with colonialism, community-based research and Photovoice work to address the exploitation and injustices in which most research is steeped. Photovoice can overcome these biases by requiring participant control, power and ownership throughout the entire process (Castleden et al., 2008).

Photos transcend language and cultural barriers, and power both adaptability and commitment to social justice (Wang, 2014) making Photovoice an ideal method for this study. Photovoice allows participants to construct and share their story from behind closed doors (Aldridge, 2014; Allen & Hutchinson, 2009), and is especially powerful as an empowerment tool for historically marginalized populations (Aldridge, 2014; Allan, 2012). Participant photography positions research subjects as collaborators that equip them with the knowledge and tools to capture the images that will stimulate and nurture the interview and focus group dialogue (Aldridge, 2014; Allan, 2012). Participants were invited to photograph their homes and collect images that were related to the research questions, specifically features of characteristics that impacted their daily life and either made things easier or more challenging. The participants were initially asked to document the three structural characteristics of visitability: entry to the home, doorways, and bathroom; however, because many people did not have these features, they were also invited to capture features that minimize or exacerbate their independence and functionality inside and outside their home.

Details and questions about the use of Photovoice were provided in the first information session. Without the use of Photovoice methods, I would not have gained access to a visual representation or understanding of the relationships between the physical home and community and their lives. The key goals encompassed within the application of Photovoice are that it first, emphasizes the participant's experiences and validates the interpretations, second, develops the collective knowledge of the participants through group process, and lastly, provides an avenue for influencing policy change through the translation of the photographed experience (Lal et al., 2012; Sutherland & Cheng, 2009). I am confident that the first two goals were met by the decision to apply Photovoice as both methodology and research method. The final goal will be met through the work that stems from the dissemination of these findings, and connections that will be made with other researchers and communities to build policy momentum on the subject of community inclusion for people with mobility challenges who live on reserves.

### *Community engagement*

My study design was community focused and purposeful, meaning that both the participating communities and the participants themselves were selected specifically for their experiences and interest. Interest from the Bands was obvious through their agreed participation in the task force, but I also secured verbal and written consent from each Band council. Community members working in the Band office and on the task force taught me some of the community protocols around hosting gatherings and gifting, and the appropriate language and communication style to use. For example, when I prepared food for the group sessions, I provided food and cooked a lot to ensure I had plenty for unexpected guests, family members, or random hungry bystanders. To not have enough to feed those who came could have been interpreted as unwelcoming as well as ungenerous, as the norm in Indigenous communities is to provide plenty of food, even enough to take some home. The input from the community was often practical. For example, an early draft of my research proposal used the word *reservations* in the title; however, Janice Rose noted how the term could be considered derogatory, and recommended using the preferred term *reserve* instead. When I was invited to talk to housing expert Linda Ross, she gave me a perspective on the larger scope of Aboriginal housing, digging into her experience as an Aboriginal housing developer who has worked in numerous capacities in the majority of local First Nations communities. Her knowledge directed my research by illuminating the challenges that builders and contractors face in developing off-reserve housing. Other feedback was useful to the specific communities. For example, I was told to refer to the Scia'new community as Beecher Bay. Still, some families preferred to be named as members of the Nation of Beecher Bay, while others preferred to be known as Scia'new. The spelling, too, for both Beecher Bay and Scia'new was also different in many places. I resolved this concern by adopting the spelling used on the Scia'new Nations' website. Over the course of the study period, I visited the communities many times, and always took the opportunity to meet new people, listen to the stories about the history of the lands, people and housing, and hear differing opinions about community development. In both communities, this level of engagement was opportunistic and not planned. My connections were random and often happened while I was waiting to meet with participants or the Band administrators. Twice, I was spontaneously invited to a community barbeque in Beecher Bay. One of the barbeques I joined turned out to be a community consultation process facilitated by the Sprit Bay developers. Witnessing this was quite helpful as it brought out some universal concerns about unemployment in Beecher Bay, and the hope for better and more economical hydroelectricity, internet, and other infrastructure concerns that were on the fringes of my study topic. This informal engagement greatly supported my understanding of the overall sense of community cohesion, as well as the variations and unique challenges that each community faces.

### *Community Scan*

I included a community scan to collect as much data about the community context as possible, and ground the overall study in order to better understand the lived experiences of the participants. I started with a short directed phone conversation with each Band's liaison administrator about reserve size, land use population, and any other housing or community related information. Prior to this, I had a list of housing specific questions, but I was unable to gain access to view the applicable Band housing policy, so I could not include this information in the findings. Although a major goal of the VTF was the adoption of visitable housing policy, this goal brought forth major challenges, and could not be implemented within the time frame of either the project or my study. Following the phone conversations with the Band administrators I collected data through direct observation and note taking. In each community, I received consent, included in the consent that the Band council gave me prior to getting into the field, for conducting a community scan. As a method, the goal of this scan was to discover community characteristics that would create more context for each of the communities as a unit of analysis, or as unique cases. As I scanned the communities, I focused on any observations that were relevant to the research questions, searching for visitable housing, barriers or adaptations, but most of all looking for community members either utilizing or in need of community infrastructure. I was also specifically interested in general community features, such as the age and quality of homes, home design, the prevalence of stairs to enter, the topography of the land, the style of road, sidewalk access, speed limits, and the availability of bus stops, as well as characteristics of the other shared buildings in and around the Band office. The community scan also generated the background context to help answer the third research question about the relationship between individual home visitability and community infrastructure.

I wrote down details about indirect and general characteristics, rather than about individual homes. I did the Esquimalt community scan on foot, walking from one end of the community to the other, and not only scanning size and style of homes, but noting the upkeep and overall usability of the roads, sidewalks, homes, and surroundings in the context of anyone with mobility challenges. I also walked up the steep road to Admirals Road and at one time drove to the other end of the reserve, in the industrial zone, where one of the participants lived. Compared to the Esquimalt reserve Beecher Bay is much larger and more spread out, so my community scan there began with the center of the community where I arrived. At this central point I could scan the shared buildings, in the context of their accessibly and the layout. Koren Bear had arranged an escort to ensure I could find the various driveways and pockets of homes, so I was literally driven to each corner of the community. I took notes on homes, focusing on the layout, and especially any notable similarities and differences between the two communities with a similar number of homes.

### *Group Session*

I conducted two group work sessions in each community. The first session was promoted as a visitability information and study recruitment lunch. I did not promote the event in any way myself. Information about the event was shared by the Band administrators directly to the selected community members in person or over the phone. The information was taken from my conversations with each administrator, and from the information letter that I had sent them by email, and that we had discussed in detail. Both administrators were extremely helpful in scheduling and reserving the meeting space. Unfortunately, as noted earlier, Beecher Bay has no accessible meeting space. The invited community members were aware of this, and three of those invited could not attend in person, and sent family members as their representatives.

The first group session had two parts, and was crucial in many ways. In the first portion, I invited the potential participants to enjoy lunch, meet me, and find out what was involved in the research project. This was my only chance to pitch my research idea, and recruit community members, but it was also my responsibility to cover all aspects of the letter of consent, explain myself, and get feedback on the study plan. While I introduced myself, I also talked about my background, my limitations and my rationale for engaging in this topic. In so doing I also brought up my own ethical misgivings about doing academic research on visitability in the First Nations context, and addressed the elephant in the room – Why is a non-Indigenous academic researcher doing a research project with BCANDS in the communities? I mentioned that I had brought this question up with BCANDS, but that I had been both invited and strongly encouraged to complete the research since there was no one else who could jump in with the task force at that time.

We started the meetings with food. While we ate, we did the introductions, so we would not take up too much time. I talked about who I was, where I came from, and why I was interested in this topic. I invited everyone to introduce themselves too. The introductions from everyone were long, informative, and included a rationale as to why each was interested in visitability. I was already generating important data; however, this was only the lunch and general information session, so I had not obtained consent and could not digitally record these first group sessions. Though I did jot down general notes. Following these introductions I served tea and dessert, and took a half an hour to carefully read and discuss the details of the research questions, process, and commitment expectations from interested community members. In Beecher Bay the attendees were less familiar with BCANDS and the visitability concept. There was an assumption that my research on housing was a collaboration with CMHC, so I also explained that my funding was not from CMHC and what my responsibilities were with regard to the completion of my Master's degree. A key point I emphasized was that I was exploring these research questions because they would be helpful for communities and could potentially inform future community or housing policy, but that policy change was not in the project scope. I was quite honest about the limitations of the study. I noted that this was a tiny project, and that it would take the community as a whole to push for changes to its housing policy. I did also tell them about my plan to publish my work through BCANDS and CCDS (and anywhere else possible), and I let them know that I was energized and passionate about this topic. After tea everyone had a chance to reread the letter of consent. I checked in with everyone one by one to clarify and answer questions. Those who represented themselves signed the letter of consent, and those attending for family members took the letters and additional information on the Photovoice portion home for the three who could not come.

The second portion of this first group session was used to introduce and educate the group in Photovoice as a practical method. I talked about the rationale behind Photovoice, and gave some examples of its application in contexts where it was hard to unobtrusively collect data. Overall, people were quite interested in getting a chance to document and share their experiences in this way. By handing out cameras, I was really handing everyone control over the data collection, and it felt great. Most of the discussion was about specifics, such as how to use the camera, how to label it, where to drop it off at the Band office, and how to reach me for questions or support. I clearly restated the research questions. I then asked everyone to close their eyes and picture some aspects of their homes that made their lives easier or more challenging, and to clarify I gave some examples of ways I could document the building we were in, noting the lack of a zero-step entry, the inaccessibility of the bathroom, the cluttered space, and also the uneven terrain outside in the parking lot. I explained that the parameters around the camera use and described how the photo would be directly linked to the content of the interview discussion, as this would provide a backbone to our interviews. The only rules were to not photograph people in an identifying way – a pair of shoes, for example, was okay to photograph in order to document someone helping them – and to only photograph ones' own home, without identifying markers such as licence plates or house number. I also ensured that if anyone needed support using the camera or documenting something meaningful, they were welcome to get help, but that they still needed to direct the photography themselves, and to keep to capturing their own experiences. I agreed to be available for phone or in person for support if needed, and arranged to pick the cameras up in person from the Band offices a week later unless I heard otherwise. I encouraged the participants to go home and take pictures while the session was fresh in their mind. I called and followed up with the three potential participants who had sent family representatives, and offered to come in person to discuss the study, and ensure that the participants fully understood the process and commitments, and wanted to be a part of the study on their own accord. I also reminded them about the option to get help taking photographs from the family representatives who had attended the Photovoice session. The three participants had all had their representatives leave signed letters of consent at the Band office, and had picked up their cameras; however, after the phone calls, I was also satisfied that the three were informed and aware. In each community, the receptionist held and labelled the cameras to make sure they were organized, and to ensure they were not mixed up through the development process at London Drugs. Some participants needed more time and reminders to finish taking the pictures, so I went a couple of times to each community. I arranged to interview participants as soon as possible following the pick-up of their photos.[2]

Following the individual interviews and preliminary analysis of the data, we met for a second Photovoice group session. This gave me the opportunity to reconnect with study participants, thank them for their contribution, and also verify and triangulate my own findings from the initial phase of analysis to the participant's intended meanings. This gave them ultimate control of the final themes and thematic hierarchies (Allan, 2012). I spent weeks trying to find a time that would work for each set of community members to meet. Eventually, I had to meet on an evening that worked for the Band administration and the majority of the participants, after having to postpone this event once in each community because of venue changes and a death in the community. Ultimately, only Colin and Jen were able to attend the Esquimalt meeting, as both of the two elderly female participants had been unwell for an extended period of time, and could not attend. The reception of the meal was not great. I had bought traditional Persian food, which I consider luxurious, but turned out to

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[2] The individual interviews are described in full in the next section, titled *Interviews*

not be that popular. We met in the same room as before, and talked casually while we ate. This session had a more formal feeling because we were in a meeting room, and because the conversation also needed probes and more facilitation.

In Beecher Bay, I had scheduled the farewell dinner at the community daycare, which is often used as a meeting venue because of the availability of a kitchen and meeting space. In both cases I arrived with plenty of food ready to serve. The Beecher Bay Band receptionist had planned to let me into the daycare, but did not show up, so thankfully Maria and her husband offered to share her home and hosted us. In this case, only two of the five participants showed up, and both brought family members as guests. I had expected three participants, and potentially six if they each brought a guest. I had not encouraged anyone to bring guests but this was not unexpected, so I made sure there was plenty of food in case they did. Ellen had brought her niece, the mother of a severely physically impaired young man. She did not wish to contribute to the discussion on record, nor did she consent to this, so I turned off the recorder when she commented once. The other new member of the group was Maria’s husband Ben, who was Amy’s son. Ben initially listened and later became quite engaged. His narratives were not used as content for the member checking, but were beneficial in stimulating discussion from Maria and Ellen, especially because he lived also with significant pain and early onset rheumatoid arthritis. After catching up from the summer we ate and chatted, and following tea and dessert got to work, but this session had a lovely casual atmosphere, largely because we were in Maria’s home.

In both groups my role was fluid as I moved from hostess and group facilitator, to observer, recorder and guest. I confirmed that the attending participants still consented to the data collection and were okay being recorded. I shared the names of the *nodes* I had been using to codify the data in NVivo, and the number of references for each node. As I listed and carefully defined these, I paused, and allowed time for natural questions, comments, and feedback, and I allowed the discussion to happen in an organic way. I did not move on until the discussion moved off topic, or there was an interlude in the conversation. I asked participants to share their reaction to a theme name or concept, and note if it did not fit with what they knew or felt to be true. Although they did not directly state that any nodes were not relevant, it became obvious which nodes were relevant by the degree of discussion that would follow. This not only reinforced, but helped develop the themes through group discussion, as the participants indicated how pertinent some of the concepts were. I carefully went through these digital recordings later, checking the themes against those that I had previously listed. This was a pivotal stage. By including this rich narrative data, I gained confidence in the overall process and heard how strongly the participants responded to having their experiences captured and reiterated. This input reinforced how the literature and all phases of the data collection strengthened and thinned out the themes so that they were clearly on track, and in culturally and contextually relevant language for each community. Conducting this member checking was key as it ensured that my interpretation of their experiences and priorities was indeed accurate. Through this session I gained confidence in the overall process and my capacity as a researcher, and got to hear how strongly the participants responded to having their experiences captured and reiterated. This process was pivotal in helping me both understand the relationship between the themes, and identify the major overarching themes that had been brought up consistently by study participants. Providing and sharing a meal and conversation before jumping into the research topic was also intentional and part of the foundational research methodology that impacted this analysis. We all had a great time, and the overall interest and rapport in the group showed that not only had the study provided effective methods, but that we had all learned a lot, and developed a great sense of comradery. At the end, the participants felt like friends and we were all more relaxed, without worries about recruitment, error or my own insecurities as a researcher out of my element. After the work was done I gave each participant a gift bag with a personalized thank you card, a litre of salmon I had caught and canned myself, and a one hundred dollar gift card. I found out that the participants in the Esquimalt group had expected the gift card. I am not sure if that was the norm or if the Band administrator had told them of the honorarium I planned to provide. Collectively, we all were satisfied with the experience of working together, and we all look forward to connecting again. Although some participants were unable to attend the second sessions, these were very helpful and indicated that my themes were on track and were relevant in both communities. They also reinforced the needs and priorities from their perspectives and gave me confidence to continue deeper analysis. I found deep satisfaction realizing that relationships were are the heart of every part of this study process, and the final thoughts from the participants at our final group session was disappointment that our work together was coming to a close.

#### *Interviews*

Once I had the developed pictures I set up an interview with each participant. All but one chose to chat with me at the band office. When I met with each participant they were again given the opportunity to pull out of the study without question; however, all the participants agreed to continue. I used a digital recorder to capture the narratives of the participant's description of what each photo was, and why the picture was meaningful to them. I spent a couple of minutes at the beginning of the session just talking about the norms around the interview, and making sure that they were relaxed and comfortable, offering the washroom, a coffee and checking into their physical comfort. Prior to recording we had a brief chat that pertained to life, and general small talk. I also gave an opportunity to ask any clarifying questions, and reminded them that we could stop at any time. The ice breaker I began each interview with was: "What does a typical day look like for you?" The rationale behind this was twofold: to open the discussion with a context rich question that would introduce me to the people, places and daily activities that impacted the daily life of the participants, and also put the control and focus onto the participant completely, in that they could share about whatever aspect of their lives that they wanted to. From this question I expected to collect data that would be relevant to all of the study questions, but especially the second, as it pertained to social interactions, supports and barriers that are not necessarily physical. The icebreaker also gave me a feel for the individual's overall quality of life, and set the context for the photos. It also fit well with my overall desire to connect in a meaningful way as both a caring human and as a researcher. This question is powerful and I had experience using it when I was working in a role as a disability advocate. It was the most effective way of helping people with disabilities talk about the relationship between their impairment and their daily living activities without prying or projecting my values or expectations. When this first question was answered we moved through the photos.

After picking up the photos, and prior to our interview I divided the photos into two groups so that the participants and I both had a copy to hold for the interview. Together we numbered them chronologically to make sure I had the order correct, beginning the conversation with photo one, the first captured image. This was done to make the interview transcription organized under photos, and for accuracy in analysis. It is important to note here under my interview method, that while I did read and discuss the research questions in the Photovoice group session, I did not talk about any part of my research methodology, or methods or remind participants of the study questions prior to or during the interview. I also ensured the participants were comfortable being digitally recorded and that they knew they could stop or take a break at any point. My interview style aimed to be casual, with my goal a relaxed process where I attempted to mitigate power dynamics between me and the participant by using open body language and active listening skills, such as open posture, matched level of eye contact, and verbal affirmations or probes when necessary. Through the photo led interview portion I used simple probes for a couple of the participants who seemed at a loss as to what to say, such as "Can you tell me more about what this photo means to you," or "What are we looking at here?" Because we were sitting looking at photos the questions were helpful to draw focus. I chose to allow the narrative to diverge as the divergence was often about the context or deeper meaning linked to the photo. Interviews took as long as the participants needed, from fifteen minutes to an hour, but were on average around half an hour. When we had gone through all of the pictures, I asked the participant if there was anything that they had wanted to photograph but had not been able, had forgot, or wanted to add to the interview. Like the first question this collected a wide range of data as some participants spoke freely and others simply said "no." After the interview I thanked each individual and reminded them we would meet at the final group session in the fall, at which time I would bring and share my preliminary findings to see how this fit with the intended meaning shared by participants, as well as get feedback and more input if necessary to ensure my interpretation of the data was accurate. These open-ended interviews flowed directly from the photos, and the themes and codes from the interviews transcriptions that follow (Allen & Hutchinson, 2009; Tracy, 2013).

## Research Process

This study transformed through my participation in the VTF in the months leading up to my field research, as well as through on-going discussions with my graduate supervisor. As an online student, the relationships I built prior to and during this study period played a pivotal role in the overall research process. Over this period, I wrote my study proposal, got information letters to the communities, and secured Band counsel support and consent. During this formative phase I reformatted my research questions. The first, which focused on visitability, was included as a way of exploring and testing the concept of visitability in the context of the community, and as a tangible and documentable aspect of my study. The other two questions came from me, and formed out of my own interest in the larger social and environmental conditions that would be paramount in understanding the lives and needs of the community members living with physical limitations. Because my research was funded by BCANDS as part of the VTF, visitability issues were by design to be a central finding of this study; however, through the research process the priorities of the communities clearly flipped the weight of the research questions, with the specificity of visitability making it too definitive and exclusive to express unique community values.

This work was developed and funded by the CCDS. The VTF and BCANDS each provided $2,500 of research funding. While the CCDS has initiated ten visitability projects across Canada, ours is the only project that took place on-reserve. The Chair of the task force was the only paid position, and during the project the Chair resigned, and was replaced. My membership in this taskforce benefited my study, and in turn my research project energized the taskforce, as without it there would not be any kind of data collection to complement the two years of community engagement work on the topic of visitability.

As a non-Indigenous researcher it took time to earn both credibility and trust with the Band administrators. I had much to learn about the housing situation, and how Band housing administration functioned. Establishing the VTF relationships influenced my study in real ways. Community connection from my past work as an advocate got me a meeting with the Executive Director of BCANDS. This could have developed trust that in turn led to my invitation into the VTF. In turn, my membership in the task force connected me to the community through the perspectives of the Band administrators and others present. Through my participation on the task force, and in discussion with its members, I had the opportunity to share my research interests, outline my drafted plan, and get input as to how best to work in each community. My attendance in this group was mutually beneficial. It connected me to the housing administrator in each community, and strengthened the visitability project as the first of its kind on a reserve in Canada. For CCDS, I produced this research component, and a summary report, which I will write following the defense of this thesis. The housing administrators became key liaisons between myself and community members, by both identifying and contacting potential participants, and later helping me access meeting space, reminding participants of meeting dates, and being extremely supportive in many ways. This study may not have happened without BCANDS and the support of each Band as the community members knew and trusted my liaisons, and showed up largely because of that rapport. Due to VTF challenges, such as communication difficulties between the past chair and the VTF members and communities, we were behind schedule on previously recorded task force goals. Also, some of the goals that the group initially had, such as developing a housing policy, were unrealistic under the time frame of the project timeline, and had not been tested or developed in the context of a First Nations community. Examples of other VTF projects and teams working in cities and communities off-reserve were interesting, but using them to help our process was less helpful due to the plethora of unique complex jurisdictional and administrative processes that influenced the development of housing policy changes in the communities. My role as a student researcher on VTF also included sitting in on a UBC Learning Circle that was live-streamed online. This gave other First Nations communities around B.C. the opportunity to network, learn and ask the panel questions about visitable housing.

To summarize the timeline, I began by driving to each reserve, introducing myself to community members, talking about the project, and hearing stories about their homes and families as these related to their lives. Through purposeful sampling, several potential study participants were identified by the Band administrator of each community. Data collection began with community scans. Band administrators then scheduled the first Photovoice group session luncheon for Beecher Bay on May 27, 2015 at 11:30. The first group session was scheduled in Esquimalt for June 9, 2015 at noon. Next, all interviews were scheduled and conducted in each community Band office, except Carol asked for a home interview in Beecher Bay. In June of 2015, I hired a professional research transcriber, and in September 2015, I began to read through the transcriptions and began checking these for precise accuracy using NVivo. After doing my initial analysis I went back to the community in early December 2015, and facilitated the second Photovoice group session.

## Data Analysis

NVivo software was especially helpful for the organization of the data. When I received the files electronically from my transcriber, I first ensured that each of the files represented a participant in the appropriate community, for example, *Com A) PAR 2* was used as the file name and the title in the transcription. I stored the personal information such as the signed consent letters and photographs in a locked filing cabinet in my office. The photo envelopes were given the same labels as the file name, e.g. *Com A) PAR 2*, and these were named to actual individuals in the letters of consent. I conducted all nine interviews in less than two weeks, often two or three in one day that worked for community members and the Band office. In NVivo, each community was contained in a separate file labeled A or B, and each participant had a corresponding number. The initial phase of coding began with me following the recommendations of Tracy (2013) and of my transcriber, and completing a thorough accuracy audit. The transcripts were complete and well formatted, and only minor adjustments were needed for some local culturally relevant words such as Big House, as well as small town names, like Ahousaht. In a couple of places, I could not understand what was being said, so I left the section blank as had the transcriber. Revisiting, and as Tracy (2013) puts it, “submerging” myself into each participant’s transcription or story made it real (p.188). As I poured over the transcript I jotted down notes and created node label tags in NVivo as I went. Selecting chunks of data that were linked or relevant to the research questions, I labeled each piece under the corresponding node name. The data generated through the photo-guided interview was very specific to each participant in the context of their home and community environment so through the coding process I needed to constantly search for the obvious as well as the deeper meanings and nuances as shared and described by them. Through the emphasis and repetition of the participant statements, NVivo coding and multiple cycles of analysis (Tracy, 2013), I discovered what the participants had in common with other mobility challenged community members, sharing their take on a unique but parallel experience. In this way these common threads evolved, and became galvanized meaningful themes, through the process.

The earliest coding work was done by simply capturing my initial thoughts on my office whiteboard following the Photovoice orientation. These included: dependence, transportation, attitude, vulnerability, risk, support needs, barriers, transportation, and administrative barriers and risks. By the time I had become familiar with the stories in the individual transcripts, numerous codes were springing up constantly, sometimes even as I tried to fall asleep. I worked through the transcript data systematically across the whole data set and collated the data by highlighting it with each corresponding code colour in NVivo. Over time through this process I realized that some codes were very similar, interesting but not answering a research question or overlapped and could be combined with another. Thus, the important codes became more established as others were pruned out through the process. The next stage was organizing into clouds. I arranged the codes under the relevant research question cloud on paper. For example, any emerging themes that were linked to visitability such as safety, physical barriers, maintenance, and renovations fell under the *visitability* cloud. I am a kinesthetic and visual learner, and although I could have done this organization in NVivo or online, I needed to play with the language and express myself in this way. Under another cloud called *infrastructure*, I listed safety, and physical barriers, and band administration. Independence, receiving help, caregiving, safety, pain management, mobility, security, and food security were put beneath *quality of life*. From this larger brainstorming and contemplative stage I really worked through the data repeatedly. I realized that I had many emerging themes that could be better described, and also that many still overlapped. In NVivo I observed that some of the themes were irrelevant to my study questions, even though I was personally intrigued. For example the attitude of the participants was not linked to the topic, and neither was pain management. Also, over time the codes that merged developed into major themes while others evaporated. I had inaccurately projected visitability as a major theme because the photographs had captured these features, yet while this concept opened the study and generated much of the content of the interview discussions, it was not a major intrinsic theme that came from the data. Rather, it was a specific set of criteria that either existed and could be observed or was absent. This absence opened the door for participants to think about the broader and sometimes more pertinent issues and priorities. A closer relationship to the data was needed to uncover the more subtle socially related codes such as care-giving, receiving help, and community, and *quality of life* moved from being a theme to what made more sense as a universal human goal that was determined according to cultural preferences and priorities.

This primary cycle of coding helped me work through the raw data as I began to make sense of the experiences, hear the obvious general themes, and begin to consider the hierarchy and relationships between them. When I was satisfied that the first level codes reflected the substance behind the data as it was related to the study questions, I took the preliminary analysis back to the communities for feedback. Our second group session had two objectives: to verify my initial key findings, and to thank the participants. I began by sharing my general understanding of what I found most interesting overall: First I noted that only one of the participants specifically identified as *disabled*, but that there was a pattern of participants identifying with community, culture, and the roles, relationships, and responsibilities that they had in the community. Other key findings had been that the majority of participants were both giving and receiving substantial help to family or community members, and that as a concept visitability missed the mark with its individualist assumptions and focus, and that infrastructure impacted mobility in a major way. I also stated the obvious, that both communities lacked visitable housing, and in the case of Beecher Bay, also visitable public buildings. Universally, barriers within the home noted by all nine participants were found outside of the realm of the three visitable housing criteria, for example, stairs. Next, I shared the meaning of the names of the NVivo nodes I had been using, and the number of references for each node. As I listed and carefully discussed these, I paused, and allowed time for natural questions, comments, and feedback to let discussion happen in an organic way. It was obvious that some themes resonated more by the depth and level of discussion that would follow. For example, while the Beecher Bay group nodded and verbally agreed to the theme of visitability, and all had referred to it many times, this was not an intrinsic theme, whereas community infrastructure was discussed for about half an hour with passion and a huge amount of interest. Later, this discussion boiled down to major concerns about safety, which helped me understand the basic root of their collective concern. I carefully went through these digital recordings later, writing bits out on paper and simply highlighting the chunks of data that were specifically related to the research questions, diverged or galvanized themes, or were points that were emphasized by the group.

This pivotal stage of data analysis strongly reinforced themes and key findings from all the phases of the data collection and strengthened and thinned out the themes so that they were clearly on track, and in culturally and contextually relevant language for each community. The list that I took to check with the participant groups consisted of the following themes that had not yet been divided into major or minor themes: quality of life, independence, reciprocated support, and access to health care, attitude, receiving help, care giving, administrative barriers, physical barriers, community, community infrastructure, maintenance, visitability criteria, and safety. In the interest of rigor I allowed the nodes that I had shared with the communities to only develop into themes from data that was reinforced in the collective member checking group data. They wanted to know which themes were most important. I shared the number of times each theme had been referenced in the transcripts, but also said that their comments and discussion would determine how the themes would be prioritized. Several concepts that initially seemed interesting or important were left behind over time as they did not capture enough of a shared experience or they were not in line with the study focus. I also combined some themes as there was still overlap with independence, access to health care, and attitude. Attitude was not relevant, and was also quite subjective, and both themes of access to health care and independence were values of mine, not theirs, and were better contained within the theme of receiving help.

The initial descriptive codes that were easiest to find were specifically tied to research questions one and two. These codes also had often been captured specifically about physical features in the participant photographs, and were stable themes through the analysis. The codes about visitability, community infrastructure, physical barriers, and home maintenance were all environmental conditions. The theme of safety was so strongly emphasized consistently through both group sessions and the interview that I declared this the master theme for the physical conditions that impacted participants regularly. The more subtle codes were those that reflected the role that the social context had on daily life, and because they were not documented, their prioritization really came out though the member checking session. When I transcribed the group session and checked it against the existing themes, I found that the social environment and processes were as important as physical safety. Capturing this large social theme in a concept that fully contained the individual, family and collective community resources, and the degree of connectivity, brought me to a term I had forgotten about, social capital. Overcoming my immediate aversion to the term, and any negative connotation this might have for participants, I found recent and relevant research that supported the utility of this theoretical construct in the Indigenous community context. Social capital was the concept that came closest to adequately capturing the real content of what I heard the participants share when they talked about the ways that they made community contributions and also relied heavily on family and community for support and additional resources. Social capital became the second major theme, and under this I placed reciprocity of support, (formally care giving, and receiving help) as this directly impacted the participants' independence and reduced barriers. Other minor themes that fit into this category were community relations and Band administration. From the list above and through comparing the final group session data with my interview data, I developed a framework to present the themes in the findings section that follows. The approach that I took to the study was both a personal fit, and also provided appropriate and ethical methods for working with and making conclusions from the intimate experiences of my vulnerable participants.

## Ethics

In accordance with the Tri-Council Policy Statement (TCPS), I have carefully applied and adhered to Tri-Council guidelines of respect, concern for welfare, and justice (Canadian

Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). I have considered the complexities that may have arisen, such as the decision making capacities of participants, vulnerability, risks and benefits associated with participation, and the overall impact, negative or positive, on individuals, families, communities, and society as a whole. In addition, this study considered the overarching principles of OCAP, or ownership, control, access, and possession of research (National Aboriginal Health Organization, 2007). I have also considered the rights to privacy, participant safety, and my influence on research outlined in the UNBC Senate (1995) guidelines, balanced my desire and right to academic freedom with my responsibility to the participants, the community, and the academic institution, and reflected on working within an Indigenous research context, as regards the complexity around issues of ownership as discussed by Denzin et al. (2008). For example, I am giving the participating communities copies of a study summary, written by me, and while the two nations will have the opportunity to be named in the title, the data is owned by me. The ethical practice in my proposed study depended largely on my own beliefs and skills such as “discernment, imagination, partiality and personal authenticity” (Baarts, 2009, p. 424). This guided me to leave space, not to assume, be creative, adaptable, and open minded. I also had to put my ego aside, and not take comments personally. These qualities were especially paramount considering that my target population is vulnerable. Therefore, each time I met with the participants I routinely discussed informed consent, anonymity, confidentiality, withdrawal rights, and photo usage. Of specific value were my own personal reflections and honest journaling about my own mistakes, challenges, and personal limitations. Part of this case includes minimizing my own risk when I am conducting research alone in communities. In addition to being in touch with the local Band housing administrator, I had to ensure that I kept in touch with my own trusted contact person without giving away the participant’s home address, that they knew which community I was in, and that they were available during the time I was conducting the interview.

At the first info session dinner in each community, we discussed the TCPS and OCAP principles in detail as we covered the research process, potential risks, benefits, and post study actions. I had to repeatedly remind participants that no housing funding would follow their study participation. The participants documented features of their homes and expressed the ways that these features impacted their families. Everyone got a copy of the photos if they wanted one, and I informed them that the photos and their interviews were stored in a secure location in my office. Some participants declined to share any photos, while others consented to the use of any basic and unidentifiable features for this Master’s thesis only. All participants preferred that I refrain from using any photos in the summary that would be shared in the communities, as I have committed to write a summary of my research for the BCANDS website, and provide a practical, concise handout, in plain language without academic jargon, that each Band office can share with the community.

# Chapter 4: Findings

## Preamble

My selected methodology and method fit with my world view, and they have been a productive way to both connect with the community and gather data. The research approach has ensured that I am accountable to my participants, and they had the opportunity to respond to and shape the evolution of the themes through the second group meeting. The themes were prioritized in each community, which provided a strong argument for future research initiatives. My first study question asked participants how the presence or lack of the three structural visitability features (a zero step entrance at front, back or side of the home; wide doorways on main floor with a minimum 32” or 813 mm with a clear door opening; and a wheelchair accessible bathroom on the main floor) impact them with regards to their physical limitations in daily life brought about by their disability. This first question generated the photographs that guided the collection of the core data I then analyzed through thematic analysis. In the findings section that follows I present several examples as evidence which clearly indicate that some visitability features like the no-step entry and accessible washroom are especially important, but that the mainstream definition of visitability does not fully capture the participants’ experience and priorities. The second question was very open-ended, asking participants to generally consider what barriers and supports impacted their quality of life. While I did not directly ask this question to the participants during the interview, it was answered through the narrative in which the home visitability discussion organically developed into one that shared about the social context where the intersection of participants’ identity and values were heard. The main findings here were that while participants reported numerous challenges, both physical and social, the level of social capital to which they had access greatly mitigated these barriers. My final research question considered how the community infrastructure influenced the participants' experiences with their own home visitability. Results showed that community infrastructure was a serious issue, and was actually higher in priority than home visitability due to its impact on the overall connectedness of families, and the range and breadth of the social support networks that were so essential to the quality of life of communities overall.

As explained earlier, initial themes that were easiest to define were specifically tied to research question one and two, as these were concrete, visible, and were therefore captured easily in photographs that painted a picture of the overall physical environment of the community, both inside and outside of the home. These themes of visitability, community infrastructure, physical barriers, and home maintenance fit well under the major theme called physical safety. The more subtle codes came later, and reflected the role that the social context had on minimizing major barriers. Themes such as community relations and reciprocal care directly impacted the participants' independence, and degree of accessible community support. Band administration was another minor theme which belonged under the big overarching theme of social capital, as this governance system requires specific steps and criteria to access resources and services for community members, which presents community specific social assets as well as some barriers that in turn impacted the quality of life of the participant. Together, the two major themes of physical safety and social capital effectively capture the dynamics of the community realities that were shared. These dynamics are fluid and interact in numerous ways that impact the overall quality of life of individuals, families, and communities.

**Community Scan Results**

On the Beecher Bay reserve, I observed several older homes spread out along the East Sooke road, and a large cluster of more modern homes, densely built in a cul-de-sac further off the road. This community scan revealed the lack of visitable homes: the observations provided an overarching perspective of the general level of accessibility for all members of the community by considering proximity to public transit and other shared spaces, and features like the absence of sidewalks. The community does not have a bus stop anywhere on reserve land. The shared buildings are un-visitable portables with stairs. One is the community daycare, one a Fisheries building, and the other the Band Office. The community members also noted that there was a Longhouse nearby, but I could not see this myself. These community governance and support buildings are clustered high above Cheanuh Marina just off East Sooke Road. At the time of this initial scan, the one community road connected East Sooke Road to both the Band offices and the new Spirit Bay housing development. At my last visit, I observed that the original road has been restricted to Spirit Bay traffic, and a newly cleared and built dirt road connects East Sooke Road to the daycare and offices. At each visit to Beecher Bay, I observed community members walking along the narrow and winding East Sooke Road with traffic speeds averaging 70-80 kilometers per hour. The roads did not have sidewalks or lighting of any kind, and at night the dense rainforest made navigating the steep terrain and curves challenging.

In contrast, Esquimalt Nation reserve is located 7.5 km from downtown at the south-western edge of Victoria, nestled between the township of View Royal to the north, Songhees Nation to the east, the ocean on the west, and off-reserve residential communities and the Esquimalt Canadian Forces Navy Base to the south. Admirals Road, a major traffic artery, divides the community, with some homes on the Eastern side and most on the ocean side. I saw only one cross walk which was about 750 meters away from where community members would need to cross. While Admirals Road does not have a sidewalk, there is an edge to the road and some street lights, with a bus stop near to where Thomas Road meets Admirals Road. The Esquimalt reserve is more compact, with homes in close proximity to each other. The observable shared buildings were the Modeste Smoke Shop just off of Admirals Road, and down the hill the BCANDS office, a modern Band office, and the new Big House, built in 2015. This large multi-use building has numerous functions, from meetings, to celebrations and ceremonies, and while the planners and general contractor ensured that the building was visitable, only one entrance is wide enough and has a no-step entry, although fire safety requires at least one more. The streets in the residential area have large speed bumps to reduce the speed of drivers, but there are numerous potholes, and the streets do not have sidewalks, making the speed bumps a major barrier to anyone rolling or walking in the community. Both communities have one visitable home, a single detached home in Beecher Bay, and a town house in Esquimalt. The Esquimalt resident did not participate in the study; however, Ellen lives in the Beecher Bay visitable home.

## Thematic Analysis Results

The objectives for the first group session were recruitment, relationship building, Photovoice orientation, and the first stage of data collection. Data collection started as I was also taught the correct pronunciation for Scia'new Nation, and was told about the participants' past experiences in committees on housing or community building initiatives. The first issues that were expressed in Beecher Bay were about the groups' collective frustrations around housing processes in general, and especially with the administrative processes that made applying and receiving support for housing modifications challenging. This initial session brought up a key concern for the participants about the lack of coordination between various stakeholders, and the need to repeat the knowledge they had forever, or reinvent the wheel without getting paid for their time. For example, participants in Beecher Bay stressed the need for studies like mine to work with the government researchers so that we do not all end up doing the same work. They said that the CMHC was always doing housing assessments and surveys, and felt that nothing in their homes changed. These frustrations were reiterated by all present, especially with the difficulties around home maintenance. They also mentioned concerns over spending their time on a project that again would lead to no real change in their lives and homes. The first question relates visitability to people with disabilities. I noted that only Ellen identified as someone with a disability, and she spoke of experience in a social justice and advocacy role. The Esquimalt group had heard the term visitability introduced to them by BCANDS, but many in Beecher Bay had expected my study to be linked to CMHC with potential housing funding as a result of participation. While no one wanted to speak negatively about the Band as a whole, some participants expressed frustrations, with history across several Band councils, of continued administrative barriers to accessing funding to help with mobility related home adaptations.

Issues of access to safe and reliable transportation came up in several different ways. Both groups depended heavily on family and friends for rides and mentioned bus access and safety as concerns. In Esquimalt, walking up the steep hill to the bus was a barrier to bus use, and in Beecher Bay the closest bus stop was a 10 minute drive. At the onset of the study general initial themes from the Photovoice orientation were related to barriers and safety concerns in each community, as well as the dependence on others for transportation. Notes I made following these sessions were *trust*, *CMHC baggage, transportation infrastructure*, and *vulnerability*. These initial data indicated that my study questions were relevant and timely in both communities, and also taught me about some differences.

My study plan took a year from conception to data collection not only to ensure that relationships were in place, but because time was also required between the data collection stage and member checking. My own preliminary analysis took four months, as I learned for the first time how to systematically do this work. I recorded my own notes, and kept a journal that I used to jot down thoughts during this process, especially after interviews and group sessions. The themes that were presented to the community participant groups represented several aspects of the participant experience. Following the verification sessions, I constructed a final list that was broken down under major themes that participants emphasized throughout the whole study period in group sessions and in their individual interviews. Physical safety effectively included themes of community infrastructure, home maintenance, physical barriers, and home visitability criteria. Social capital is the theoretical container for themes such as reciprocated support (formally receiving help and caregiving), band administration, and community .*Figure 3* shows the separate but interconnected dimensions of social and environmental conditions that were found to be most important to the overall mobility and quality of life of participants. They are listed in order of priority, based both on number of references and frequency across all participants.

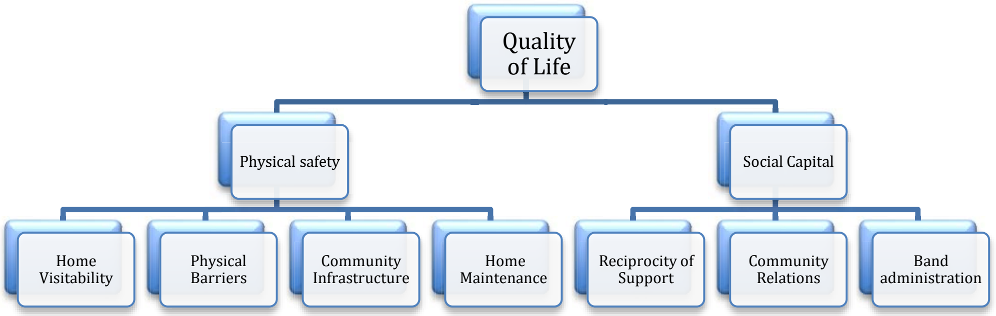

*Figure 3:* Thematic Relationships

In the following sections, I present the final themes including evidence that supports or if applicable, contradicts the theme. Where permitted, I have included some of the pictures taken by the participants.

## Home Visitability

The first study question assessed the impacts of home visitability on the lives of people with mobility challenges. Ellen was the only participant who lived in a visitable home based on the three CCDS criteria. Most participants had one or two features, most commonly an open main floor, but were still restricted by having a washroom on another floor, and only Carol had a no-step entry, the most commonly missing feature of the three. In the following section I have divided collected examples of data excerpts that directly addressed the prevalence of the no-step entry, washroom usability, and living space maneuverability and how this impacts the participant's daily life.

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*Image 1:* Access to toilet on main floor

Eight out of nine of the participants struggled to access the washroom at different times and for a variety of reasons. Sheila had the largest and most functional washroom, but due to her stairs she was unable to enter with her walker, and had to leave it at the door.

> "This is the doorway to the bathroom. They are all very narrow. If you had a wheelchair you couldn't get in there. That's the one I have no problems with the bath. My bathroom is fairly large so I could—I have a chair in there that when I get out of the bathtub I can sit down in the chair" (PAR 2, Sheila, Interview, Community A)

Betty described how the lack of functional washroom space impacts her:

> "—there is no way anybody with a wheelchair can get there and look after themselves." (PAR 4, Betty, Interview Community B)

Carol's main floor bathroom sink was out of order:

> "Yeah, 'cause it is annoying 'cause when you go to the bathroom, I come out and I have to either use the (kitchen) sink or the other bathroom to wash my hands." (PAR 5, Carol, Interview Community B)

The bathroom feature made a significant impact on the visitability of the home, and in Carol's case was also a health and safety issue, requiring her to leave the bathroom and contaminate her walker and whatever else she touched as she got to the kitchen to wash her hands.

*Image 2:* No-step entry

The no-step entry was by far the main focus of the Photovoice project, and by capturing the doorways to their home, participants were inspired to also document features outside their home that were linked to their freedom to come and go with ease. The zero step entry could be anywhere, at the side, back, or front of the home. In Ellen's case, her raised driveway provided a zero step entry at the rear of her two-story home. Because she designed and built her own home, she has a wraparound driveway that is flush with the second floor of the house at the back, creating a slope as the driveway wraps to the front where it becomes flush with the bottom floor. The significance of the barriers that steps or other hazards had for the participants was noteworthy. This was a focal point of interview data because it impacted the visitability of their home in the most basic ways, keeping people from visiting, or putting visitors at risk, as in Betty's case, if the visiting member had to be carried in. The other features made visits nicer, but the no-step entry determined if someone could even enter the home.

> "And I have had—my uncle's wife comes over through the summer and she has a hard time getting in and usually has to end up being packed in." (PAR 4, Betty, Interview, Community B)

Although Ken spoke about his own chronic pain, he also was impacted by the lack of a zero step entry as his partner Pat was dependant on him for help as she slowly used the stairs. She also required his assistance, as she could not bring the walker up or down the stairs alone.

> "And that's where it is falling apart. And this is a huge lip. You know, it's not like you can just walk right out there with her stroller. It has changed a little bit, but she can't just wheel herself in. She takes a good ten minutes getting down the stairs." (PAR 1, Ken, Interview, Community B)

Maria described how her mother-in law also needed help to manage the lip or small entrance step:

> "like I always push her and her walker up the ramp and everything 'cause it is an uphill grade and then there is a step to step into the house. Whereas, I pick up the walker and I put it in and then I stand behind her and push her up, so that one step is pretty hard." (PAR 3, Maria, Interview, Community B).

While some shared stories centered around overcoming the barriers and getting their much wanted guests in their homes, this put both hosts and guests at risk. Also those who live alone, such as Heather, often cannot manage this.

> "Yeah, looking at my front door. If anybody had a wheelchair or anything, they can't come into my house." (PAR 1, Heather, Interview, Community A)

To contrast, Ellen described the ease with which her guests benefit from the visitability of her home:

> "Now my Aunt ("Amy") and Grandma can come right through our bedroom which is here, straight through to the living room, or they can come through the big doors." (PAR 2, Ellen, Interview, Community B)

*Image 3:* 32” wide doorways and halls for maneuvering.

Compared to the no-step entry and availability of an accessible and functional washroom, the width of doorway was not a major discussion point. When it did become relevant, it was linked to home occupancy and crowding. Four of the homes were occupied by multiple ages and family members, despite tight living quarters. Ken described his partner’s challenges navigating through the narrow hallways on a daily basis as we looked at his photo:

> “Okay, this is right at the end of the hallway that goes into Pat’s room. So this is what she has got to squeeze through—this is what I hear from her every morning when she comes out of the room, she is starting to bang the walls—see the little knick in the walls—‘cause she’s just got no room to come out of the rooms with her walker.” (PAR 1, Ken, Interview, Community B)

Jen talked about the narrow doorways in their home and helping her aunt get into her home:

> "And the door is too narrow so there is one pulling in the front and then there is one pushing in the back with their hands pulled into the middle of the body—the one in the wheelchair 'cause it's too narrow." (PAR 3, Jen, Interview, Community A)

Betty has a house full with six family members under one small roof. She shared her concerns about her husband's upcoming hip surgery and the lack of space.

> "But it is really, really small. I guess with my husband going to need this operation, it is going to be really difficult for him to manoeuver around." (PAR 4, Betty, Interview, Community B)

While the Photovoice project invited participants to document visitability features, adaptations, support, and anything else that impacted daily life positively or negatively, maintenance of the home was closely related to home visitability because it also directly affected the structural utility and safety.

a) *Maintenance*

*Image 4*: rotten stairwell

Ken was my first interviewee, and he particularly expressed his frustrations with his community members assuming he was healthy and capable, meaning that he was often left to do work on his own that should have been taken care of by the Band. He strongly argued that his home needed to be maintained and completed before visitability was even considered, as this impacted his mental health daily.

> "You know, I mean there is so much that I had to do on my own without the Band's help, so I think by me taking initiative, by fixing things myself, they just figure "*He'll just do it if we just leave him alone*". (PAR 1, Ken, Interview, Community B)

> "I won't let her go out there right now anyways because of the porch, but the back porch is falling apart." (PAR 1, Ken, Interview, Community B)

Maria emphasized how the rotten ramp, deck, and stairwell are serious hazards in her mother-in-law's home.

> "Well it's weather worn and the plywood is very soft and the more it rains, the more softer it gets. Like one day somebody will go through it one day, unless somebody puts more plywood down. But it should be repaired. It should be up-kept. Doorways, the step, the ramps, the back steps are worse than the front steps….You walk on them and you can feel the whole step systems shaking like crazy. Yeah, it's bad." (PAR 3, Maria, Interview, Community B)

As noted earlier, Carol is impacted by her non-functional sink taking up room in her main floor washroom:

> "They put the toilet in alright, but they couldn't put some piece in it for the sink, so I just got a sink—nothing works ever since we moved in….So he was thinking of just taking that out 'cause when they did renovations they still never fixed it." (PAR 5, Carol, Interview, Community B)

Maintenance of the home space includes the fence. Heather lives in fear of break-ins and trespassing from various people in the area.

> "Oh, that was just that hole in the fence. That's where that kid ran when he was running away from the police, so that used to happen a lot—the kids were running from the cops. They run through here and either break through the fence and go over the fence, or they go up on a roof and run across the roof all the time." (PAR 1, Heather, Interview, Community A)

### *b) Physical barriers*

*Image 5*: large stairwell

For the purpose of this study physical barriers include any physical feature in the home that exacerbates the physical limitations a person already experiences, but does not refer to barriers experienced outside of one's own home in the community, and excludes descriptions related to visitability criteria. Most barriers related to stairs, as every participant had stairs in their home, and struggled with them in some way.

Ken talked about the ways in which the physical barriers contributed to his pain, but also how they made his partner Pat much more dependent on him for help, as well as for coming and going from the home. This relationship between the physical barriers, supports, and decreased independence is one that was broached by several participants, and is linked to reciprocity of support, in that the support helped mitigate the effect of the barriers. In Ken's case he was an exception as a male in a caregiving role where he did not receive support. His interview data was full of examples that hinted at care-giver burnout. He was at his limit and much of his time was spent driving and caring for Pat, often at the expense of his own self-care. This, combined with his push through the pain attitude and pride, put him at risk both mentally and physically.

The home feature that made physical barriers a key theme for participants was the fact that the visitability of the home was measured without consideration of stairs inside the home. All participants had stairs to contend with, even those who had no-step entries, and the one with a visitable home. Stairs were mentioned in every interview and were documented in every photo-set, sometimes multiple sets of stairs. Stairs as barriers brought out a variety of discussion points. Sheila, Colin, Jen, and Maria all talked about their experiences with falls, as well as fears of future falls, or the risk of injury to friends and family visiting their home. Colin and Jen both talked about getting their mobility restricted family members through the doors, and carrying, lifting, or pushing them up the stairs.

> "I mean everywhere I go is stairs or some kind of obstacle that she can't get up and—I can't even get her to help—she wanted to move the laundry things upstairs and I was like, "*Well, no, I can't move everything upstairs...*" (PAR 1, Ken, Interview, Community B)

Heather brings up her health trajectory, realizing that the restriction she is already experiencing will be magnified in the future, making her bedroom and upstairs washroom shower inaccessible. She related how in the winter, low air pressure and cooler temperature, among many other contributing factors, aggravated her arthritis, but that the heat and therapeutic treatment which the shower provides would require a painful trip upstairs first.

> "But in the fall and the winter it is hard to get up those stairs—up and down—so it is go up, have a shower, come down, stay downstairs and then crawl up or haul myself up to bed, so that's it. But I know like in another 10 years or so that's probably going to be the most difficult thing, I won't be able to get upstairs." (PAR 1, Heather, Interview, Community A)

In Sheila's case, and similarly to Maria's account with her mother-in-law, both are forced to leave their walker when faced with stairs or a dangerously steep ramp grade. Sheila described the task of moving laundry up and down two flights of stairs with little strength and without the support of her walker.

> "I just have problems carrying them upstairs, so I usually just put them in a bag and I can drag the bag downstairs. Like I leave my walker down below and I walk up the stairs." (PAR 2, Sheila, Interview, Community A)

In the following two data extracts Jen discussed how the physical barriers impact their guests in a wheelchair. In the first example, she admits that her home is not an option for everyone, meaning visiting often happens in the yard. Obviously this is less than hospitable, without options for eating, resting, using the washroom, or escaping the wet island weather. In the second example the connection between door width, driveway, and two flights of stairs shows the relationship between the features like the driveway or road, to those included under the visitability criteria, and how these features compound the dangerous and major barrier of stairs.

> "So we try not to go up the stairs with the friend that comes with the wheelchair because it is too many stairs to go up for an individual… depending on the weather we don't go into the house, we sit outside." (PAR 3, Jen, Interview, Community A)
>
> "The door itself isn't fixed for people with disabilities like a wheelchair or scooter. It is a little step into the door and it is kind of narrow if they go through the front door, do the driveway and then the little sidewalk to our front door is a bit narrow if they have a scooter. And then they gotta climb 12-14 stairs to get to the main living room upstairs and about 8+ myself, so it is a bit of a challenge to get up two flights." (PAR 4, Jen, Interview, Community A)

Stairs were an important symbol of cookie cutter home design, and all participants, even Ellen, struggled with the barrier that they represented. The discussion that they motivated also brought up the real functional limitations that people were experiencing, as well as the role that access to social capital had in overcoming these.

### *c) Community infrastructure*

*Image 6:* pothole

The third research question's objective was to better understand the ways in which community infrastructure influenced individual home visitability. Community infrastructure for this analysis includes physical features that were shared by the reserve or larger community, and were a collective responsibility, and not in the home or yard of the participant. From the very first Photovoice session, both participant groups talked passionately and without initiation or probes of the grave lack of resources allocated to roads, lighting, and transportation.

Spending time in community gatherings was important to community members, as these gatherings are the backbone to the overall collective social capital of the community, including its connections to other nations and family groups. In addition to the Big House or Long House, the overall utility of the other shared buildings for the study participants was dependant on their level of accessibility. Colin noted that while the main floor was visitable, with a spacious and accessible washroom, the modern Band office in Esquimalt lacks an elevator to the second floor. Although meetings can be relocated to the main floor to accommodate physically limited Band members, the fact that the offices lack of an elevator mattered to him.

> "Band Office the only thing I can think of is it is just upstairs for some of the people that have their office upstairs—there is no elevator, just stairs. I'm not saying an elevator would fix everything, but it would make it easier for some of the people that have the disability to get up to the office and upstairs." (PAR 4, Colin, Interview, Community A)

Transportation was a major factor under community infrastructure. In the following example Ellen brought up the risks and limitation of the transportation options available to community members. Her comment on members needing to give notice refers to the two days' notice needed to get a ride to an appointment in the Band's ride van. Ellen owned a car and was able to drive herself most days, and she also provided a ride service for many vulnerable community members to give them options other than spending money on cabs or hitchhiking when they needed rides on short notice. Ellen refers to handyDART, which is a specific transit option for people who are eligible for a provincially designated annual transit pass. B.C. transit does not serve the reserve and neither would the handyDART, unless the levies were paid by the Band. Maria too expressed concern.

> "…I see the accessibility for those other disabled [people] that I help—they have to thumb it, they have to do this by 6:00 in the morning or they have to be there, and like they say, they do get rides here, but you've gotta give two days' notice. Sometimes you can't do that when you are disabled. You hurt and you gotta go, you need help, so that is my only thing is that I wish that we had really good accessibility to each house like handyDART." (PAR 2, Ellen, Interview, Community B)

> "I would have loved for a lot of things like a bus to come out here—a handicapped bus to come out here to pick some of the other people up. (PAR 3, Maria, Interview, Community B)

Roads were the subject of much conversation in the interview and final group discussions. Rocks and potholes were a safety concern that became a barrier to home entry and therefore also influenced the overall visitability of the home.

> "That tells me that a wheelchair will never go there. There are big bumps in the road, big rocks sticking out." (PAR 4, Betty, Interview, Community B)

> "Oh, sometimes my wheel on my walker gets caught in the potholes and I know about six months ago one of my wheels got caught in a pothole and it broke off and so my walker went over and I went with it." (PAR 2, Sheila, Interview, Community A)

Heather linked her concern about the quality of the road and potholes to the need for additional lighting and means of safely crossing from one side of the reserve or Admirals Road, to the other.

> "….so I think we should have at least—like what they have in the gorge and that—those little flashing lights that let you cross. Pedestrian cross. Pedestrian control. That's mainly it, plus there is big potholes here." (PAR 1, Heather, Interview, Community A)

> "It's the driveway of my home and we have a friend that's in a wheelchair we would have to help push over the driveway." (PAR 3, Jen, Community A)

The first and second research questions shared the objective of their collective ability to capture the data about the physical home environment. By not specifying in the second question, and broadly asking about general barriers and supports, question two bridged the area of the participants' home environment to the third question about community infrastructure, as they chose to capture features such as potholes and other safety concerns beyond the realm of the interior of the home. Also, this second question provided the participants the opportunity to consider how their social environment or *support* also impacted their overall quality of life. Considering that the word support was their only invitation to discuss the social realm, I think it is significant that this was important enough to everyone that it needed to be shown as the second major theme, parallel to that of physical safety.

## Social Capital

The concept social capital emerged intrinsically though the process of conducting the final analysis when I had clearer insights about the concept including the distinct differences in the ways that the physical and social factors in participants' lives affected their daily life. The mobility challenged participants had socially complex lives, and many had roles with significant responsibility. Ellen, Betty, Carol, Colin, and Jen all described the visitability of their home in relation to the kind of life they had at home, and also the style of hospitality offered and the visiting that happened, or that they wanted to experience in their own home. Four of the houses were full; only one, Jen and Colin's, fit the nuclear family model. The other three were examples of intergenerational families. Carol's adult children stayed with her, and lived full time with their young children; Ellen's kids came intermittently; and Betty had family living full time, a long term guest getting cancer treatment, and a weekend visit from her special needs grandson.

*a) Reciprocated support*

Care was fluid and was described in different ways by different people. The care of family members increased social capital, and in turn was often reciprocated, but it was not always reciprocated at the same time in life. For example, in the case of Sheila in Esquimalt, and of Maria's mother-in-law Amy, they were too frail to reciprocate the support they received now, but earlier in life they had, cared for family to such an extent that they had earned their "social credits," or had invested in their future "social capital." There were two exceptions to

*Image 7:* firewood

this rule. One was Heather, who did not talk about children or family, but instead mentioned that she did receive and rely on Band administrated home support for tasks she was unable to do. Ken talked about being his partner Pat's caregiver, but he talked about negative relationships with stepchildren, and he did not expect or receive any help despite needing it, and by the end of the study period, he was no longer living with Pat.

> "With Pat I really take care of Pat—I have turned into her caregiver. You know, we are together, but we are—I just take care of Pat. I have just been her caregiver…so it is getting very hard for me to take care of the home/Pat and the little things." (PAR 1: Ken, Community B)
> "…about 7:00 o'clock I'll wake up the kids, [get them] ready for school, and about 8:30 I drop the kids off at school, go back home." (PAR 4, Colin, Community A)

This reciprocity is a social and cultural norm that seemed implied, and was expected from women, like Ellen who had moved her own mother into her home to care for her for the final five years of her life. In the following pieces of data Betty described her family members: first, the granddaughter, Sally, who Betty has raised since birth as a daughter; her brother who moved in with her and quit his job when he got cancer; and her son and grandson, who live in her home, and have major developmental setbacks. I have included this text to show the kind of responsibility she shares with her husband (who awaits hip surgery) and her adult granddaughter in maintaining the home and care-giving.

> “Well she has lived with us all her life, so I mean she is our child….My brother lives with me. He is not well. He’s got—what the heck do you call it—leukemia…I forgot to mention my grandson. I get him when he is not with his dad and he is mentally challenged and he was only 1 lb. 13 oz. when he was born, so he has got a lot of setbacks, but he is progressing really well…And my son too with his brittle bone thing, so we have really just had to kind of watch him and he does not express pain, that’s just the pits of it all. He has never known how to express pain and they even try to teach him in the hospital.” (PAR 4: Betty, Community B)

The participants’ roles in their family and community were influenced also by how they received assistance through the various family and community networks. This is another angle where social capital flows towards them in a variety of ways. In the interviews, and then later in the member checking sessions, it became obvious how essential this help was for the participants’ ability to remain in their own homes and enjoy more independence because of the support they receive. Maria described some of what she does for her aunt, the most elderly member of the community, who lives in a two-storey home that she cannot enter or exit without help from family.

> “If I’m not taking her to the doctor’s, I’m preparing her foods, then I do the housework/yard work—whatever I can for her to make it easier for her because she can’t do a lot of things herself.” (PAR 3: Maria, Community B)

Jen describes how her family members carry some of the work load, as well as help with transportation.

> “I don’t have—it’s not a struggle for me considering I have a husband with a lot of sons and a sister-in-law that is willing to do stuff for me. It is not a big issue for me to get to and from appointments.” (PAR 3, Jen, Community A)

The following two examples show how the lines between caregiver and receiver of help blur. In the first example, Colin talks about his children learning to cook. It takes energy to teach and supervise, and in turn the kids are taking some of the household chores, and responding to the increased level of responsibility.

> “When they are home they do laundry, they learn to cook… But the other two, Lee and Paul, they cook a lot too. Clean. Really help out a lot so I am thankful that they listen and hear me and they help me and my spouse—my wife.” (PAR 4: Colin)

Ellen similarly is an example in which the care for her young grandchildren benefits her as she guides them to help her out around the house.

> “Other than that I either get ready to watch the grandchildren and in that I use my cane and walker with them around the house and everywhere, and do some clean-up of the house with their help…” (PAR 2: “Ellen” Community B)

Reciprocity was a core theme. The fluidity within this concept was discussed as something that would shift in balance over the lifespan, for example, with children growing up cared for by family members, and in turn at some point reciprocating this care for their parents or grandparents.

### *b) Community relations*

The degree of connectedness that the participants experienced expanded beyond the family and into the community and this social atmosphere is contained under the theme of community relations. This theme has been left ambiguous to leave space for a broad range of experiences, and is intended to include the participants’ perception of social bonds, trust, and confidence in the larger community to protect their reputation, interests, and collective property. Of course, this is linked to the previous theme of reciprocity of support. An excerpt from Maria’s interview links these two themes well. She talks about why she needed to step in as a caregiver.

> “Oh god. Well, for instance, before I started looking after her, she was very sick, she wasn’t eating properly, she forgot when to take her pills. She always forgot about her appointments and it was hard to get somebody to take her because everybody would

> charge her $40 for gas, and then they would make her take them for lunch and everything.” (PAR 3: Maria, Community B)

However Maria and several others referred to feeling socially unsafe and threatened in a variety of ways. She referred to her mother-in-law Amy’s own mentally ill daughter stealing from her on an on-going basis.

> “She still comes into the house once in a while and takes stuff out of the fridge and the cupboards, but we keep bare necessities in there. As I am there every day, I can keep an eye and keep track, but you can’t keep nothing unlocked in that house because of that. We are in the process of having her charged with Elder abuse, by the way, and getting her evicted. She is too close to my mother-in-law.” (PAR 3, Maria, Community B)

> “I mean you can’t even leave anything valuable outside because we have actually gone to court over some stuff and that is a really—it gets me.” (PAR 4, Betty, Community B)

Heather and Betty brought up community perception and reputation:

> “Yeah. Well it was nice living way over there with no neighbours and nothing like that. Yeah. I’d rather live over there than down here—too much drama down in this area… Just too much people involved in each other’s lives and you got really no privacy. Everybody knows your business.” (PAR 3, Heather, Community A)

> “Yeah, yeah. I don’t really associate with anybody here. I kind of stick to myself because I just found out it was better that way from earlier experiences, so I stick to myself and just come to work, go home, and the only social life I really have is I go to bingo once a week and then my kids come out quite frequently… I lived in town for many years and I never had the problems I have here. (PAR 4, Betty, community B)

Ken reported that community reciprocity was dependant on his relationship to his neighbours, his community, and the larger municipality, and brought up his experiences of racism and prejudice both from his Nation and the larger community of Victoria.

> “I mean I am always in the yard and I am always doing something for, you know, depending on how I am being treated through the community, I’ll be nice to the neighbours. If I see something wrong, I will go help them do something. If they were a little nicer to me, I would go cut their friggin yard, but they are not. I’m treated like a white person. I’m here and I’m white. When I leave this reserve, I’m an Indian, so every time I leave or even step out my door I don’t know who I am until I am off the reserve and not treated differently by everybody.” (PAR 1, Ken, Community B)

There was a point in the interview where I detected frustration in Ken's voice. He spoke of the external "helper" and the stereotype of the poor and dependent Indian, and his scepticism with outside help.

> "So I mean it is very—it's like people are only helping because they want to… *help them Indians*", so it is very frustrating for me. I just can't help but think that people have other ulterior motives for themselves, let alone wanting to come and help the poor Indians." (PAR 1, Ken, Community B)

In contrast Ellen talked at length about how the visitability of her home has turned it in to a venue for Elder gatherings. Her positive attitude towards community members being in her space contrasted that of the other participants. To her, the safety and utility of her home and yard was a point of pride.

> "I work with a lot of disabled people and Elders and they meet at my house for confidentiality or to come and just relax. I tell them to go sit in the yard, "*It's your time, you can come and visit*". And we have people that come and just sit in the bush just to be alone and that's why I did that was because they can't move well on the gravel or anything and that is why my husband got also different gravel so that they wouldn't fall easy with the big gravel." (PAR 2, Ellen, Community B)

Within the social relations theme, I included a variety of experiences that showed the diversity in the sample with regards to how invested and socially engaged participants were, while I also presented an indicator for the participants like Ken and Heather who were quite isolated, and who especially stood out as not feeling engaged, or socially or physically safe in their own community. The research topic stimulated the participants' discussion of the relationship between social and physical safety, and the power that the Band holds over housing policy decisions, as well as its influence as acting liaison between CMHC, AANDC, and the participant.

### *c) Band administration*

Early in the first group session, participants emphasized how important the administration of housing and home maintenance was to their sense of safety and mobility in their community. This theme was maintained and developed through the entire process of the data collection. For the purposes of the study, Band administration included participant references to ways the Band's decision making impacted their home environment positively or negatively. This theme strongly links the social and the physical dimensions of this exploratory study because the Band organization is an elected governing body that administer sits own housing policy, and also submits grant proposals and program applications to AANDC and CMHC. Although the participants spoke of understanding the constraints that the Band had to contend with as regards to funding allocation in the community, the reality of how this resonated with and impacted participants was diverse. In the first example, Ken talked about the Band administration's with the failure to complete tasks in his home, noting that leaving these small jobs left undone will cost the community more later.

> "Just you can really notice the corners that they cut in saving money. Like I have had to put new plumbing fixtures in because they didn't put plumbing fixtures in that you can unscrew and take things out for unclogging drains and stuff like that. Cutting corners on just little things like just not finishing homes off. Really has an effect on how much is it going to cost them to fix that thing now because it is not getting any better, it is just going to get worse. So if they don't address a silly little water problem right now, it is going to be huge later." (PAR 1, Ken, Community B)

Ellen, and most of the other participants, experienced barriers such as lack of clarity around the application process. Bands apply on behalf of their members, so it is the competency and organization of the administration rather than the individual that directly impacts their home life.

> "I did try for the $22,000 home owners grant that you can get through CMHC, as well as a member for Band housing, but that wasn't approved as well and that was because [there were] a lot of others ahead of me. I eventually ended up on the housing

> program, so then that is where we started, you know, the list is still going on now." (PAR 2, Ellen, Community B)

## Summary

My first research question considered how the existence or need of the three visitability features (of the zero step entry, the wheelchair accessible doorways and hallways, and an accessible washroom on the main floor) impacted people with disabilities. Two important points emerged from the mere application of visitability in the community context. The first was that past visitability work had been done from an individualistic value system, and the second was that disability was not a term that many participants identified with. The participants clearly expressed that the mainstream definition of visitability did not adequately capture the reality or social norms of the participants, their families, or communities, specifically where it concerned conflicting expectations around home occupancy and visitation norms. Based on the CCDS criteria, only Ellen's home was visitable. The maintenance of the bathroom, main living spaces, and especially the home entrance also directly impacted home visitability. The issue of the stairs came up as a key content of both photographic evidence and discussion, and bridged the first question on home visitability to the second research question about broader barriers and supports.

Barriers and supports were reflected on multiple levels, through both group sessions and during the interviews. My second question asked how these barriers and supports most impacted the quality of life of participants' living with disabilities. Again, findings reinforced that the focus of the study participants was not on themselves as an *individual* with a *disability*. The most obvious physical barrier that impacted daily life was the stairs. Stairs was strongly linked to limiting social connections, and putting themselves, family, friends, and support workers at risk, and had resulted already in several falls. Barriers like stairs were consistently linked to barriers found in the yard, road, and community, all of which were part of the participants' overall assessment of their quality of life described as safety in the home and community. Home maintenance was closely tied with home visitability and physical barriers. The homes that were documented and described often had partially completed basements and needed repair, and had railings, plumbing, or ramps that were better unused for the lack of reliability due to deterioration. These, as well as the points that will be summarized under the final question about community infrastructure brought up serious issues with safety and the emergency responsiveness, and led to the major theme of physical safety. While not a physical barrier itself, the role of the Band administration was strongly woven through the narratives from all of the participants, and was another important theme under social capital. The Band held power to give access to housing and home modification funding through CMHC, as well as process and carry out home maintenance repairs. Therefore, this theme could both work as a social support or a barrier, depending on the Bands' organizational capacity, relationships, and numerous other factors. This second question was relevant and on target, despite being quite broad. The portion that pertained to support led to the second major theme, social capital, which was a priority for the participants. The concept of social capital effectively captured the resources and processes that when present, strongly mitigated the effects of the various barriers in the home and community. Seven out of nine of the participants described reciprocity of support as an essential process within their social networks. The third and final theme under social capital was community relations. Results illuminated community issues with trust and security (theft of property), and identified that these strains were brought about by a combination of scarce resources, unsafe homes, incomplete infrastructure like transportation options and street lighting, and complex and traumatic family and community histories.

My last study question asked participants to consider if and how community infrastructure influenced the visitability of their home. Almost half of the photos that were taken and discussed were of the outside of the home: of the driveway, or of the community. This was surprising, and clearly identified how much the community features like roads, railways, signage, lighting, transportation options, and access to utilities play out in the quality of the lives of those living with mobility challenges on a daily basis. Both the themes of community infrastructure and home maintenance are linked to home visitability as well as social capital. For example, poor maintenance of the home impacts the utility of the home, and even the adaptive features such as ramps or washrooms, as well as that of the shared community spaces. These findings indicate that the sample of participating community members clearly cared and partook in this project to bring up issues with the physical safety in their homes and communities. The strength and resilience of the social networks is admirable, but also points to a community need for additional supports, both for family caregivers, and those who do not have access to this kind of help. Some people did not have access to as much social capital, or opportunities to invest when their health permitted, so if this mitigating force was reduced or severed, it would have a serious negative ripple effect through the community. The participants lived with some major environmental safety issues, but the higher their access to social capital the more these relationships mitigated the physical and social risks.

# Chapter 5: Discussion

## Preamble

The underlying impacts of colonialism, and both historical and contemporary legally sanctioned racist policies, have led to multiple levels of discrimination over many generations since Europeans made contact. This has traumatized generations through land theft of traditional territories, loss of traditional governance systems, marginalization, imposed assimilative policies such as the introduction of residential schools, and sanctioned violence. Throughout this traumatic history, the adaptability and resilience of First Nations communities is visible through the strong family and community ties that have mitigated the numerous social inequities experienced over generations. Multiple levels and types of racism, like racism-related violence and structural racism, have impacted the communities, families, and individuals who have participated in this study, but the narrative that is most dominant is one of authentic relationships and caring. The literature that I reviewed to better understand the research topic reinforces Canada's failure to acknowledge how racist ideology continues to contribute to inequitable access to resources like quality, appropriate and safe housing, and community infrastructure. The housing that has been built on Canadian reserves has not been designed and built to suit the needs of Indigenous families, but rather to suit Eurocentric values that justified colonialism as socially beneficial (Kelm, 2001). The belief that First Nations were inherently diseased and lacked sanitary knowledge prevailed to such an extent that the western medical model pushed this conceptually to mean that Indigenous communities were blamed for having an unhealthy and immoral life style, and placed the responsibility into the hands of individuals (Kelm, 2001). This pattern of victim blaming perseveres today with the perception that First Nations health discrepancies are the fault of the individual or their unhealthy culture, without understanding the bigger social inequalities (Kelm, 2001). Intersectionality theory presents a means of understanding how the multiple levels of discrimination have played out in the lives of participants. It is at the intersection of ability, class, and race where the identity of the study participants occurs in a cyclical way, and impacts overall quality of life. The two larger and overarching themes that I identified through these studies were physical safety and social capital. Physical safety managed to describe the participants' key environmental priorities in their homes and communities, while social capital effectively captured how essential the human resources and kind family networks were to their quality of life. There are four categorical themes under physical safety: physical barriers, home maintenance, home visitability, and community infrastructure. Social capital contains the themes of community relations, Band administration, and reciprocity of support. I have organized the following discussion into sections based on the theme categories and have discussed their relationship to each other and the original research questions, through the identification of the major points of interest. Key findings for discussions are related to the new community interpreted theoretical construct of visitability given the data, multiple identities through the intersectionality lens, and the ways that social capital impact the overall quality of life and physical safety of the community members.

## Physical Safety

For the purposes of this discussion, physical safety refers to the protection from preventable harm and physical injury by reducing recognizable physical risks or hazards that impact the daily lives of community members. As Adelson (2005), Kendall (2001), and Wilson et al. (2011) have clearly indicated, the social inequalities which have produced and continue to maintain significant health disparities in Indigenous communities are related to the collective experience of geographical displacement, removal from culturally specific family social structures, the institutionalization of children and adults, and fragmented service delivery – all of which result in the severing of essential kinship ties. State policies continue to maintain that the major discrepancies between First Nations and non-native rates of disability are directly linked to the large portion of people who become disabled through preventable accidents or injuries (BCFNLC, 2005; Durst et al., 2006). Overall, participants did not feel socially or physically safe in their homes and communities, to differing degrees. Reflecting on this expressed lack of physical safety through the intersectional lens places the physical risk as an aggressive residual consequence of colonialism. The creation of the reserve system also established a class system where socio-economic inequalities have been maintained through laws, policies, and practices. In addition to racism and classism, the exclusion of vulnerable Indigenous community members with unique mobility needs has further marginalized them through ablest norms entrenched into one size fits all home and community design. The reduction of risk of injury is a major advantage of visitable housing, but participants told me that these features were often absent in their own home and did not do enough to reduce risks in their homes and community. As a major macro theme, physical safety was pushed from its original position under home visitability, and transformed into the overarching environmental conditions theme. Physical safety was reduced into four smaller themes, physical barriers, home visitability, home maintenance, and community infrastructure. Although the themes interconnect, I will discuss them individually, and conclude with the points' interconnection.

### Home visitability

The definition of visitability that was used throughout this study comes from CCDS (2013) and includes three specific features that are now considered visitable building standards: a zero step entry, wide doorways (813mm or 32") and open halls, and an accessible toilet on the main floor. The mainstream definition of home visitability has offered an easy way to measure and reduce physical barriers, and increase safety in the home for everyone, while also improving ones' connectedness and inclusion within the community (CCDS, 2013), yet it fails to address the impact of other important environmental factors. Without this context it provides an inadequate assessment for my research context. Throughout my search for literature on home visitability, in the Canadian context I have only found grey literature that has been done by groups created through the CCDS, informed by stakeholder priorities in large urban centers, and funded through government departments or CMHC (CCDS, 2013). What I have reviewed so far has neglected to include First Nations at all. In fact, the existing American research from Maisel (2006), and Truesdale and Steinfelt (n.d.) focuses only on the "single family housing market" (Maisel, 2006). My study is the first on visitability in an Indigenous context, and because First Nations communities have not been part of the visitability movement, the current definition does not adequately capture the lives and needs of my study participants due to its Eurocentric individualistic values and assumptions. Some values that conflicted with the current definition linked the physical and social dimension results. Most participants did not identify as disabled, often talked about the needs of their family members, and identified most through their social roles and participation in the community. Participants spoke with pride about being able to have guests and house family who needed a room or support. The assumption that home residents with mobility challenge owned their own home, wanted to live alone, and hosted visitors for a short time, missed the mark. For example, while Betty and Carol's homes could be considered crowded by CMHC standards, their full homes may not be as big a concern to the family as the alternative: a family member's homelessness or institutionalisation.

While mainstream home visitability prides itself with being the simplest and most basic standard of accessibility (CCDS, 2013) these minimal features have failed to adequately capture the realities of cultural norms around home tenure options, occupancy, hospitability norms, and the socio-economic barriers experienced at the community level for the two First Nations communities in this study. While the mainstream definition has been developed to be inclusive to the physical needs of people with disabilities, both the visitability movement and the broader disability movement have neglected to include the impacts of race and class in their analysis. Reflecting on Maisel's (2006) principles of visitability, it becomes obvious that these cannot exist within the current housing administration system, where the administration of reserve housing already faces numerous barriers generated through a legacy of structural racism and inadequate funding. For example, the principles of visitability, such as the right to new homes being built to be accessible, and good design being cost effective and simple to implement, are not necessarily priorities or options to communities when bigger housing and community concerns prevail (Auditor General, 2011). While home visitability in mainstream settings is political, and is impacted by provincial and municipal regulations or standards, home visitability in Canada is highly political and further complicated by long established jurisdictional divisions and public apathy (Alter et al. 2011). The restrictions to private home ownership and home tenure for First Nations on reserve also can determine if a resident has access to resources which provide the opportunity to access a new home or adapt an existing home. Harrison (2004) made an important finding with regards to adapting the home, arguing that it was pointless to only focus on physical features in the home unless they were tested in the socio-economic context. Part of the lack of effectiveness of the current definition of home visitability is in its assumption that the person living in the home has autonomy and control over the home like private owners do. Harrison (2004) also noted how important home tenure was as a factor to test in context, as this impacted the power over home decision making. It will require the coordination of each First Nation to generate the collective will to prioritize and push AANDC and CMHC to create and implement visitable housing policy for all social housing that is provided to First Nations. I suggest starting with CMHC social housing considering that CMHC has already partnered with CCDS by funding home visitability research in urban centers in Canada.

The data in this study strongly indicated that for a Beecher Bay or Esquimalt home to be considered visitable from the perspective of the participants, this design phase must also include at least one bedroom for overnight visits and ensure that the accessible washroom has a walk-in shower or bath.  The visitability criteria would also still include: a no-step entry, and open doorways and living spaces, with the new addition of one accessible bedroom, and a bath or shower in the accessible washroom. These additional criteria would both support the improved quality of life for family, friends, and the participants who themselves struggle to access upstairs bedrooms. These additional features would eliminate the risks associated with people with disabilities being forced to use the stairs to get to the washroom or bedrooms upstairs. The goals of the home visitability movement projects like the Visitability Task Force (VTF) I participated in were to promote visitable housing and raise awareness about visitability to those living with disabilities and seniors, and to better understand the role that building policies and practices have with regards to the real life impacts and barriers experienced by home occupants (CCDS, 2013). While there is a literature gap and no example of a cost benefit analysis in the context of reserve housing, the rate in which the housing stock is degrading is noteworthy, with almost half of the homes on reserves in need of major repairs (Auditor General, 2011). The Auditor General (2011) reports that this is happening because homes are neither being built well, nor being well maintained. The effects of overcrowding and a general housing shortage make a strong argument for the overall improvement of home design and construction practices on reserves. Instead of aiming to build as many homes as possible, a goal might be to build a home with the highest universal utility to as many people as possible, over the life span, starting with CMHC funded social housing. The findings from CCDS (2013), Maisel (2006) and Truesdale and Steinfelt (n.d.) consistently indicate how planning and careful design of visitable homes would mitigate the need for expensive renovations later –saving individuals, the community, and government resources. The needs for a context specific definition of home visitability might hinder the universality or standardization of building standards, but while the findings in this study should not be generalized to every community, the future of First Nations housing policies must be based on the assessed needs and wishes of each community.

## Physical barriers

For the purpose of this study physical barriers included any obstruction that impacted the mobility of the participant, and was included in the one-on-one interview. The only physical barrier that was consistent through both group sessions as well as the interview sets was the negative impact that the stairs had on the quality of life of participants and their families. Regardless of whether the stairs were a barrier to entering the home, to getting up to the main floor, or to the bedrooms that were usually on the top floor, stairs mattered a lot to everyone. Several participants shared experience of falling, or carrying family members up the stairs, as well as being restricted to visiting outside the home due to inaccessibility. Hwang et al. (2011) found that by reducing physical barriers for an elderly population, their functional independence increased, and costs were saved as they were able to live at home longer. Although my sample provided a range in ages, only three were in their thirties and forties, and their housing needs may be very different than those more elderly. Wilson et al. (2011) looked at elderly Indigenous Canadians and argue that they face unique challenges and that their needs have not been focused on enough in policy. My study results clearly showed that the stairs were a health and safety issue for everyone. For example, it would be impossible to get a home support agency to administer care in a home that put both the client and the worker at risk of fall or injury, or that required someone to lift, push, or pull anyone on the stairs. The one visitable home in our study was Ellen's, and she noted that even with the three visitable housing features that she was unable to collect wood on her own to heat her home because of the stairs to the basement, leaving her dependant on assistance. For the community members that are less likely to go out or to participate in a study like mine, it is also important to remember that the community members that are most isolated may experience the most barriers (Wilson et al., 2011), like Maria's mother-in-law Amy who felt she was in jail, unable to leave her home unassisted. It is also likely that those most isolated community members have the least access to social capital. Stairs were the major physical barrier most responsible for putting the home resident, their family, and care-givers at risk in the home. Considering the ample body of research on the social and economic barriers, I am amazed I was unable to reference any study about physical barriers in a First Nations setting. Even internationally, barriers are an issue in need of prioritization. Participants unanimously agreed that stairs impacted quality of life daily. For these families, the visitability design features with an accessible bath or shower and the addition of a bedroom on the main floor would remove the need for even the most mobility challenged home occupant to put themselves, or others at risk in this way, and would reduce the disproportionate number of First Nations people who become disabled through falls and injuries associated with stairs.

## Community Infrastructure

Literature from Wilson et al. (2011) Adelson (2005), Kelm (2001), Senese and Wilson (2013), Kendall (2012), and de Leeuw et al. (2012) all argue that colonialism continues to inform land politics, as is visible in inadequate community development resource allocation. Gibson et al. (2011) note housing is an upstream determinant of health, the housing crisis in communities is a health crisis, and that studies must consider the area characteristics as I have with the community scan.  Both Gibson et al. (2011) and Harrison (2004) discuss area safety in addition to internal physical housing conditions. The ways that community infrastructure has impacted the visitability and overall utility of the participants' homes were identified differently by the communities. In semi-rural Beecher Bay, participants really emphasized the issue of transportation, but as it related to obtaining safe rides or the desire for accessible public transportation, especially the desire for the B.C. handyDART service, which offers flexible rides to those persons with disabilities (PWDs) designated by the provincial criteria. The lack of the B.C. transit bus option due to the Band's choice or inability to pay for the necessary levy, is an example of a disconnect between the Band Council and developmental opportunities for community infrastructure, which indicates an issue with financial SIR (Mignone, 2003). The lack of transportation options significantly shows how desperate community members felt, forcing some people to feel dependant on others for rides, while others choose to hitchhike or become obligated to pay an inflated gas fee, as in the case of Maria's mother-in-law Amy. Indigenous women are particularly vulnerable, especially those who are physically restricted. Maria and Ellen could drive, and mentioned often that they provide rides on good days, but shared feeling stuck on bad days when people depended on them for rides and they were in need of rest themselves.

Another result specific to Beecher Bay was the concern of respondents about the lack of emergency preparedness. On the west coast there are large windy spells that regularly take down power lines, but on the Beecher Bay reserve there is neither back-up generator power, nor a system of checking in on the most vulnerable. The community has unreliable cell phone coverage, and if the phone lines are out there are few other options. In addition, the combination of poorly constructed drafty homes, windy weather, and unreliable power means many use wood stoves. The use of wood burning fires is a great back-up, although the poor home maintenance can generate fire hazards, and the need for help with collecting and applying firewood. This is further exacerbated by the lack of a functioning volunteer fire department at this time (CMHC, 2013). The CMHC (2013) reports that reserve homes have twice the rate of incidence for fires due to the insufficient infrastructure, and that only 28.5% of reserves have fire protection at all. An important finding that came up in the final group session with the Beecher Bay group was that their youth are generally not being encouraged to participate or invest their energy in the community, so the only two members of the volunteer fire crew are older and getting less able bodied. The combination of inaccessible homes, unreliable phone lines and reception, lack of back-up power source, and incompetent and incomplete volunteer fire crew poses a serious risk to Beecher Bay's most vulnerable. Of the themes under physical safety, community infrastructure revealed how rural communities are most vulnerable because of the lack of safety measures, communication and transportation systems, and how much more this makes everyone dependant on relationships to overcome these barriers.

In the more urban setting of Esquimalt, the community has access to a bus system, but the road to the closest bus stop is so steep that a wheelchair could flip backwards or slide, so most cannot roll up Thomas Road to Admirals Road. Thomas Road also has major speed bumps, and the community’s need to reduce road traffic speed may be prioritized over the utility of the road for people with mobility limitations. The speed bumps, lack of sidewalk, train tracks, and steep road to the one bus stop create a situation where participants like Sheila are putting themselves at risk of falls and injury on a daily basis, or opting for rides that reduce independence. Other features, like the need for better lighting in the community to prevent crime, and a pedestrian controlled cross walk to cross Admiral Roads, would make the biggest impact for families. All four participants felt insecure as pedestrians in their community. This was related to poor lighting combined with high crime, lack of cross walk on Admirals Road, poor visibility, and insufficient maintenance on roads and trails.

Both communities had issues with the shared buildings being poorly planned for usability for people with mobility challenges, and with the lack of fire escapes. Even the new Esquimalt Band Office had two flights of stairs and no elevator. As the Auditor General (2011) reports, housing shortages have been reported for decades, and of the homes that do exist almost half are in need of major renovations. The reserve housing stock devalues at a faster rate due to substandard building practices, poor quality building materials, and inadequate maintenance. All of these infrastructure points were essential to the overall community assessment, and painted a bigger contextual picture of the decreased opportunities for improvement to overall community mobility. These inadequacies also show how families and communities are impacted by the lack of clarity around specificity of AANDS's legislative responsibility for housing, which is further complicated by resource shortages and administrative barriers both within First Nations, between Nations and AANDC, and between government jurisdictions (Auditor General, 2011).

Imrie and Thomas' findings (2008) emphasize how urban planners too often neglect to include the preventative measures which are responsive to the needs of people with physical impairments, and in so doing further disable them and exclude them from society. These issues of excluding marginalized groups from community planning and policy development sit at the intersection between where classism demotes some to a lower socio-economic status determining access to opportunities for skill development, status and power, and ablest values that normalize creating communities based on the needs and priorities of able bodied people, despite the inevitability of impairment over the lifespan. Also piled onto this are the socially constructed barriers associated with the racist policies on which the reserve system was created. Because the complexity around the development of community infrastructure depends not only on the voting members and priorities of communities, but the administration of resources between jurisdictions, the planning for accessibility over the lifespan needs to be considered a given at every stage of policy and planning. While there is a lack of research that specifically looks at the impacts of reserve infrastructure on the lives of First Nations with physical challenges, Harrison (2004) shows how improvements to urban planning policies are best done when they are actually tested in the real socio-economic environment. Harrison's research included important factors, such as the critical role of autonomy and control over decision making and home tenure, as well as the accessibility and availability of important institutions.

### Home maintenance

The CMHC and AANDC have an interest in incentivizing First Nations to maintain their homes, but lack the understanding that the community housing reality requires a deeper inquiry. Home maintenance is complex and dependent on the quality of housing stock, type of home tenure arrangement, and the governing Band housing policy. The Auditor General (2011) argues that the disconnection between First Nations and AANDC has resulted in four key issues. Home tenure options on reserve are complex, as the Crown is ultimately the holder of the land, meaning that options for securing financing for building or improving a home is tied to getting a Ministerial Loan Guarantee through the Band (CMHC, 2013). The first connection I made between home visitability and home maintenance was last spring in May when I visited the communities for the first time. Home maintenance was a hot topic that came up in every interview and group session and related to all three of my research questions. Maria discussed how poorly her mother-in-law’s ramp was both built and maintained, and I observed that not only was the plywood ramp and staircase into the home rotting, but the slope was dangerously steep, and there was a soft spot on the patio which would not hold weight. This example points to several issues, first that there is a strong relationship between the maintenance of a home and the visitability of a home, and second that home maintenance support and funds are dependent on the kind of home tenure. Collectively, these issues build community resentment and directly isolate the home resident. There are several components to designing and constructing a home with the accessibility features that work for communities, but all will fail without upkeep and regular maintenance inside and outside of the home (CMHC, 2013). In Amy's situation her home was passed down to her from her father, who she had cared for in the home until he had died. Because the home is not owned by the Band, she is neither eligible for Band funding for home maintenance, nor a RAP-D grant to renovate her patio, entry ramp, and stairs. Neither she nor her family can afford to do this large renovation, and Ellen and Mary both expressed displeasure with the policy that creates a disincentive to home ownership for someone who is poor or physically unable to do this kind of work, as it is often the case with Elders who have a home in their name. Often Band housing policy allows for homes that are owned to be passed down to next of kin, so although it is a gift, an owned home in poor repair may become a financial burden or a health and safety issue for the person who inherits it. The essence of what the findings indicated was that the interconnected quality of home maintenance as a theme shows how the development of visitable housing policy is not enough if there is no support and maintenance policy to ensure that these features are protected for the safety of home residents.

Another aspect of home maintenance also showed some confusion within the community with regards to what is included in maintenance for Band members. This leads to misunderstanding and even resentment between community members, which links this to the community relations theme. The interview and final member checking session data confirmed that negative social interactions were usually related to home tenure because of lack of access to maintenance support. Ken talked about his experiences being perceived in the community as an able-bodied man who took great pride in caring for his home. He tried not to show his pain and wanted to be stoic, and although he was waiting, eligible, and in need of maintenance support, but he was left to his own devices as a man who was assumed fit enough to do his own work. Ken's sharing of community perceptions included experiences of discrimination from community members because of his non-native blood, and jealously over his car and groomed yard and experiences of racism from non-native community members when he was seeking employment off-reserve. Home maintenance is connected to quality of life. As a person is more restricted in the home, they are also less able to take care of their home. In turn, the poorer the home maintenance, the bigger the barriers become. Carpets, cracks, and step lips all commonly cause falls, whereas issues with plumbing can become a problem of sanitation and public health. Maintaining the home usually includes the inside and outside of the house, the yard, and the infrastructure that is linked to the home functionality.

With the complex variations on home tenure, problems with home maintenance came out of the data as a key finding, but one that was difficult to define. Depending on the home, if it is considered social housing, individually owned, communal housing, or general Band housing, one may or may not receive funding directly budgeted for home maintenance (AFN, 2010). Maintenance funds are not given for homes that are paid off, and at that time the occupants may become responsible for doing or paying for the work needed. Ellen, Ken, and Maria talked about observing the maintenance funds having been received in the Band accounts, but that often the money was considered of higher priority elsewhere, and was not necessarily spent on maintenance at all. This competition and negativity is the consequence of insufficient resources for housing overall. The politics around who gets a house, a renovation or maintenance gets politically divisive in a small community (Wilson et al., 2011). Depending on the type of home tenure, community culture, and the administration of the Band housing policy, the avoidance of necessary internal or external maintenance of the home can also jeopardize the rental agreement. In this way the community members who are unable to care for their own homes and need to have maintenance support to both keep them safe and housed.

## Social Capital

An important early finding that emerged for me was that study participants did not particularly identify as disabled individuals, but rather, they talked about their experiences in their homes and communities as strongly tied to family roles, community participation, and collective responsibilities as members of their Indigenous community. This was a fundamental finding that supports and draws on intersectional theory, and can be positioned under the umbrella of social constructivism. I have used the concept of social constructivism only to provide a very broad tool of analysis for better understanding the layers of society – from families, communities, to the larger city of Victoria, and also to the federal level – as a learning experience to complete the research, and also to compassionately understand the complex ways that the identities of the participants interact and create multiple forces of discrimination. Most relevant to this topic are race, gender, class, and ability. I am drawing from the social model of disability, but for the duration of the discussion will consider the social model of ability, due to the lack of cultural relevance of disability for the participants.

While my research questions were strongly focused on conducting an evaluation on the environmental conditions inside the home and in the community, the second research question aimed to evaluate the level of social supports or barriers, as these impacted participants' overall quality of life. The photos captured the design features, but these features became important to participants because of how they represented their relationship to family and community. As previously described, my major theme of social capital was the most intrinsic of all the themes, as it contained and included the division of the socially constructed themes from those that were structural and visible. I do not want to impose all parts of the theoretical construct to this discussion because as a late addition this construct was not checked within the member checking session. Social capital captures the multidimensional social assets, processes, and gaps in communities. The themes that the participants verified were reciprocity of support, community relations and band administration, with community relations and reciprocity falling under the component of culture (Mignone, 2003). The complexity around the last theme of Band administration makes it fall under the component of socially invested resources. I did not define for the participant's terms like quality of life, person with a disability, First Nation, or any other term other than visitability, as this was new to some of them. They had the freedom to organically come to the ideas that they did. From the data, quality of life was obviously tied closely with community connectedness and overall physical safety.

### Reciprocity of support

As I have discussed in the home visitability section, individual participants' homes were very important with regards to their overall safety, but the data also indicated how the visitability of the home held value for its ability to connect the participants to their families and communities. The mobility within the home and community increased opportunities for independence and participation with family, for example as a care-giver, and these produced positive relationships, self-concept, and identity in general. Despite different levels of community infrastructure and unique community characteristics, the theme of reciprocity was universal between communities and participants. What was most interesting to me was that this care flowed in both directions, though not necessarily at the same time in life, which showed a shared culture of reciprocity between communities in the dimension of bonding.

This give and take often compensated for gaps in infrastructure or physical barriers that might otherwise have made a bigger impact. An important finding on reciprocity was that it was tied to trust, given that the giving and taking would not necessarily happen simultaneously. For example, whereas I heard participants share fears of community insecurity, I also saw evidence for human SIRs. Ellen, Maria, Colin, Jen, Carol, Sheila and Betty all brought this up in different ways. Reflecting on Mignone (2003) these investments by the participants into their children, grandchildren, and parents produces a kind of social credit that can compensate for many of the service and infrastructure gaps in communities that would impact them more in the future, like getting rides. In addition to helping reduce barriers, this norm of reciprocity could also fill in gaps that are the result of other dimensions of oppression, such as impacts of poverty and sexism with regard to gendered expectations of care-giving and the larger systemic inequalities stemming from systemic and violent racism.

The relationships between community members was the highest priority for the participants. I was shocked to see that the two themes of reciprocity (of care) and community relations actually were found within the dimension of bonding so tidily under the component of culture. Of the four components, trust and norms of reciprocity were of the highest priority to the participants. The investment that the participants made within their family and community was reciprocated through the care they received. An important observation that could not be described by my study methods was that there were varying degrees of how this reciprocity was balanced. For example, older and more physically limited participants could not reciprocate in the way that younger and more able-bodied participants could. An example of this came from Colin and Jen. They are relatively young, in their thirties or early forties with older kids and teenagers. Both parents have degenerative diseases, and the trajectory of how their care is reciprocated will change over the next decades, with the kids shifting from helping with light housework to either taking on the majority of the household chores in exchange for room and board or using their skills to manage or coordinate home support for them. Reciprocity of support importantly mitigated the risks associated with all unsafe home and environmental conditions; therefore, it identified those less connected or more isolated as more at risk in general. The participants who lived in a full house may have been crowded, but they spoke about their families and homes positively, and it was obvious that the role and responsibility they had in their family was tied to their positive self-esteem. Additional minor themes that I organized under social capital were Band administration and community relations, both of which can be potentially assistive or barriers.

The value of family and community relationships cannot be emphasized enough, and was one of the most important findings in this study for future social housing policy and on-reserve home support. I had a hunch that the need for social supports would be big, but the degree that this system mitigates the risks was surprising, and obvious by the comparison of those who did not have as many options, like Heather. The key process was the exchange of social support between the participant and their family members, a theme I labeled reciprocity of support. Only Heather lived alone. Ken, Ellen, and Maria’s mother-in-law Amy lived with their life partners. Ken reported being in a caregiving role, and called himself a caregiver, also noting that this was the extent of their relationship now. Ellen and her partner live in their visitable home that allowed her to care for her mother, who suffered from dementia, for five years; and more recently her grandchildren; and in the future, her partner following his expected surgery. Amy does not care for anyone as she is dependent on Maria for daily support with her personal care, meals, and rides. This reciprocal exchange of social support was woven throughout the interview conversations with everyone. Colin, Jen, Carol and Betty all lived in a small home with six family members, and while all four reported that their kids and adult children took responsibility for the care of the home and cooking, Betty, Colin, and Jen were in strong caregiving roles. This was exemplified in some excellent ways from the interviews.

Some values that I heard as universal across both communities, and that should be understood here, are that kids and adult children are welcome to live in the home if they need to, women are expected to be caregivers, and that family members forgive and help one another, even if that means someone sleeps on the floor. The reciprocity of support is familiar to me, as I recall it in my childhood. Whenever my father shot a moose, we gave away a leg to anyone who helped with the packing and cleaning of the animal. Also, members of the community who were not able to hunt, or were elderly were always brought meat, and if they tanned hides, the skin. Reciprocity and generosity is valued in many First Nations cultures, and it is also expected.

## Community Relations

Community relations was a theme that was not only described in stories about wanting and needing connections, and not just help, but also contained data examples that showed disconnection and in both communities, a large degree of distrust. Using Mignone's (2003) construct of social capital, this theme also falls under the dimension of bonding. The lack of connection between the participating communities, as well as others locally was noteworthy in this study. The strengths of the community relationships were discussed under reciprocity of support. The community relations theme reflected some community social issues, described by participants as experiences of distrust, fear, inertia, and lack of control.

Under this theme the components of the social capital framework that are most relevant are human and financial SIRs and cultural norms of trust, participation, collective action, and reciprocity. I have adequately identified the norm of reciprocity as an imperative strength that makes up for many social issues and structural inequalities in the community. I found it interesting that while on the one hand participants like Ken, Heather, Betty, and Sheila commented on frustrations with community crime, gossip, and leadership corruption that the discussion moved on quickly to center on how to improve the community from a positive perspective. Reflecting on both communities, I observed another difference. Through the colonial history and families' histories, participants showed how animosities have been passed down through communities. Stories about community inequality, injustice, and greed were also expressed in both communities, yet this was not linked to names, or specific leadership. Rather, it was acknowledged as a reality that needed the will of the whole community to overcome. I also considered the willingness of community members to voluntarily participate in a study that involved an unknown researcher from an unknown university, and to also show openness and an eagerness to improve the collective quality of life.

## Band Administration

My third research question collected data on the environmental conditions in the community. The combination of home visitability and infrastructure brought in the need to consider the role of the Band council in the quality of life of the community. As a theme this was placed under social capital because of its link between formal institutions like AANDC, CMHC, and commercial banks, as well as participation with Indigenous organizations, and choices around community development (Mignone & O'Neil, 2005). Band councils are not traditional forms of governance, and Ellen and Maria spoke at length about this at the final member checking session. They, like the participants from Esquimalt, recognize the potential for their elected Band council to work on their behalf. Applying the construct of social capital has powerfully helped me deepen my understanding of the collective experiences in both communities, and also explained why there were some major differences. Recalling that there are three dimensions, bonding (discussed under the themes of community relations and reciprocity) bridging, and linking, without this third question, I would not have ground to include the larger political context that plays a major role in the quality of life of the participants. The data did not adequately capture consistent or meaningful evidence that could identify the organizational culture or social capacity of either the Esquimalt or Beecher Bay Band administration. The data made sense with regards to the dimension of linkage of the Band administration between the communities and formal institutions, with the components of SIR, culture, and network playing a part (Mignone, 2003).

Using the social capital framework, each community's Band administration had potential to aid in the accessing of all five SIRs. Of specific value to this subject are those of physical, as in more housing stock, visitable Band housing policy, sidewalks, crosswalks, lighting, curb cuts; financial, by getting access to funds for major renovations and adaptations, or credit for fees such as the transit levy; and investments in the human resources of the community. Between the communities, much of the findings were similar, but in the area of community infrastructure this was not the case, and was potentially the only indicator for variances in the linkage capacity of the communities. For example, in Esquimalt, the Band housing administrator reports that of the six people living on reserve, all six are living in inaccessible housing and have been denied RAP funding, some several times

(Rose, 2016, personal communication). The reapplication process continues with the involvement of both community members and housing administrators; however, although these barriers are predictable, they require the precise language that will fit with the CMHC eligibility criteria. The disconnection between AANDC and the communities trying to access programs, resources and services is an on-going historical pattern (Senese & Wilson, 2013; Kelm, 2001).

More than any other dimension, this gap is clearly linked to the history of colonialism and fragmentation between Nations, other communities, and both public and private institutions that all have a role in the overall access to increased opportunities for support, reduction of barriers, and further development of community infrastructure. The historical context and the generations of physical and social unsafety can be understood through the intersectionality lens, where racism, sexism, classism, and ableism interact, and at different times have played a major role. The structurally racist policies that emerged from the Indian Act, like the continued existence of the Indian Reserves, are observed through the long term insufficient investment into the infrastructure on Canadian reserves, and have created communities with economic inequities (Adelson, 2005; Alter et al., 2011; Wilson et al., 2011). With the release of the Truth and Reconciliation Report (2015), and a planned inquiry into the many murdered and missing Indigenous women, Canadians are obligated to be aware that it remains dangerous to be Indigenous. The statistics tell a story in which the first peoples are more likely to become disabled due to trauma and violence (Durst et al., 2006). The research I conducted strongly underlined not only how unsafe the participating community members felt in their homes, but how important this was to them as a focus for future community improvements.

The structure and organizational culture within the Esquimalt and Scia'new Nations Band Councils were not specifically a component of my research, but results showed how much power the Band had over housing decisions, and how the control is not always balanced in communities. The Band administration has high potential to create housing policy that is based both on the needs of its members, and follows the administrative requirements of the Government of Canada. Despite the control that Durst et al. (2006) argue that First Nations have, the voices of disabled First Nations are not heard within the community governmental processes. The varying levels of political organizations have unique administrative processes, and barriers which are equally as unique.

# Chapter 6: Conclusion

This study explored two communities with a Photovoice method style of data collection to allow participants the opportunity to capture and share about their living conditions in the way that they chose. Photovoice proved to be powerful as a method, as it was situated in principles that genuinely give participants the control over creation of meaning and the verification of my later interpretations. By using photography, my research approach was deeply contextual and gave community members the opportunity to both locate and learn about themselves and their needs, and articulate them in a safe way. The key goals encompassed within the application of Photovoice are that it first emphasizes the participant's experiences and validates the corresponding interpretations, second develops the collective knowledge of the participants through group process, and thirdly provides an avenue for influencing policy change through the translation of the photographed experience (Lal et al., 2012; Sutherland & Cheng, 2009). The first two goals have been achieved through this study process, demonstrating the priority of both the vulnerabilities and challenges associated with issues of physical safety and the impact that the access to and availability of social capital has on the quality of life of the Scia'new and Esquimalt participants. The third goal is only beginning to be addressed, as this will require the will and coordination of several stakeholders and funders. The action on policy change is complicated because this needs to be done at the community level, by the communities themselves, but I am willing to support this if desired. I have and will continue to seize any opportunities for sharing the findings in various venues, possibly with participants, as well as publishing wherever possible. I plan to seek research funding for a larger study done at the community level with Indigenous researchers. This study makes a clear argument for further inquiry in several areas, most of all for the need to include the most marginalized people in the decision making that impacts their daily lives. I have been strongly influenced by the work of Tuhiwai Smith (1999) and Brown and Strega (2005), as well as many of the Indigenous people in my life, who have reinforced that the research process is always more important than the outcome. The fact that the research participants now know who I am, and that they want to work together again, was a priority to me.

The rationale for visitable housing is undeniable, but it must not be assessed out of context. It is practical and could work to alleviate many of the current housing pressures experienced by First Nations communities, while also saving health care funds (Hwang et al., 2011), and holistically addressing some of the upstream determinants of current health disparities (Gibson et al., 2011). As the anticipated aging population bulge looms, so does the rising costs of health care, making a strong rationale for the visitable housing movement. The evidence is even stronger for First Nations communities, where AANDC, CMHC and Band councils are planning and constructing new homes with little consideration to the overall life span of the home, or the utility of the home over the lifespan of the occupant and their family (Auditor General, 2011). Having safer homes and communities in turn would prevent illness, disease and injury, and would simultaneously improve access to and opportunities for investment in the social capital of communities by creating healthy living conditions for the long term. In an era where Indigenous rights and title are constantly being revisited with an on-going reorganization of State and indigenous relations, cost effective and practical housing remains an issue that falls outside priorities for Band councils as well as the federal government. Housing is an issue that falls between the jurisdictional cracks in that the *land* question is tied to housing, and is deeply complex, politicized, and requires community based organization and negotiations.

The housing crises of shortages of stock and deteriorating homes also indicate that there is a need for a new approach to the planning, administration, and construction of reserve housing (Auditor General, 2011). Designing better homes with adequate ventilation, space and visitability features would serve families across the life span (Auditor General, 2011) and be cost effective by reducing health related costs associated with injuries or out of home care (Kwang et al., 2011; Wilson et al., 2011). It is important to me that this study was initiated in partnership within community, especially considering that this proposed study is the first about home visitability on *reserve* housing. As the federal government allocates funding to First Nations communities for additional infrastructure and housing stock, there is a need to insist that CMHC develops its own visitable housing policy for all new social housing dwellings. These homes are provided to the most vulnerable community members, and as State funded homes must be obligated to offer safe and inclusive places with the greatest potential utility for any potential occupant. Also this policy push could come from CCDS considering that CHMC has funded past visitability related research off-reserve.

At the June 2015 First Nations Summit Meeting in Vancouver, the visitability housing resolution was presented by Rosie Holmes who was the chair of our then active Vancouver Island VTF. When our resolution was passed, this indicated a profound interest and support by other First Nations in British Columbia. The study results have the potential to greatly benefit, and give leverage to the local nations who could take on a leadership role for other Nations by developing culturally appropriate visitable housing policies, and share the lessons learned through this process with others who may be interested in doing the same.

I hope to work to promote and present on visitability wherever I can, in a multidisciplinary approach, and with participating communities if they are interested. Following the completion of my degree, I plan to share a research summary with the communities and BCANDS. The scope of this study was small, with a sample size of nine. The methods employed do not claim to be generalizable. Rather, this research provides an example of a research approach that can help inform future and larger scale studies to come. Research participants were identified and recruited through the Band administrator which may have worked to encourage or discourage recruitment in each community. Some of the potential participants who could have been hardest to locate and include may have not been invited, or may have been unable to participate. Because I did not want to impose any kind of label or specific health related criteria to avoid the deficit model of disability, and to encourage the exploration of the social model, I likely have missed opportunities for collecting medical and demographical data that other researchers may find essential for future work.

At the time of the original proposal both community housing administrators had intentions of developing visitable housing policy as part of the goals of the visitable housing taskforce. After the task force dissolved, the plans were pushed back due to higher administrative priorities, but visitable housing has been enshrined into the Esquimalt Housing Strategy, (Rose, 2016, personal interview) and have been recognized at the 2015 First Nations Summit. In Esquimalt, the study participants had been regularly exposed to the concept of visitability, both due to the small nature of the community and because BCANDS is twenty feet from the Band office. The band administrator sat on the task force from its conception, and attended most meetings, whereas the Beecher Bay housing administrator was replaced part way through and community members were even unaware at the time of what

BCANDS was. The differing awareness of the topic required different skills from me as a researcher. Some of the differences between the communities might have affected the methods as well as the findings.

I also spent time clarifying misunderstandings about my role as researcher. I reiterated my inability to fund housing renovations, and identified myself as an independent researcher who is held to specific academic requirements for the completion of my degree. I selected methods that were founded in participatory action research values that supported community leadership, autonomy, and participation, and that recognized the social construction and intersectionality of race, gender, and disability. The influence that my own social position had on this study is important as I turned the intersectionality lens onto my own life and work in this project. I was not able to truly decolonize my research methodologies, in that my relationship with the communities and the constraints of the political realities that impacted this research reinforce the degree in which colonialism is pervasive through the administrative barriers reported in both communities. This study could not follow the PAR principles, as I needed to fulfil thesis requirements in a shorter timeline, as well as develop the skills required for doing ethical research in a community setting. The participants did not have the opportunity to design this study or chose how the findings are shared, nor as Chataway (2001) muses, were they given the opportunity to study my community and social location. While I invited the input of my study participants with regards to research the research process and verifying the data, the participants did not have an opportunity to develop or influence my research questions.

Finding and applying the appropriate methodology has been my biggest challenge. For example, at the start of my research I thought concepts like critical race theory and postcolonial theory would be helpful and potentially supportive, but over time I realized that they were not on target, whereas the concepts of intersectionality and social capital fit my topic. While I refer to and borrow from social capital research, I cannot use this fully or comprehensively. This is a western research concept, and a term that has been tested and applied in only a handful of small communities in northern Manitoba. As such, the people here in B.C. may not find it a fit, relevant, or complete. While I have applied this conceptual framework to the communities of Esquimalt and Beecher Bay, I recognize that neither community had the opportunity to buy into or define social capital for themselves. There is ample evidence that promotes the stereotype of the victimized, troubled, and diseased native, but this narrative has not been carried by Indigenous voices. Families have survived and are holding on to their beliefs, languages, songs, stories, and dances, and becoming more and more active as leaders on their territories. As the aging population continues to grow and indicate preferences to “age in place” (CCDS, 2013, p. 4), people living with permanent physical restrictions and support needs must be accommodated within their homes and communities for as long as possible. The alternative is the continued institutionalization of indigenous bodies, cared for by unfamiliar professionals in long-term care facilities far from their communities (BCFNLC, 2005). In addition to the most obvious personal benefits from maximizing one’s autonomy, there are also significant economic and social advantages. Visitable housing policy with sufficient resources to support it could positively impact those living with disabilities, as well as the community as a whole, support intergenerational living, and keep First Nations from moving unnecessarily into costly formal care settings. Housing design directly impacts the level of function of an individual living with a physical limitation, and potentially enables those living with disabilities to stay in their homes longer, while also improving their quality of life (CMHC, 2003).

The highly politicized nature of reserve housing and its exclusion from health care policy shows how housing must be included in comprehensive health policy that relies on a contextual and holistic understanding which includes the lands, histories, and peoples for which it delivers services. The three research questions on visitability, supports and barriers, and community infrastructure worked well together to provide a broad environmental assessment of the how well the homes and communities' accessibility impacted the daily needs of the Scia'new and Esquimalt participants. The results showed that the original definition did not adequately fit the environment, where the inclusion of additional features such as a bed and bathroom with a shower or bath made it possible for either a visitor or the participant to stay on the main floor and manage hygiene without being forced to navigate dangerous or impossible stairs. Like the mainstream version of visitability, our definition could strongly increase access to the social capital for both the participant and their family. Our definition of visitability also needed to acknowledge the connectivity of the community through family ties, rather than only considering the individualized person with a disability. In fact, another major finding was that the participants did not identify as people with disabilities, but as members of their family, both for giving and receiving care. This fits well with this study's overarching theoretical assumption from the social model of (dis)ability: that one is only as disabled as their environment makes them. In the case of this study, the three study questions focused on the physical environment, yet the inclusion of the second part of my second question generated data on social supports. This was essentially the heart of what was protecting the participants from the risks associated with their unsafe home and community characteristics. That this was captured in the theme called reciprocity of care was key, as this depended on the internal family relations, as well as the whole community relational climate, including connection to other First Nations, organizations, and the competencies and priorities of the Band. The Band, or other existing governance bodies' ability to navigate within its own community as well as with others at the macro level points towards future opportunities for better connections and communication. Increased access to internal social capital capacity could provide the ideal climate for a comprehensive shift in reserve housing. This study generated evidence of a need for a larger and more comprehensive mixed methods study that communities could voluntarily conduct themselves with chosen Indigenous researchers and community leaders to better inform their own Band housing policies.

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