

Indigenous Self-Determination in Health in Guatemala: Lessons from Chile and Canada

by

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Bachelor in Biomedical Sciences, University of Guelph, 2014

Master's Project Submitted in Partial Fulfillment of the
Requirements for the Degree of
Master of Public Health

in the

Faculty of Health Sciences

Faculty of [Name]

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SIMON FRASER UNIVERSITY

Fall 2016

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Date Defended/Approved: December 6th, 2016

Abstract

As a response to the poor health conditions that indigenous people experience worldwide, indigenous groups in many countries have demanded increased autonomy and control over health care in hopes of developing more accessible and responsive health services. The purpose of this work is to explore factors required for self-determining indigenous health systems, and consider whether these would work in Guatemala. To accomplish this, a review of the literature was conducted and two examples of indigenous self-determination in health from Chile (Makewe Hospital) and Canada (NAN's Crisis Teams) were selected. The formation and implementation process of these initiatives was analysed to identify factors that enable indigenous self-determination in health. Factors that would be feasible to replicate in Guatemala include strong community involvement in organizing health care, revalorization and revitalization of indigenous knowledge and culture, leadership capacity, flexibility, and integration of Western and traditional medical systems.

Keywords: self-determination in health; Guatemala; indigenous health systems; health inequality; indigenous health care; ethnicity and health

Acknowledgements

I would like to give special thanks to my senior supervisor, Dr. Nicole Berry, for her time, patience and invaluable mentorship throughout my time at SFU. It was such a pleasure and privilege to learn from the insight and wisdom you shared with me. I would also like to acknowledge the assistance and guidance of Dr. John Calvert. I am very grateful for having the opportunity to discuss my paper at length with both of you and thank you for the thoughtful questions during my defense and invaluable feedback on this paper.

Thank you to the Faculty of Health Sciences staff and faculty members for their assistance throughout these two years at SFU. Lastly, I would like to thank my family and friends for their love and support.

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List of Acronyms

CT	Crisis Teams
FNIH	First Nations and Inuit Health Branch
IA	Indigenous Association
NAN	Nishnawbe-Aski Nation
MoH	Ministry of Health
PROMAP	Programa de Salud con Pueblo Mapuche/ Health Program with Mapuche People
SSAS	Servicio de Salud Araucania Sur/ Health Service of South Araucanian Region

Introduction

Indigenous people world-wide experience a disproportionate burden of ill-health compared to dominant ethnic groups (Lavoie et al., 2010). Colonial and post-colonial policies as well as a history of marginalization have eroded indigenous peoples' cultures, languages, and social structures, and have led to widespread social and economic marginalization (Lavoie et al., 2010). In Latin America and the Caribbean, indigenous peoples are some of the most marginalized groups (Montenegro and Stephens, 2006, p.1859). They experience higher mortality and morbidity rates than non-indigenous people. They are also more likely to be poor and lack access to education (Montenegro and Stephens, 2006; Ruano et al., 2014).

Latin America has achieved considerable economic progress and improvement of health outcomes; however, significant ethnic, generational, gender and health inequalities are still present (Castro, Savage and Kaufman, 2015). It is also one of the regions in the world with the highest inequalities in terms of income and wealth distribution (Popay et al., 2008). The richest 10% have incomes between 200% and 300% higher than those of the bottom 10% (Popay et al., 2008). Furthermore, between 1980 and 2006 the number of people living in poverty increased from 136 million to 205 million (Popay et al., 2008).

In Latin America, indigenous people experience multiple barriers to accessing quality health care services including physical, financial, cultural, and language barriers. However, discrimination in health care settings has been identified as a major barrier to accessing quality health care services (Castro, Savage, and Kaufman, 2015; Montenegro and Stephens, 2006; Ruano et al., 2014; Ceron et al., 2016). For example, in a recent study by Ceron et al., indigenous people from a rural community in Guatemala identified discrimination as one of their top three problems when seeking health care in the public health system (2016).

Researchers have documented a variety of ways in which discrimination impacts indigenous peoples' ability and willingness to access and use public health care (Ceron et al., 2016; Castro, Savage, and Kaufman, 2015). In, addition to the discussion above concerning connections between indigeneity and difficulties in receiving high quality care, indigenous men and women have also reported being subjected to longer waiting times based on ethnicity in Mexico, Peru, and Guatemala (Ceron et al., 2016; Berry, 2013). Experiences of discrimination and abuse have a negative impact on patient adherence, satisfaction, and willingness to access health services (Ceron et al., 2016). Additionally, sharing experiences of discrimination with friends, family, or neighbours further shapes the perception of individuals. For instance, Ruano et al., (2014) found widespread feelings of distrust towards the public health system among community members from two indigenous communities in Guatemala.

Numerous different types of responses have emerged worldwide to address the barriers that prevent indigenous people from accessing and utilizing public health services. For instance, in recent years, indigenous peoples in many countries have been advocating for increased sovereignty in health care in hopes of gaining more accessible and responsive health services (Lavoie et al., 2010). These efforts have gained momentum and support internationally. It is widely accepted by international organizations and many scholars that indigenous self-determination is a necessary step to improve indigenous people's health (Lavoie et al., 2010). The Harvard project on American Indian Development provides evidence that indigenous control of the health system has improved the health conditions of the Choctaw Nation people and other American Indian tribes (Mashford-Pringle, 2013). Scholars argue that indigenous self-determination in health is important to create culturally appropriate and responsive health systems that meet the needs of indigenous communities. Additionally, self-determination in health gives indigenous communities an opportunity to maintain and revitalize their culture and language (Mashford-Pringle, 2013). This in turn creates a sense of belonging with regards to traditional culture and community, which has been linked to improved health and wellness (Mashford-Pringle, 2013).

This paper will focus on initiatives that give indigenous people more autonomy and control over their own health care. The purpose of this work is to explore the factors that aid indigenous communities in achieving self-determination in health as a strategy to create health systems that are appropriate and responsive to their cultural and socio-economic needs.

This capstone has been prompted by my own reflections on indigenous health as a non-indigenous dual national of Canada and Guatemala. While health outcomes for indigenous peoples in both countries are dire, Canada has increasingly tried to address indigenous health through increasing indigenous autonomy and control over health care. This project is motivated by my interest in finding feasible examples of indigenous autonomy and control over health care, as well as exploring whether or not these strategies would work for Guatemala. To accomplish this goal, two examples of indigenous communities were chosen that have gained some level of control over their health care, one from Chile and a second one from Canada. The work first describes the formation and implementation process of each initiative, then proceeds to describe key factors that enable and those that limit indigenous communities' self-determination in health care. The second part of this paper provides a discussion of key opportunities and challenges that indigenous communities in Guatemala may encounter when striving for self-determination in health. This work is based on the knowledge I have acquired about the political, social, and economic context in Guatemala.

Methods

A review of the literature was performed from available online databases including PubMed, Google Scholar, EBSCO host, Medline, and Web of Science in Spanish and English. The keywords used for this search were the following: "indigenous health", "Guatemala", "Latin America", "discrimination", "intercultural health", "Aboriginal health care services", "Canada", "First Nations health". MeSH terms were employed in Medline to account for varied terminology.

The inclusion criteria for case studies were as follows: 1) articles that were published between 1980 and 2016; 2) articles about indigenous self-determination in health across countries in Latin America and North America; 3) studies about indigenous grassroots initiatives; 4) studies about indigenous groups living in isolated rural areas with little or no access to health services. Preference was given to indigenous grassroots experiences because grassroots initiatives provide opportunities for real political action from below. The Guatemalan government is known to invest very little or no resources into the health sector particularly with respect to improving the health conditions of the indigenous population. Therefore, it was given priority to those initiatives that started at the grassroots level and then advocated for accountability and support from the government, a process that indigenous groups in Guatemala would be required to follow if they want to advance their efforts in achieving self-determination in health. In addition, studies about indigenous groups that live in rural isolated areas with access to limited and low quality health services were prioritized because it is a context similar to what most indigenous groups in Guatemala experience.

The intention was to find experiences of indigenous self-determination in health across countries in Latin America and North America because it contributes to the dissemination and exchange of ideas and best practices. Only two examples were selected to keep within the narrow scope of this paper. The key words used above directed the search towards the article: "Best practices in intercultural health: five case studies in Latin America". From this article the Chilean case study was given preference because it was one of the most successful initiatives in terms of reducing barriers to access health services and it met the inclusion criteria. In terms of the example from North America, initially the experience of the First Nations Health authority was of particular interest, however, it was hard to compare it to the Guatemalan context and there is limited evidence of its success because it was implemented very recently. Studies on Aboriginal healthcare in Canada directed me to Ontario and eventually by reviewing the reference lists of selected articles the Minore and Katt's (2007) study on Nishnawbe-Aski Nation's Crisis

Teams in northern Ontario was found. Additional sources were obtained by reviewing the reference lists of selected articles.

Part 1: Examples of self-determination in health in Chile and Canada

Indigenous self-determination in health in Chile: The case of Makewe Hospital

Makewe Hospital provides an example of an indigenous group obtaining autonomy and control over their own health care by running a community hospital. The Makewe Hospital initiative is an important example of contractual relationships between government and an indigenous organization through an intercultural health model. Besides background information and implementation strategies, I will also describe the key aspects of this example that made it successful and those aspects that limit its success.

The information for this example was mainly obtained from the dissertation by Park (2006) because of the richness of the analysis she provides about the formation and implementation process of Makewe Hospital. There are several researchers that have studied the Makewe Hospital initiative and most of these studies have used a qualitative approach to their research. Therefore, it was given preference to Park's (2006) study because it used a mixed-methods approach and thus there are less methodological shortcomings. In Park's (2006) study a quantitative survey provided information about patient's level of satisfaction with Makewe Hospital while interviews with patients and health workers elucidated how patients and health workers "feel", "understand", and "react to" cultural differences, which influence the quality of health services (p. 34). In addition, interviews provide more detailed information about community participation in the Makewe initiative. It is important to note that heavily relying on only one source can be a limitation.

Intercultural Health in Chile

In Chile, 4.6% of the population is indigenous with the largest group being the Mapuche, accounting for 87% of the indigenous population (Park, 2006). Similar to other countries around the world, the indigenous population in Chile suffers from dire health conditions as well as social, political, and economic inequalities (Lincoln, 2015). Interculturality, a form of multicultural social policy, emerged in Chile as a policy objective to address the crisis of the public health system and the poor health conditions of the indigenous population (Park, 2006). Overall, intercultural health in Chile seeks to incorporate and integrate traditional medicine within the Western public system (Lincoln, 2015).

State goals on intercultural health include increased community participation, political legitimization and improvement of health services (Park, 2006). The state wants communities to take control of their own health issues with minimal state intervention. In contrast, communities seek to increase participation as an opportunity to recover political power, improve the quality of health services, and provide political recognition of their cultural rights. One of the demands from the Mapuche communities on intercultural health was to integrate Mapuche medicine into the Western medical system (Park, 2006).

Formation and implementation process of Makewe Hospital

Makewe Hospital provides an excellent example of intercultural health in a rural area. It is located in the territory of Makewe-Pelale in the municipalities of Padre Las Casas and Freire of IX region (Torri, 2012). It was founded by the Anglican Corporation in 1927, and since 1999, it has been under the administration of a local Mapuche Association (Lincoln, 2015). The Makewe-Pelale region is mainly inhabited by Mapuche people with a population of about 10,000 people (Torri, 2012). It serves approximately 70-80 Mapuche and non-Mapuche patients per day and has its own pharmacy which provides both pharmaceutical and herb medicines. Records show that in 2009 hospital staff consisted of about 44 people, including six physicians, one physiotherapist, a dentist, four nurses,

two midwives, six paramedical auxiliaries and service auxiliaries (Torri, 2012, p.36). Physicians attend the hospital three times a week and the rest of the hospital staff consists of a stationary team including midwives, nurses, auxiliaries, secretaries, etc., and an advisory team which includes Mapuche traditional healers (Torri, 2012).

In 1993, the Anglican Corporation decided to close down due to lack of funds to cover even basic services (Park, 2006). Mapuche communities surrounding the hospital organized and formed the Support Committee for the Makewe Hospital after learning about the hospital's intention to close. Mapuche communities mobilized on a massive scale and held protests to show their opposition to the closure (Park, 2006). These protests became part of the collective memory and gave the communities a sense of pride for being part of the efforts to save the hospital.

To prevent the hospital from falling in the hands of a private entity, Mapuche communities collectively decided to assume the administration of the hospital (Park, 2006). In 1997, the Support Committee for Makewe quickly organized and formed the Indigenous Health Association Makewe-Pelale with the support of 32 communities. The Indigenous Association (IA) submitted a proposal to the SSAS (Health Service of South Araucanian Region) to administer the hospital with a focus on intercultural health, and incorporate their Mapuche medicine within the Western medical system (Park, 2006). The IA also initiated negotiations with the state to gather support for their proposal. In the end, the IA gained support from the SSAS and the state for their request (Park, 2006). After two years of serious negotiations between the IA, the Anglican Corporation and the SSAS, an agreement was reached. The agreement allowed the IA to use all hospital facilities and administer the hospital for five years until 2004 with a no-interest loan and with no transfer of debts. The land and infrastructure remained under the ownership of the Anglican Corporation until 2003 (Park, 2006).

The second attempt at closure: Limits of community participation

In 2003, the Anglican Corporation notified the Indigenous Association that it would not renew the no-interest loan of hospital facilities and land (Park, 2006). The president of the IA responded immediately by sending an open letter to the SSAS and Mapuche organizations stating that the true intention of the Anglican Corporation was to close the hospital because they did not respect the Mapuche religion and culture. He also added that their intention was to eliminate Mapuche culture and made a call to the communities in the area as well as in Chile to support the IA (Park, 2006). Conflicts between the Anglican Corporation and the IA ensued and eventually intensified. However, the SSAS maintained a passive and neutral position on the issue (Park, 2006).

The Indigenous Association and the state developed a relatively loose partnership, which can be noted by the reluctance to resolve the conflicts between the Anglican Corporation and the IA (Park, 2006). The Makewe Hospital was initially a private hospital. Therefore, the government did not feel responsible to sustain it financially. Public hospitals on the other hand are owned by the state and thus the state has all the responsibility to ensure financial sustainability (Park, 2006). It was not until the IA paid a visit to the central government in Santiago that the state took on a more active role in addressing the conflicts between the IA and the Anglican Corporation. The IA demanded the state to provide enough resources to sustain the current system as well as to develop new hospital facilities (Park, 2006). They asked the government to be more accountable to their commitments, referring to the governmental development program, *Origenes*, which had placed intercultural health as a priority, and yet Makewe Hospital, being an intercultural hospital, was at risk of closing down. After the visit to Santiago, the SSAS declared they will be actively mediating the conflicts between the IA and the Anglican Corporation (Park, 2006). In 2004, the SSAS bought the land and the hospital facilities from the Anglican Corporation and Makewe became a public hospital. The IA still remained in charge of the administration of the hospital; however, the SSAS became the official owner of the hospital (Park, 2006).

Factors that enable and limit indigenous self-determination in health

Collaboration and Communication

The Indigenous Association successfully negotiated with the state and gained its support due to several factors including the political situation, the strong community participation, the crisis of the public health care system and a favourable intellectual environment on intercultural health issues (Park, 2006). The state's support is reflected in the relatively cooperative interaction between the Indigenous Association and the SSAS.

In terms of the political situation, one aspect was the state's urgent need to re-establish political legitimization among Mapuche communities (Park, 2006). The failure to resolve conflicts over land rights between forestry companies and Mapuche communities resulted in criticism of the state over indigenous rights abuses both at home and abroad, jeopardizing the state's legitimacy (Park, 2006). In the Makewe-Pelale area, where the hospital operates, conflicts over land rights and forestry companies are absent, and according to Park (2006), this made it easier for the state to cooperate with the Indigenous Association. The primary concerns of Mapuche communities located in the Makewe-Pelale area were related to the improvement of social services. In addition, the state's plans for democratization and decentralization of health services coincided with the demand of the Indigenous Association to administer Makewe Hospital on behalf of the Mapuche communities (Park, 2006).

The strong community participation gave the IA more legitimacy as true representatives of the interests of Mapuche communities and also strengthened their political position to negotiate further with the state (Park, 2006). For instance, the SSAS agreed to continue subsidizing the services at the hospital and to increase the level of funding (Park, 2006). The IA also received a new ambulance from the Ministry of Health (MoH) and funding from PROMAP for one registered nurse, one paramedic and one kinesiologist by submitting a proposal. Moreover, accepting the proposal from a Mapuche organization gave legitimacy to the SSAS among Mapuche communities (Park, 2006).

Furthermore, the favourable intellectual environment in relation to intercultural health and the serious crisis of the public health care system in the IX region also contributed to the state's support of the intercultural health program (Park, 2006). The IX region has the poorest health indicators in Chile and the largest Mapuche population. The SSAS already had an interest in promoting intercultural health in the IX Region as a means to address the poor quality of health services in the area (Park, 2006). They designed PROMAP, the first state program to promote interculturalism in health. In addition, the director of the SSAS at the time had been one of the advocates of intercultural health since the late 80s (Park, 2006). This led to a cooperative relationship between the SSAS and the Indigenous Association. After receiving the proposal from the IA, the SSAS committed to support them by sending Dr. Jaime Ibaxache, one of the founders of PROMAP, as the director of the technical team (Park, 2006).

Flexibility

The relationship between the state and communities determines the degree of flexibility of the program (Park, 2006). The IA enjoyed a high degree of flexibility in program design and implementation because its relative autonomy from the state allowed them to be free from the bureaucracy of the dominant health care system. As a result, the IA was able to implement innovative measures to improve the quality of health services and expand participation among the communities (Park, 2006). For example, they introduced flexible visiting hours for family members of hospitalized patients. The IA also incorporated Mapuche medical knowledge into the health services. For instance, the hospital developed strong connections with *machi* (Mapuche shaman) in the area, referring patients when necessary and receiving constant feedback from *machi* to improve the health services at the hospital. The hospital also provided transportation to patients who want to visit *machi*.

The Indigenous Association was able to maintain substantial autonomy in the administration of the hospital and the freedom to run their own health service model in response to the priorities of the Mapuche communities (Park, 2006). Part of the reason

was that the hospital was legally “private” until 2003, even though 90% of its budget came from the SSAS. Therefore, the government did not feel responsible to get involved in its administration or sustainability (Park, 2006). Furthermore, the political environment also contributed to the level of autonomy and control of the IA. For instance, one of the neoliberal policy goals of the state includes encouraging community involvement in addressing their own health issues with minimal state intervention (Park, 2006).

Sustainability

The intercultural health program in Makewe Hospital experienced significant financial issues (Park, 2006). One of the main resources to maintain the program was strong community participation. Strong community participation gives the Indigenous Association political and cultural power, as well as autonomy from the State and the Anglican Corporation (Park, 2006). However, it does not ensure financial sustainability, particularly when the communities involved are poor and marginalized. The financial support that the communities can provide to the hospital is very limited (Park, 2006).

The state was interested in supporting the intercultural health program but with minimal intervention (Park, 2006). It increased its economic support to the hospital but not substantially. Park (2006) argues that the strong community involvement in the administration of the hospital made the state less willing to play an active role in the face of the economic crisis of the hospital. However, in the end, the IA with strong community support challenged the state to play a more active role in mediating the conflict with the Anglican Corporation (Park, 2006). The conflicts were resolved in a way that was acceptable for both the state and the IA, and most importantly, the IA was able to retain control of the administration of the hospital (Park, 2006). It is important to note that this was successful because there was both constant and strong participation from communities interacting with a state that was seeking political legitimacy within communities. Without these factors in play, the Indigenous Association would have had to choose either autonomy or the maintenance of the hospital (Park, 2006).

Satisfaction

An unusually high level of satisfaction was observed among service users in the answers to survey questions and in-depth interviews conducted by Park (2006). People indicated that they used services from Makewe because of its high quality of services, proximity, and lower cost. The intercultural health program not only addresses problems with the delivery of health services but also the cultural problems within the service delivery system. For instance, Mapuche people often face language and cultural barriers as well as poverty and discrimination on the basis of ethnicity or socio-economic status when accessing the public health care system (Park, 2006). To ensure effective communication between health care workers and patients, health workers fluent in Mapudungun, the language of Mapuche people, were incorporated in the hospital. For example, one of the doctors who is also the director of the technical team speaks fluent Mapudungun, and one paramedic is Mapuche and a native speaker of Mapudungun. In addition, the majority of Park's (2006) interviewees felt that doctors' explanation of illness was clear. Incorporating health care workers who speak the language of the communities being served improves the effectiveness of communication between patients and health care workers which has a positive impact on treatment adherence and patients' levels of satisfaction (Park, 2006).

The Indigenous Association was able to improve the cultural sensitivity of health workers by making every effort to eliminate discrimination of Mapuche patients in the hospital. Several strategies were implemented by the IA to address discrimination within the hospital including educational workshops with hospital staff, SSAS workers, and medical students in the area as well as a careful hiring process to ensure health workers are respectful toward Mapuche patients and culture (Park, 2006). In addition, having Mapuche people administrating the hospital makes health workers more careful with how they treat Mapuche patients. It addresses the power differences between traditional and Western medical systems. In Makewe Hospital, health care workers have shown a

genuine and concerted effort to understand and respect Mapuche culture (Park, 2006). This has played a significant role in making patients feel safe and comfortable. For instance, the majority of the households interviewed rated the quality of attention given by health workers as very good, and there was not a single household expressing dissatisfaction (Park, 2006). In addition, many patients have stated that they felt “known” in the hospital. This sense of familiarity also facilitates communication and enhances patient’s satisfaction with the services (Park, 2006).

Moreover, when problems of favouritism and discrimination often experienced by ethnic groups are addressed, patients’ perceptions of waiting time changes. One of the main complaints about the public health system in Chile is its long waiting times (Park, 2006). For example, when Park (2006) asked patients about the waiting time at Makewe hospital she found a discrepancy between her observations and patients’ feelings on waiting time. Patients felt they were waiting less than what they were actually waiting. They also stated that they felt confident they were being served on a “first come, first serve” basis without being discriminated against based on their ethnicity or socio-economic status (Park, 2006). Not having to worry about discrimination undoubtedly makes services at Makewe highly satisfactory for Mapuche patients in the area.

Efforts to incorporate Mapuche knowledge and integrate the two medical systems also increased the perceived adequacy of treatment among service users (Park, 2006). Mapuche people have expressed their concern that Western doctors would not be able to find the true cause of their disease because they lack knowledge about their culture and “Mapuche illnesses”. However, they know that doctors at Makewe Hospital learn about both cultures and thus are more confident about a doctor’s treatment, knowing that they will be referred to a *machi* if necessary (Park, 2006). The adequacy of the treatment is closely associated to the effectiveness of communication and trust between health care providers and patients. Also, adequacy of treatment is also closely linked to the attitudes of doctors toward Mapuche culture (Park, 2006). When communication between health care providers and patients is effective, patients are more likely to adhere to the treatment.

The level of autonomy of the IA allowed them to implement creative and flexible measures that are patient focused and responsive to the needs of the Mapuche communities which ultimately improves patients' levels of satisfaction (Park, 2006). For example, the implementation of multiple channels for participation stimulated constant and extensive participation from communities during the design and implementation of the program. Strong community participation improved accountability of the program and hence made it more responsive to the needs of the patients (Park, 2006). The incorporation of other innovative measures such as extended family visiting hours for hospitalized patients and provision of Mapuche herbal medicine in the hospital also increased the levels of satisfaction. The particular working environment and rules that exist at Makewe Hospital make health workers more effective, respectful and accessible to Mapuche patients (Park, 2006). The level of satisfaction is closely linked to the feelings of the patients about the services. For example, the majority of service users interviewed by Park (2006) feel services at the hospital in general are very good. The high levels of satisfaction give power and legitimacy to the IA in Mapuche communities and increase the political position of the IA in further negotiations with the state (Park, 2006).

Accountability

Accountability is closely linked to the level of participation from the communities (Park, 2006). Higher levels of community participation lead to more accountability. This is a highly significant aspect for indigenous populations since they have been historically excluded from social and political spaces and thus have lacked the means to make the state accountable to them (Park, 2006). Accountability is a key aspect that needs to be present to expand the cultural rights of indigenous populations. In the case of Makewe Hospital, the degree of accountability was very high as a result of having the Mapuche communities themselves administer the service as well as having substantial autonomy from the state (Park, 2006). The IA was able to implement multiple channels of participation which allows communities to voice their opinions and concerns. For example, one of the ways the Association galvanizes participation is organizing meetings where all

members of communities are invited as well as governmental officers at times when it needs to negotiate with the state (Park, 2006). This led to an intercultural health program that responds to and reflects the needs of the Mapuche communities in the area. This type of strategy gives the IA a better political position to negotiate with external actors (Park, 2006).

Mobilization and participation

The Indigenous Association was successful at galvanizing massive community participation in the design and implementation of the program due to several factors. For example, the collective memory of participation and the struggle against the hospital closure gave the communities a sense of ownership of the hospital and encouraged further participation (Park, 2006). In addition, the successful negotiation of the IA with the state and the Anglican Corporation also stimulated further participation.

Furthermore, the establishment of multiple channels for participation also encouraged greater participation (Park, 2006). For example, the IA organizes meetings with all members of the communities to share their opinions and concerns and reflect their priorities in negotiations with external actors and in the policies implemented in Makewe Hospital (Park, 2006). The IA also implemented the Committee of the Wise consisting of *lonkos* of the communities. A *lonko* is often an elderly person who has legal and social power in each community (Park, 2006). The role of the Committee of the Wise has been key in designing the health model of the hospital and making the proposals of the IA legitimate. In addition to the Committee of the Wise and the general meetings, communities receive frequent visits from officials of the Association to discuss the management and services of the hospital, especially from the director (Park, 2006). Members of the Association are often community leaders in the area of Makewe-Pelale and are elected by 35 member communities (Park, 2006).

Another form of stimulating participation is through campaigns for donations. During these campaigns officials of the IA visit each community in the area and share

information with community leaders as well as members about the problems of the hospital, which are often financial (Park, 2006). The purpose of these donations is to generate political support since communities are unable to provide significant financial contributions for the hospital. Lastly, another method is the constant monitoring of the service where communities assess the service and provide their feedback to the Association (Park, 2006). Community members can also contact the IA directly since it consists of community leaders.

Makewe Hospital has become a critical source of empowerment for the mobilization of communities to expand the cultural rights of Mapuche communities (Park, 2006). Several meetings and workshops were organized to raise awareness about indigenous rights to promote these rights (Park, 2006). The IA was also active in promoting intercultural health programs in other communities such as Colpanao. The strong community participation also gave the IA a stronger political position and strengthened their organization (Park, 2006).

Cultural diversity

The intercultural health program at Makewe Hospital has been successful at creating a culturally sensitive and culturally diverse environment within the hospital in terms of: 1) changing the attitudes of health care workers toward Mapuche medicine and culture, and 2) combining Mapuche medicine and Western medicine in the hospital the “Makewe way” (Park, 2006). Changing the attitudes of health workers was one of the primary goals of the IA to eliminate institutional discrimination towards Mapuche patients. The IA tries to hire workers that are culturally open-minded toward Mapuche patients and their culture and are interested in learning about Mapuche culture (Park, 2006). The Association states that they would prefer to hire Mapuche health workers or doctors but they are in short supply (Park, 2006).

The most influential factor that contributed to changing the attitudes of health workers in the hospital is the new power relation within Makewe. Changing the attitudes

of health workers is not a simple task in part because of the existing hierarchy between Western and indigenous medical knowledge leading to power imbalances between health care workers and indigenous patients (Park, 2006). Having a Mapuche organization in control of the administration of Makewe has allowed for a new power relation, one in which Mapuche knowledge and culture is not inferior to Western knowledge. This has made health workers respect the culture of the administration (Park, 2006). For example, in interviews conducted by Park (2006), not a single patient reported experiencing discrimination in the hospital. Numerous patients added that it was impossible to be discriminated against in Makewe because the administration was controlled by Mapuche and they felt free to complain at any time if they felt discriminated against (Park, 2006). The presence of multiple channels for evaluating the services at Makewe is linked to the power and influence Mapuche communities have over the hospital. Health workers are respectful and sensitive toward Mapuche patients and their culture. In fact, many non-Mapuche workers expressed interest in learning more Mapuche culture, engaged in research projects related to Mapuche medicinal herbs, and tried learning basic conversation in Mapudungun, the language of the Mapuche. The elimination of discrimination within Makewe has increased patient satisfaction and brought legitimacy to the IA among the Mapuche communities in the area (Park, 2006).

Integration of Western and Mapuche Medicine

The IA found a creative way to combine the two medical models without contradicting Mapuche culture or state law. The “Makewe way” of combining the two medicines consisted of making strong connections with *machi* (Mapuche shamans) and *lonkos* (community leaders) in the area (Park, 2006). Their participation played a significant role in shaping the intercultural health program. A *machi* is a religious, spiritual, and medical authority in Mapuche culture (Park, 2006). The IA chose not to have *machi* practice within the hospital because one: it is illegal, and two: it is not culturally appropriate. According to Mapuche culture, the source of spiritual power of the Machi is her land and if she leaves her territory she loses the spiritual power (Park, 2006).

The hospital has developed a strong referral system between *machi* in the area and doctors. The hospital makes appointments with a *machi* if a doctor thinks it is necessary for the patient or if a patient requests to see one (Park, 2006). The doctors have a list of *machis* who work with the hospital in the area. In addition to making appointments, they provide transportation for patients who wish to see a *machi*, if it is necessary (Park, 2006). At the same time, *machis* of the area transfer their patients to Makewe when they believe Western medicine is needed. Doctors and *machis* then meet once the transfer happens to discuss the patient (Park, 2006). The decision is always left to the patient; they are free to say no to the recommendations. Makewe Hospital is also very unique in its services as it offers hospitalized patients various herbal medicines if requested or if deemed necessary (Park, 2006). In addition, the hospital is very involved in studying and marketing herbal medicines. They opened a pharmacy specializing in Mapuche herbal medicine in Temuco in 2003, and opened a branch in Santiago in 2004 (Park, 2006).

The Makewe-way of integrating Western and Mapuche medical knowledge is the result of the interaction between strong community participation and a distant yet supportive state (Park, 2006). The relative autonomy of the Indigenous Association from the state has created the perfect environment for creative and flexible solutions that are responsive to the needs and priorities of the Mapuche communities and ultimately improved cultural diversity within the hospital.

Limitations of intercultural health in Chile

Despite some important successes, there are also some limitations in Chile with respect to intercultural health. First, there is no official definition or guidelines for intercultural health programs (Park, 2006). Second, intercultural health programs in Chile seek to combine Western and traditional medical knowledge but there is a lack of clear guidelines on how to integrate the two medicines. Lastly, under the Health Code of Chile it is illegal to practice medicine without a license and there is no licence currently provided

to *machis* (Park, 2006). This is a significant limitation for the recognition of Mapuche medical knowledge as well as for its revitalization and continuity. It can also be a major barrier in rural settings where there are limited resources and combining various health models in a single facility could be the most cost-effective or feasible way to do it (Park, 2006). Furthermore, indigenous communities do not give any clear solutions about how to combine their medical knowledge with Western medicine because there is no consensus among different indigenous groups about how to combine the two medicines (Park, 2006).

Community Crisis Teams in Nishnawbe-Aski First Nations

The Community Crisis Teams (CT) provide an example of several First Nations communities obtaining autonomy and control by running a local health program. This section will provide a brief description of Canada's Aboriginal health care system and describe how Canada has tried to address indigenous health through increasing indigenous autonomy and control over health care. Next, a description of the formation and implementation process of the CT initiative is provided as well as the aspects of this example that made it successful and those aspects that limit its success. The CT initiative is an important example of contractual relationships between governments and an indigenous organization.

For this example, information about the Nishnawbe-Aski Nation CT was obtained from Minore and Katt's (2007) study because it was the only study available about this initiative. The lack of robust data available for this initiative is a limitation. In addition, Mashford-Pringle's (2013) study was used because of its detailed information about First Nation's self-determination in health care in Canada.

Canada's Aboriginal Health Care System

There is considerable legal confusion as to whether the federal or provincial governments are responsible for the provision of health care services to First Nations people in Canada, especially those with "Indian" status (Minore and Katt, 2007). In addition

to the legal confusion, there are several government entities that deal with First Nations health both at the federal and provincial levels. These factors further complicate who, how, and what health care and social services are delivered to First Nations people on reserve (Minore and Katt, 2007).

The federal government funds and delivers health services to those who have status and live on-reserve through Health Canada (Minore and Katt, 2007). The federal government also provides significant support to services normally under provincial jurisdiction, especially in cases where they would otherwise not be available, such as in remote rural areas (Minore and Katt, 2007).

The provinces have finally come to recognize, after years of reluctance, their legal obligations to their Aboriginal citizens that go beyond providing health care to all its citizens (Minore and Katt, 2007). This change is evident in the creation of policies and programs that aim to improve the provision of health care to Aboriginal citizens (Minore and Katt, 2007). For instance, the province of Ontario implemented the Aboriginal Healing and Wellness Strategy (AHWS) where management is shared by both the province and Aboriginal organizations (Minore and Katt, 2007). The AHWS has an intersectoral governance structure, and decisions are made by consensus involving 10 ministries and 8 Aboriginal organizations representing all Aboriginal People, including non-status Indians, Inuit, and Métis (Maar, 2004). The AHWS funds a variety of Aboriginal community-based health and mental health initiatives in Ontario and oversees a combined budget of about \$38,000,000 per year (Minore and Katt, 2007). In short, Aboriginal people in Canada receive health services from multiple levels of government—federal, provincial, territorial, Aboriginal—that leads to a complex and uncoordinated system with gaps in services, overlapping coverage, and duplication of funding (Minore and Katt, 2007).

Transferring control of Aboriginal health

The increased collaboration between the provinces and Aboriginal organizations is a reflection of the shift that has been taking place in the area of Aboriginal health in

Canada for the past few decades (Minore and Katt, 2007). It is widely accepted now in Canada that self-determination has a positive effect on community well-being and is necessary for the improvement of Aboriginal people's health. For example, Minore and Katt (2007) argue that "self-determination has become the defining characteristic of Aboriginal-specific health policies and, to some extent, practices in Canada" (p.16). The widespread consensus on Aboriginal self-determination in health has been the result of an evolution in thinking about Aboriginal health and changes in policies and legislation. It is also the result of Aboriginal people's advocacy efforts for their inherent right to self-government (Minore and Katt, 2007).

In 1989, the federal government made available the Health Transfer model for Aboriginal communities, allowing them to be able to assume administrative control over a range of community-based and regional programs (Lavoie et al., 2010). Many Aboriginal organizations have negotiated with the federal government to transfer health services to community control and are now in charge of delivering health services to their communities (Minore and Katt, 2007; Mashford-Pringle, 2013). Most First Nations today and some Inuit communities are able to independently manage their local health care systems through 4 different models of funding including health transfer or integration agreements, and self-government negotiations (Mashford-Pringle, 2013). These models enable communities to take control of the delivery of health and social programs and provide for significant input into decision making in health related matters (Mashford-Pringle, 2013).

Formation and implementation process of community Crisis Teams

In remote Aboriginal communities across Northern Canada, suicide rates among young people are disproportionately high (Minore and Katt, 2007). For example, in parts of northern Ontario, within only seven years, 129 youths from 49 small First Nations communities had taken their lives while hundreds had attempted to commit suicide. These 49 First Nations communities are represented by the Nishnawbe-Aski Nation (NAN), a

political indigenous organization in charge of the communities' health, social welfare, education, and legal interests (Minore and Katt, 2007).

The Nishnawbe-Aski First Nations experience a higher burden of disease by nearly every indicator compared to the rest of Canadians (Minore and Katt, 2007). These health disparities are associated with social, economic, and political disparities (Frohlich, 2006). For instance, they suffer from poor housing conditions, poverty, lack of education and problems with addictions, suicide, and mental health (Minore and Katt, 2007).

In these communities, only essential primary health care is available and mostly provided by the federal government since only a few of the communities have negotiated transfer agreements. To access secondary and tertiary health care, community members have to travel to the nearest regional centre (Minore and Katt, 2007). The lack of job and education opportunities for youth as well as living in isolation likely contribute to the self-harming trend observed among young people (Minore and Katt, 2007).

In 1993, as a result of community concern about the suicide crisis among their youth, the chiefs of NAN communities created a youth-led forum on suicide to examine the causes and provide recommendations on how to address the crisis (Minore and Katt, 2007). The Youth Forum on Suicide, led by a group of youth, spent three years carrying out private and public hearings in the communities. The teams conducting site visits were composed of youths, adults, mental health counsellors and elders (Minore and Katt, 2007). Resident health teams and commissioners received extensive training on how to handle disclosures and support people through the stressful process of disclosing painful and traumatic experiences. They also received training on how to manage stress or anger expressed by some of the individuals testifying (Minore and Katt, 2007). Two weeks before conducting the hearings, assigned teams spent time explaining the process to community members as well as addressing their concerns. The hearings lasted approximately two weeks and were followed up by visits from mental health experts (Minore and Katt, 2007).

The youth forum found that a complex set of factors were contributing to the suicide crisis, ranging from personal traumas such as sexual or physical abuse, to factors rooted in communal practices and systemic issues (Minore and Katt, 2007). For instance, in the more traditional elder-dominated communities, young people's opinions were not valued or welcomed; young people felt undervalued and voiceless. In terms of systemic issues, communities were dealing with intergenerational trauma from residential schools and the continuing removal of children by Child and Family Services (Minore and Katt, 2007).

The Youth Forum produced a final report, *Horizons of Hope: An Empowering Journey* which outlined specific recommendations for each particular group: community leaders, communities as a whole, political leaders, youth, elders and adults (Minore and Katt, 2007). Also, a Chiefs Task Force on Suicide was created and given the task to implement the recommendations from the Youth Forum final report. However, with such a daunting task, a more pragmatic approach was taken that involved focusing on a few high-risk communities and developing a specific program (Minore and Katt, 2007). The Youth Forum promoted the implementation of a Crisis Teams (CT) program inspired by an event at Kingfisher Lake in 1987. A group of people from neighbouring Muskrat Dam provided a supportive visit to community members from Kingfisher Lake during their immediate grief after the death of three people (Minore and Katt, 2007).

The main purpose of the Crisis Teams program is to develop community capacity to respond to crises and emergencies through a capable crisis team that can effectively and efficiently assist in traumatic situations (NAN, 2016). The role of the Crisis Teams system is to provide assistance to community members during traumatic events, primarily suicide and family violence. Crisis Team members work on suicide and family violence prevention within their communities and well as on minimizing the impact of traumatic stress and promoting healing (NAN, 2016).

Factors that enable and limit indigenous self-determination in health

A discussion will be provided about key aspects that enable and those that limit First Nations communities in achieving self-determination in health with most of them taken from the “Self-determination Criteria” developed by Mashford-Pringle (2013) and can be found in Table (1).

Leadership Capacity

The NAN chiefs and council have demonstrated leadership capacity through the creation and implementation process of the CT program (Minore and Katt, 2007). For example, they mobilized community members to form the Youth Forum to assess the causes of the issues at hand and develop potential solutions in collaboration with the member communities. The chiefs and council make local key decisions such as selecting and evaluating the crisis team coordinator as well as deciding how to best respond to requests for team services (Minore and Katt, 2007). Moreover, the NAN is in charge of managing the flow of funding provided by the Ontario Government’s Ministry of Community and Social Services and of distributing it to the NAN member First Nations (NAN, 2016). Additionally, NAN has also played a leadership role by actively advocating for funding at the federal and provincial levels to ensure the financial sustainability of the program (Minore and Katt, 2007).

Funding

Sufficient and secure funding has been one of the major limitations for Nishnawbe-Aski First Nations to achieve self-determination in health. During the beginning of the program, NAN received funding from FNIH to cover the expenses of flying volunteer crisis teams where they were needed (Minore and Katt, 2007). Most of the NAN First Nation communities can only be accessed by airplane or, during the winter, by icy roads cleared over frozen lakes and rivers. However, the federal government did not intend for this to be

an ongoing commitment; but rather, it was provided on an emergency-basis (Minore and Katt, 2007).

The NAN chiefs benefitted from a provincial Aboriginal health policy that had been recently implemented in Ontario at the time, the AHWS, to receive ongoing funding for the crisis teams (Minore and Katt, 2007). However, this is not sufficient and some communities still need outside assistance for funding and end up paying by using their own resources. Some communities have developed creative ways to secure emergency funds (Minore and Katt, 2007). For example, in Cat Lake, \$10 is deducted from the paycheque of every single employed resident to go towards the so-called Hope Fund. This money is used to bring in crisis teams as well as to fund other community projects (Minore and Katt, 2007).

Collaboration and Communication

NAN has formed key partnerships with multiple actors to ensure the continuity and sustainability of the program as well as the delivery of quality and culturally-appropriate services. At the federal and provincial level, NAN was able to successfully negotiate with FNIH and AHWS to obtain some funding for the program as mentioned above. NAN has also developed partnerships with local organizations to ensure crisis teams were well trained to respond efficiently and effectively to crises and emergencies. For instance, Noding Counselling Services were contacted to help with training; they provide mental health services in Sioux Lookout (Minore and Katt, 2007). Lastly, NAN's Community Health and Wellness Department is actively collaborating and communicating with community members. It is in charge of overseeing the Crisis Team program, the NAN Crisis Coordinators and several other programs (NAN, 2016).

Clear Boundaries

NAN has been able to communicate the ideas on clear boundaries that they would like to have with respect to legal, political, policy, and health factors through their self-government negotiations with the Canadian government (NAN, 2016). However, this has

been a long process that is still under negotiation. Nishnawbe-Aski First Nations lack financial resources as well as jurisdiction and therefore are forced to work within the constraints imposed by the federal and provincial governments. This dependency has hampered their ability to achieve self-determination in health (Minore and Katt, 2007; Ladner, 2009).

Community Participation

Community participation was not included in the self-determination criteria developed by Mashford-Pringle (2013) but is considered to be an essential aspect for indigenous communities to achieve self-determination in health (Park, 2006).

The creation and implementation of the Crisis Team program led to increased community participation. Records show that approximately 614 people were members of various CT across the region (Minore and Katt, 2007). The hearings conducted by the Youth Forum on Suicide gave youth a chance to participate by either being part of the teams conducting the hearings or being interviewees talking about their own experiences and quality of life (Minore and Katt, 2007). This was an opportunity for young people to not only express themselves and be heard but also to feel valued by doing something useful in their communities. For instance, young people would be asked to be part of a crisis team to provide high-risk monitoring or patrol because they are more physically fit than other adults or elders (Minore and Katt, 2007). Their skills would also be widely known across the region if they become part of a crisis team. The high level of social interaction and support provides an indication of the high degree of community participation (Minore and Katt, 2007).

Flexibility

The CT program emerged as a grass-roots response to the communities' needs and guided by their own local priorities and worldview without external intervention (Minore and Katt, 2007). Overtime, the program became essential to the communities' response

to the growing suicide crisis. The reliance on the program is evident in the records showing that in only one year, 65 travelling teams were dispatched from one community to the next (Minore and Katt, 2007). The high demand for this program is also an indication that social interaction, sharing and community support are an integral part of the lives of Nishnawbe-Aski First Nations. A program that is culturally sensitive is more likely to be embraced by the communities (Minore and Katt, 2007).

There have been key decisions made at the local level. For example, how to best respond to requests for team services is up to the local chief and council (Minore and Katt, 2007). The skills of individuals and the competencies of particular teams are widely known across the region. Additionally, selection and evaluation of the crisis team coordinator is also up to the chief and council (Minore and Katt, 2007).

Although NAN has enjoyed some level of control over program implementation, there have been some important limitations to their local control that are worth noting. Some of the decisions made have not been in accordance to the communities' norms, laws and culture (Minore and Katt, 2007). For instance, the must-pay-one policy was imposed on NAN communities by the AHWS. The must-pay-one policy requires having one paid coordinator per community (Minore and Katt, 2007). However, this policy does not align with the communities' preference regarding how to distribute funding. Paying only one person for what others do voluntarily has brought about some tension (Minore and Katt, 2007).

Moreover, the bureaucratic characteristics of government entities have limited NAN's flexibility. In order to effectively manage a large number of different programs and a multi-million dollar budget, the AHWS has standardized and streamlined its processes (Minore and Katt, 2007). NAN's flexibility is diminished when they have to meet requirements for accountability imposed by the AHWS/FNIH, which often do not align with the cultural and socio-economic realities of the communities. If NAN does not meet these requirements the funding it receives could be jeopardized. It is paradoxical, because within

a system founded on the ideal of local Aboriginal control, self-determination is being undermined (Minore and Katt, 2007).

As long as indigenous communities depend on government funding they will be required to be accountable to the government instead of the community (Mashford-Pringle, 2013). In addition, First Nation's ability to provide services based on the community's needs is constrained by requirements for accountability established in the contractual agreements. Government bureaucrats dictate a community's level of flexibility and control over their health care as well as whether a community is ready for self-determination or self-government (Mashford-Pringle, 2013). These decisions are made based on criteria often created without input from indigenous communities. Even though the AHWS is co-managed by Aboriginal organizations, the bureaucracy undermines local autonomy (Mashford-Pringle, 2013).

Part 2: Opportunities and challenges for indigenous self-determination in health care in Guatemala

Guatemala is a multi-ethnic, multicultural, and multilingual country constituted of four major peoples: Maya, Garifuna, Xinca, and Ladino/mestizo people (Peren, 2007). The largest one of these groups is the Maya people, made up of 22 ethnic groups. The Maya people were the main victims of the internal civil war in which they suffered geographical displacement and systematic violence in the form of rape, torture, and mass killings (Ceron et al., 2016). Indigenous people make up approximately 45% of the total population and reside mainly in rural areas where there is limited access to health and social services (Ruano et al., 2014). The exact proportion of indigenous people in Guatemala is still debated. The indigenous population experiences a disproportionate burden of disease; they have worse mortality and morbidity indicators compared to the dominant ladino population (Peren, 2007). In addition, they are more likely to experience poverty, chronic malnutrition, lack of education, and marginalization. The social and political exclusion of

this population is evident in the observed health and socio-economic disparities (Peren, 2007).

The health system in Guatemala is divided into public (Ministry of Health (MoH) social insurance) and private care (Peren, 2007). Indigenous people access mostly the public system due to financial reasons. However, when accessing public care they are often exposed to limited and low quality health care services, discriminatory practices and a lack of cultural sensitivity (Harvey, 2008; Sunil, 2012; Ruano et al., 2014; Ceron et al., 2016). As mentioned previously discrimination in the health care setting has been identified as a major barrier to their ability and willingness to access health services (Ceron et al., 2016).

The dominant health care system in Guatemala is based on a Westernized biomedical approach to health that expects to find the biomedical “patient” role in anyone and everyone that seeks wellness regardless of context (Harvey, 2008). It is a system that is not appropriate and responsive to the cultural and socio-economic needs of the indigenous population. For instance, all services are provided in Spanish when the indigenous population mostly speaks only the language of the ethnic group they belong to. Additionally, it excludes other forms of knowledge and practices such as the Maya medicine model, which is widely utilized and operates in parallel to the dominant system (Peren, 2007).

Guatemala has some of the highest maternal mortality rates in Latin America, especially among indigenous women (Bhatt, 2012). To improve access to maternal health services, the government introduced an intercultural model for maternal health services (van Dijk et al., 2013). The intercultural model attempted to integrate traditional Mayan birth attendants, or *comadronas*, into medical facilities. However, research has shown that *comadronas* were often disregarded by the biomedical providers and Mayan women were still not receiving culturally-appropriate care (Castro, Savage and Kaufman, 2015). Instead of having a two-way exchange of knowledge, the biomedical staff of the facilities focused

on “training” *comadronas* as biomedical providers (van Dijk et al., 2013). Successful integration of *comadronas* into the Western medical system cannot be achieved when power differences between biomedical and traditional health practitioners are not addressed. The intercultural model was not based on a genuine recognition, respect, and understanding of the sociocultural differences of the indigenous population (van Dijk et al., 2013).

To this date the Guatemalan government has yet to experiment with giving autonomy and control over health care to indigenous communities as a potential strategy to make health services accessible and responsive to the cultural and socio-economic needs of this population. Potential opportunities and challenges that can be encountered by indigenous communities in Guatemala when striving for self-determination will be described below.

Strong community involvement in organizing health care

Strong community involvement is a key element in reducing barriers to access and improving user satisfaction, as observed in both the Makewe Hospital and the NAN’s Crisis Teams experience. It is also an important resource for program sustainability and a source of empowerment for the mobilization of indigenous communities to expand their cultural rights. In the Makewe initiative, strong community participation in the design and implementation process ensured health services were culturally appropriate and client focused (O’Neil, Bartlett, and Mignone, 2005). Based on both the Canadian and Chilean examples, it was observed that strong community participation provides indigenous communities with cultural and political power and strengthens their political position to negotiate with government and other stakeholders. Moreover, strong political organization of communities can result in improved access to both Western and traditional medicine as shown in the Makewe case study (Park, 2006). Lastly, the implementation of multiple pathways for community participation, present in the Makewe initiative, represents new

mechanisms of legitimization from below that leads to higher a degree of accountability to the community instead of the government.

This particular aspect has a lot of potential to be feasible in Guatemala because there is social capital available within indigenous communities that can be used towards achieving self-determination in health. For instance, one of the key values of indigenous communities in Guatemala is community service that is done within a framework of a local institutionality with their own indigenous or community authorities. This institutionality has different scopes, nuances and organicity between indigenous communities, however, it is present in most (PIES de Occidente, 2013).

Indigenous community development

Indigenous community development including revalorization and revitalization of indigenous knowledge, cultural continuity and pride as a people. These factors have been linked to indigenous health because they contribute to the development of a positive sense of belonging to traditional culture and community which in turn can have a positive impact on people's health and well-being (Mashford-Pringle, 2013, p. 25).

This is a feasible aspect in Guatemala because there is available cultural capital within indigenous communities. For example, PIES and ASECSA are examples of indigenous organizations that have been working for many years towards the revitalization and revalorization of Maya medical knowledge (PIES de Occidente, 2013). The revitalization of indigenous knowledge in Guatemala is crucial as it is slowly disappearing (Hawkins and Adams, 2007).

Leadership capacity

Leadership capacity is essential to advance indigenous proposals to improve healthcare and to negotiate with government and other stakeholders and ensure their financial and/or political support (Mashford-Pringle, 2013; Park, 2006). Additionally, it is

necessary for communities to be able to deal with health and policy issues as well as to advocate for funding. Strong leadership encourages community participation, organization, and mobilization to respond to community health issues (Mashford-Pringle, 2013). In turn, political mobilization gives indigenous communities a better political position and the opportunity to have more influence on health policy at local and national levels. Lastly, it is also an important factor to be able to form key partnerships with multiple actors to ensure the continuity and sustainability of initiatives as well as the delivery of quality services (Mashford-Pringle, 2013).

Leadership capacity can be developed or strengthened in Guatemala because the system of Maya authorities has been characterized by high levels of organization and accountability to their communities. The legitimacy of these authorities is obtained by the practice of community service and the recognition and respect that community members grant these authorities for their work within the communities (PIES de Occidente, 2013).

Coordination and Integration

Based on the Makewe Hospital experience, it appears that a higher degree of integration of both Western and traditional systems can be achieved when management of both systems is controlled by an indigenous organization. This management model played a crucial role in addressing the power differences between biomedical and traditional medical systems which ultimately led to elimination of discrimination within Makewe Hospital (Park, 2006). Furthermore, patients' trust in the health system increased because patients feel confident they will receive culturally-appropriate care and will not be discriminated against. The opposite has been observed when management of both systems is not controlled by an indigenous entity as it has been the case with the intercultural model for maternal health services in Guatemala (van Dijk et al., 2013).

The synergy of the two medical models in Guatemala is both an opportunity and a challenge. Combining the two medical models can bring several benefits to Guatemala. It would be a cost-effective and sustainable strategy. Cost-effective because ideally it would

involve combining available resources from both medical traditions to create an improved health system. It would be a sustainable strategy because the cost aligns with the economic capacity of the population (Peren, 2007). Maya healers receive a payment that is either in cash or in kind according to the financial situation of each patient. Also, the Maya medical model has survived for centuries because it is driven by a spiritual commitment rather than by profit (Peren, 2007). Moreover, the Maya healers contribute to maintaining indigenous health. They are more likely to care for their patients and provide personalized, individual, and culturally-appropriate care because they share the culture of their patients and often live within the same community as their patients (Peren, 2007).

Flexibility

Flexibility in program design and implementation has a positive impact on indigenous self-determination. The Makewe initiative shows that minimal state control and freedom from the bureaucracy of the state and the dominant health care system provides great flexibility. In this initiative, the IA enjoyed considerable flexibility and local control which allowed them to implement innovative and creative measures that respond to the priorities and needs of the community (Park, 2006). In contrast, the NAN's Crisis Teams initiative shows that local autonomy was undermined by the bureaucratic characteristics of the FHIS and the AHWS. When a community must meet requirements and objectives imposed by an external entity its ability to introduce its own input is restricted (Mashford-Pringle, 2013).

Indigenous communities in Guatemala striving for self-determination in health need to be aware of the existing tension between indigenous and state control of health care. Scholars argue there are two main risks: 1. the institutionalization of traditional medicine where traditional practices become absorbed by western paradigms; and 2. the loss of autonomy in relation to the design and implementation of health systems in the attempt to integrate both medicines (O'Neil, Bartlett, and Mignone, 2005). To avoid this requirements for accountability as well as program objectives and goals need to be

developed in collaboration/consultation with indigenous communities or at the very least the cultural and socio-economic context of the community should be considered.

Cooperative government

It is important to have a cooperative government that is willing to support communities with funding, human resources, capacity building, as well as help communities to build partnerships with other levels of government. The success of indigenous communities in achieving self-determination in health will depend on whether the government accepts their demands or is willing to negotiate to find solutions. The Canadian and Chilean governments have been more proactive at addressing indigenous health by increasing indigenous autonomy and control over health care through contractual agreements with indigenous organizations.

In Guatemala, having a cooperative government is a major challenge for indigenous peoples. Historically, the government in Guatemala has not been proactive or effective at improving the health conditions of the indigenous population. Instead, indigenous peoples have been excluded from the benefits of the state and subordinated through violent measures in order to maintain the status quo (PIES de Occidente, 2014). In addition, national health expenditure in Guatemala is known to be among the lowest in Latin America (PAHO, 2012). Moreover, the lack of a cooperative government is an important limitation to integrating western and traditional medical systems. The government is the only institution that has accountability to the people and the ability to develop and implement policies. Unfortunately, in Guatemala there is very little interest in indigenous medicine on the part of the state, in combination to the racism of those who reach political leadership positions (PIES de Occidente, 2014).

Funding

Lack of control over funding and dependency on government funding will always be a major barrier and a limiting factor for indigenous communities to achieve true self-

determination. In both experiences from Canada and Chile, indigenous organizations have obtained funding through contractual agreements with the government. As long as indigenous communities depend on government funding they will be required to be accountable to the government instead of the community. However, Mashford-Pringle (2013) argues that self-determination in health can be achieved through funding agreements only when funding objectives and goals align with the needs of the community. Indigenous communities in Guatemala can find alternative sources of funding by partnering with external health care organizations, university institutions, or establishing health insurance schemes controlled by indigenous organizations as some indigenous communities in Colombia have done (Mashford-Pringle, 2013; O'Neil, Bartlett, and Mignone, 2005).

Legal Framework

The lack of an appropriate legal framework for traditional practices can contribute to the erosion of traditional indigenous knowledge and prevent an effective synergy of Western and traditional medical systems. In Guatemala, there is a lack of a clear legal framework that recognizes and protects the practice of traditional medicine and there are also guidelines on how traditional medicine can best interact with the dominant Western system (WHO, 2001). Under the Guatemalan Health Code it is illegal to practice medicine without a licence and currently there is no official license to practice traditional medicine, placing both traditional healers and doctors at risk of litigation. There is a permit issued to *comadronas* only if they complete a training course, but their legislative situation remains unclear (WHO, 2001; O'Neil, Bartlett, and Mignone, 2005). This affects the willingness and ability of western health practitioners and indigenous healers to collaborate. The recognition and legal protection of traditional healers is important as they contribute to improving indigenous health.

Self-determination and not self-administration:

There are important lessons to take away from the Canadian experience with indigenous self-determination in health. It is important to make a distinction between self-determination and self-administration. Different definitions of self-determination between governments and indigenous communities can impede indigenous communities from achieving the desired level of autonomy (Mashfor-Pringle, 2013). It is important to clearly define self-determination and that it is done collaboratively by including all stakeholders (i.e. indigenous peoples/organizations, local and national governments) so that everyone is on the same page. This aspect could also be a challenge in Guatemala due to either a lack of cooperation from government or no consensus among indigenous groups about the definition of self-determination.

Moreover, governments need to move away from a paternalistic approach when creating policies and criteria related to indigenous self-determination in health because these undermines indigenous self-determination (Mashford-Pringle, 2013). For example, current contractual agreements between the Canadian government and First Nations peoples tend to provide very limited local autonomy because of the paternalistic approach and bureaucracy characteristic of government entities. The federal government in Canada controls when and how self-determination is granted to First Nations people based on criteria developed and applied by government bureaucrats with no input from First Nations. As a result of not including First Nations input, the requirements for accountability they must meet often conflict with the health needs as well as the cultural and socio-economic realities of the community.

Conclusions

In this capstone, I have explored the factors that can aid indigenous communities in achieving self-determination in health as a strategy to create health systems that are appropriate and responsive to their cultural and socio-economic needs. The two cases discussed throughout have outlined how indigenous communities in Chile and Canada have achieved some level of autonomy and control over their health care. It is important

to note that every context is different and only some principles and organizational aspects can be replicated. Both the Mapuche and the Nishnawbe-Aski First Nations have developed solutions to their health problems based on their culture and socio-political history. The variations in geographical location, culture, and socio-political history that each community have faced have influenced the community's current level of self-determination in health care.

Key factors that enabled and those that limited self-determination in health in each initiative were identified and described. Key enabling factors included flexibility, strong community participation, culturally safe environment, strong leadership, collaboration and communication. On the other hand, limiting factors included insufficient and insecure funding, undue government bureaucracy and control, and lack of an appropriate regulatory environment. This information was then used to identify and describe potential opportunities and challenges that could be encountered by indigenous communities in Guatemala when striving for self-determination. With respect to Guatemala, key opportunities include: strong community participation, leadership capacity, indigenous community development, coordination and integration of Western and traditional medical systems and flexibility in program design and implementation. Significant challenges could also exist, such as lack of government cooperation, a culturally-inappropriate regulatory environment, lack of financial resources, and lack of a clear distinction between self-determination and self-administration.

While health outcomes for indigenous peoples in all three countries are dire, Canada and Chile have been relatively more proactive in addressing indigenous health than Guatemala. Canada has increasingly tried to improve indigenous health by increasing indigenous autonomy and control over health care through contractual agreements between government and indigenous organizations. Chile has supported intercultural health efforts with the intention of improving indigenous peoples' health and gain political legitimacy at home and abroad. On the other hand, the government in Guatemala has been for the most part absent and incapable of providing effective

multicultural responses to the needs of a multicultural country where about half of its population is indigenous. As already mentioned, to this date the Guatemalan government has yet to experiment with giving autonomy and control over health care to indigenous communities as a potential strategy to make health services accessible and responsive to the cultural and socio-economic needs of the indigenous population.

In conclusion, the lessons gained as to what has and has not worked, identified from experiences with self-determination in health from other indigenous groups, can serve as a framework of reference for indigenous communities in Guatemala. However, it is also important to note that the broader political and economic factors shaping Guatemala provide a way of framing the challenges facing indigenous people, significantly limiting the some of the options available in other jurisdictions. Clearly, the potential exists in Guatemala for indigenous self-determining health systems, and for cooperation, research, and education that are required for the successful integration of Western and traditional medical systems, thus providing a much improved framework to support the health of the indigenous population. Given that almost half of the population in Guatemala belongs to an indigenous ethnic group, an integration of traditional medicine based on the ancestral practices of these communities, would greatly expand the coverage in terms of access to health in this nation. This would translate into improved health conditions of the majority of the population and would begin to solve one of the major cultural barriers that is discrimination of indigenous people in public health settings.

References

- American Psychological Association (APA). (2010). *Publication manual of the American Psychological Association*. Washington, DC: Author.
- Bhatt, S. (2012). Health care issues facing the Maya people of the Guatemalan Highlands: the current state of care and recommendations for improvement. *J Global Health Perspect*.
- Berry, N. S. (2013). *Unsafe motherhood: Mayan maternal mortality and subjectivity in post-war Guatemala* (Vol. 21). Berghahn Books.
- Castro, A., Savage, V., & Kaufman, H. (2015). Assessing equitable care for indigenous and afrodescendant women in Latin America. *Revista Panamericana de Salud Pública*, 38(2), 96-109.
- Frohlich, K. L., Ross, N., & Richmond, C. (2006). Health disparities in Canada today: Some evidence and a theoretical framework. *Health Policy*, 79(2), 132-143.
- Fassin, D. (2003). The embodiment of inequality. *EMBO reports*, 4(6S), S4-S9.
- Harvey, T. S. (2008). Where there is no patient: An anthropological treatment of a biomedical category. *Culture, Medicine, and Psychiatry*, 32(4), 577-606.
- Hawkins, J. P and Adams, W. (2007). *Health care in Maya Guatemala: Confronting medical pluralism in a developing country*. University of Oklahoma Press.
- Health and Welfare Canada. (1974). *Policy of the Federal Government Concerning Indian Health Services* Ottawa: Health and Welfare Canada
- Katt, M., P. Kinch, M. Boone, and B. Minore. 1998. "Coping with Northern Aboriginal Youths' Suicides." In *Suicide in Canada*, edited by A. Leenaars, S. Wenchstern, I. Sakinofsky, R. Kyck, M. Kral, and R. Bland. Toronto: University of Toronto Press.
- Ladner, K. L. (2009). Understanding the impact of self-determination on communities in crisis. *International Journal of Indigenous Health*, 5(2), 88-101.

- Lavoie, J. G., Forget, E. L., Prakash, T., Dahl, M., Martens, P., & O'Neil, J. D. (2010). Have investments in on-reserve health services and initiatives promoting community control improved First Nations' health in Manitoba?. *Social Science & Medicine*, 71(4), 717-724.
- Lincoln, E., Liang, B. A., & Mackey, T. K. (2015). Interculturalidad and Chilean health: Stakeholder perceptions and the intercultural hospital delivery model. *International Journal of Indigenous Health*, 10(2), 66-87.
- Marion Maar, B. S. C. (2004). Clearing the path for community health empowerment: Integrating health care services at an Aboriginal health access centre in rural north central Ontario. *International Journal of Indigenous Health*, 1(1), 54.
- Mashford-Pringle, A. R. (2013). *Self-Determination in Health Care: A Multiple Case Study of Four First Nations Communities in Canada* (Doctoral dissertation, University of Toronto). Minore, B., and Katt, M. (2007). *Aboriginal health care in northern Ontario: impacts of self-determination and culture*. Institute for Research on Public Policy.
- Minore, B., & Katt, M. (2007). *Aboriginal health care in northern Ontario: impacts of self-determination and culture*. Institute for Research on Public Policy.
- Montenegro, R. A., & Stephens, C. (2006). Indigenous health in Latin America and the Caribbean. *The Lancet*, 367(9525), 1859-1869.
- Nishnawbe-Aski Nation (NAN). (2016). *Nationhood: Governance Secretariat*. Retrieved from <http://www.nan.on.ca/article/governance-secretariat-355.asp>
- O'Neil, J., Bartlett, J., & Mignone, J. (2005). *Best Practices in Intercultural Health: Report Prepared for the Inter-American Development Bank and the Pan American Health Organization*. Centre for Aboriginal Health Research, University of Manitoba.
- Pan American Health Organization (PAHO) (2012). *Healthcare expenditure and financing in Latin American and the Caribbean*. Retrieved from http://www.paho.org/hq/index.php?option=com_docman&task=doc_view&gid=20057&Itemid=2518
- Park, Y. (2006). *The state, Mapuche communities, and multicultural social policy: a comparative study of three intercultural hospitals in Chile*.

- Peren, H. (2007). Revival of Maya medicine and impact for its social and political recognition (in Guatemala). Health Systems Knowledge Network of the World Health Organization's Commission on Social Determinants of Health.
- Popay J, Escorel S, Herández M, Johnston H, Mathieson J, Rispel L: Understanding and Tackling Social Exclusion: Final Report to the WHO Commission on Social Determinants of Health. Lancaster: WHO; 2008.
- PIES de Occidente. (2013). Plan estrategico Asociacion PIES de Occidente 2014-2018. Retrieved from <http://www.asociacionpiesdeoccidente.org/assets/plan-estrat%C3%A9gico-pies-2014-2018.pdf>
- PIES de Occidente. (2014). Medicina indigena en guatemala: una mirada historica y prospectiva jurídica. Retrieved from [http://www.asociacionpiesdeoccidente.org/assets/medicina-ind%C3%ADgena-en-guatemala-una-mirada-hist%C3%B3rica-y-prospectiva-jur%C3%ADdica-\(1\).pdf](http://www.asociacionpiesdeoccidente.org/assets/medicina-ind%C3%ADgena-en-guatemala-una-mirada-hist%C3%B3rica-y-prospectiva-jur%C3%ADdica-(1).pdf)
- Ruano, A. L., Sánchez, S., Jerez, F. J., & Flores, W. (2014). Making the post-MDG global health goals relevant for highly inequitable societies: findings from a consultation with marginalized populations in Guatemala. *International journal for equity in health*, 13(1), 1.
- Torri, M. C. (2012). Intercultural health practices: Towards an equal recognition between indigenous medicine and biomedicine? A case study from Chile. *Health Care Analysis*, 20(1), 31-49.
- van Dijk, M., Ruiz, M. J., Letona, D., & García, S. G. (2013). Ensuring intercultural maternal health care for Mayan women in Guatemala: a qualitative assessment. *Culture, health & sexuality*, 15(sup3), S365-S382.
- World Health Organization (WHO). (2001). Legal Status of Traditional Medicine and Complementary/Alternative Medicine: A Worldwide Review. Retrieved from <http://apps.who.int/medicinedocs/en/d/Jh2943e/5.11.html>

Appendix A.

Tables

Table 1. Self-determination Criteria

Self-determination Criteria	Structured Criteria
Ability to make community decisions about health care	<p>-First Nations leadership (Band and/or health) can make decisions about policies, programs, services and staffing for community health care</p> <p>-First Nations Community leadership holistically develops policies, programs and services with knowledge of the impact on the health of the community members</p>
Leadership capacity	<p>-The leadership is knowledgeable about health and health care with a vision of future directions to improve the health of the community.</p>
Funding	<p>-First Nations communities have or are advocating for funding to provide the necessary programs, services and health care in the community</p> <p>-Health transfer funding is provided for secondary and tertiary services like diabetes in the community</p>
Collaboration & Communication	<p>-First Nations leadership collaborates and/or partners with federal, provincial and/or local governments to improve the health and health care in community</p> <p>-Communications between health workers, community and band leaders are working well.</p>

Based on own norms, laws and cultures	-First Nations have control of policies, programs and laws that incorporate their norms, laws and cultures.
Clear boundaries	-First Nations must establish clear boundaries around legal, political, policy, and health to have self-determination

Retrieved from Mashford-Pringle, 2013, p. 68