Health, health communication, and identity in (unrecognized) Indian Country: A community-based research project with the Brothertown Indian Nation

By

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Abstract

As of 2017, there are 566 federally recognized American Indian tribes in the United States today. However, little is known about the hundreds of federally unrecognized tribes, including the Brothertown Indian Nation (BIN) of Wisconsin.

This research develops a better understanding of the Brothertown Indian Nation, and potentially other unrecognized Indian nations, especially relating to the issues of health, health communication, and identity. This research was completed using a community-based, Indigenous approach, which means that BIN citizens maintained control of the research questions, overall plan, and resulting data.

Semi-structured, in-depth interviews were conducted with a broad cross-section of BIN citizens and were co-analyzed with the research liaison of the BIN. These data showed that there is not a consensus about what it means to be a BIN citizen. Additionally, these data showed that the BIN has many strengths and positive social norms, including a dedicated volunteer base, family connections, a diversity of citizens, a commitment to consensus, highly educated citizens, and pride in community. These data also showed the challenges BIN citizens perceive for themselves, including the participation of future generations, geographic distance, maintaining its volunteer force, and exclusion of its citizens and others.

This research contributes information about health promotion and health communication in the Brothertown community. Most BIN citizens have access to health insurance and care through private insurance or federal programs. BIN citizens have many of the same health concerns as their federally recognized counterparts, including diabetes, hypertension, heart disease, obesity and its complications, inactivity, mental

health problems, and substance abuse issues. Additionally, they prefer to access their health information interpersonally from family or trusted physicians, and some have limited utility for online information. These data presented many opportunities for positive health communication strategies moving forward using framing theory, the Theory of Planned Behavior, and narrative communication theory.

Alongside the BIN research liaison, a series of recommendations were made which resulted in the development of health communication strategy to improve BIN citizens' access to health care and information.

Chapter 1: Introduction

I believe it is because I am a poor Indian. I Can't help that God has made me So; I did not make my self so. – Samson Occom

The Brothertown Indian Nation (BIN) is the only non-federally recognized Indian nation in the state of Wisconsin. Today, the BIN continues to operate as a tribe out of a leased community center in Fond du Lac, Wisconsin with a tribal government, events, and various initiatives. It has an enrollment of around 3,000 people who are located in all 50 states. As with many Indian nations, they have a robust, complex, rich history whose effects ripple yet today.

Little is known in the academic literature about the experiences of citizens of unrecognized tribes, even though there are over 300 unrecognized tribes in the United States today (Office of Federal Acknowledgement, 2017). This lack of knowledge extends into the health and health care delivery realms, as well. However, the academic literature is robust concerning the health of federally recognized American Indians. American Indians have some of the worst health outcomes of any racial group in the United States, and are at an increased risk of diabetes, hypertension, certain types of cancers, substance abuse, suicide, and accidental injury (American Indian and Alaska Native Populations, 2014). These health disparities are in no small part due to social determinants of health, or social conditions that worsen health outcomes. For American Indians, these include lower socioeconomic status, lower education levels, intergenerational trauma, and difficulty accessing health care. American Indians do have access to Indian Health Service, a federal health agency that provides access to some health services as per treaty agreements with Indian nations. These clinics, typically located on or near Indian reservations, typically provide basic services and health

information to the Indian community in which they're located. Additionally, the knowledge of the health challenges facing American Indians and the resources available to support and improve the health of citizens of federally recognized tribes has led to many successful health promotion efforts through communication strategies (e.g. Arcury, Quandty, & Dearry, 2001; English, Fairbanks, Finster, Rafelito, Luna, & Kennedy, 2008; Horn, McCracken, Dino, & Brayboy, 2006; Teufel-Shone, Siyuja, Watahomigie, & Irwin, 2006; Letiecq & Bailey, 2004).

The communication literature abounds with examples of successful strategies and campaigns to improve health, both for American Indians and other groups of people suffering from poor health outcomes. Although this is by no means an exhaustive discussion of that literature, theories of framing, narrative communication, tailoring and targeting, and behavior change have laid an extensive foundation for health communication strategies.

Framing theory looks at how a piece of information is characterized, typically by highlighting some pieces of information and not others (Scheufele & Tewksbury, 2007). This theory was initially examined by Kahneman and Tversky, who were looking at how highlighting different pieces of information changed peoples' decisions and evaluation of options presented to them (Kahneman & Tversky, 1979). Framing has since been studied in the health communication literature to present information in ways that resonate with audience's underlying schema, or ways of thinking, to encourage people to make positive choices in regards to their health.

Often, framing in the health communication field focuses on highlighting either the risks and benefits of a particular action or inaction. For example, presenting

information about what one can gain from an illness prevention strategy can be more effective in changing behavior than presenting information about what one can lose with some audiences (Gallagher & Updegraff, 2012). Other studies have looked at how a risk itself is framed, finding that a risk presented in relative terms was more persuasive than a risk presented in absolute terms (Malenka, Baron, Johansen, Wahrenberger, & Ross, 1993). However, framing effects can be difficult to identify in real-world contexts, as the social context of the message delivery can have effects, as well (Rothman & Salovey, 1997).

Framing can additionally be moderated by several other variables. The actual behavior one is hoping to affect can change the effects of framing as well. For example, the certainty of the utility of the behavior can affect framing's influence. This means that the gains one receives from brushing one's teeth are clearer (and thus more receptive to gain-focused framing) than the gains one receives from getting a flu shot (Latimer, Salovey, & Rothman, 2007). Framing effects can also be affected by the individual and their tendencies. For instance, an individual's tendency to seek out positive outcomes or avoid negative outcomes can moderate the effectiveness of an issue's framing (Mann, Sherman, & Updegraff, 2004).

Narrative communication can also play an important role in health communication. Storytelling, or narrative communication, is a common way of communicating in general through dramas, personal experiences, or historical accounts (Hinyard & Kreuter, 2007). Narratives are especially relevant in American Indian cultures, where oral tradition and storytelling have been the primary way to share information instead of texts and the written word (Fixico, 2003). The use of narratives

has proven to be effective in changing a variety of health behaviors. For example, using narratives as part of a broader HIV/AIDS health intervention gave people real-life examples of of how to prevent the illness, which proved effective (Fishbein, Higgins, Rietmeijer, & Wolitski, 1999). Narratives can be adapted so they are able to provide culturally-specific information, which may resonate more with targeted audiences (Larkey & Hecht, 2010). For example, the National Cancer Institute's Centers of Excellence in Cancer Communication Research initiative worked with African Americans to collect narratives to develop culture-specific messaging to promote mammography (Hinyard & Kreuter, 2007). Baezconde-Garbanti et al (2014) found that developing a culturally-grounded narrative intervention targeted to Mexican-American women significantly increased rates of cervical cancer screening. Larkey & Gonzalez (2007) also found positive results using a narrative intervention to promote colorectal cancer screening in the Latino population.

Culture-specific information can also be added to health communication through tailoring, or individualizing communications for their target audiences. Tailoring changes components of the message to make it more relevant, which hopefully supports a larger behavioral change in response to the message (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008). For example, a message may contain cultural references, appropriate language, or a call-to-action that is culturally relevant for the individual.

Lastly, behavior change theories may identify factors affecting behavior change and provide helpful information to support positive behavior change. The Health Belief Model states that when one is likely to engage in a behavior, one weighs the perceived benefits of a behavior against its perceived barriers while considering the perceived threat

of a behavior, one's sense of self-efficacy, and any calls for action (Rosenstock, 1974). The Theory of Planned Behavior states that one's attitudes about a behavior combine with social norms surrounding the behavior and perceived barriers and self-efficacy regarding the behavior to predict the intent to perform a behavior (Ajzen, 1985). These behavior change theories give us a foundational understanding of some variables that go into determining one's health choices and behaviors. Therefore, we may be able to develop an understanding of these variables in a community and then influence them through strategic interventions, utilizing message-related theories such as framing, tailoring, and narrative communication, to promote healthier behaviors.

Although many of these health communication strategies have been used with federally recognized American Indian tribes, little is known about health and health communication in unrecognized tribes. Citizens of unrecognized Indian nations do not have access to Indian Health Service-funded care, grant funding, and other resources. There is no academic literature about how they access health care and information, or how other parts of their experience as citizens of unrecognized Indian nations might be affecting their health and health outcomes. We do not know how to best support the health and well-being of those American Indians who are not seen as such in the eyes of the federal government.

In this study, I used a community-based, asset-driven qualitative approach to address these issues in collaboration with citizens of the BIN. Guided by the research interests of tribal citizens, I conducted in-depth interviews to explore the experiences of BIN citizens around their health and develop communication strategies to address access to care and other issues impacting their health and well-being.

As a non-Indian, White academic researcher, it is important that I ground this work within the confines of my own identity and experience. Throughout this process, I have tried to keep in mind the history and strength of American Indian peoples, knowing that I, as an outsider, can never truly understand the Native experience. I have also tried to be aware of my own privilege as a White academic researcher and use it for the goal of social justice whenever possible.

Because I am using Indigenous research methods for my project, I would also like to begin this paper by explaining the background development of my perspective. I am writing as White, educated, middle class heterosexual cis-gender woman, which means that I have not had to face the adversity and oppression that many others must encounter on a daily basis. I have had the financial, social, and cultural resources to pursue my graduate education relatively easily. I have no American Indian ancestry and cannot personally relate to many of the issues facing Native peoples today. I am working to be aware of my own privilege personally and professionally.

In particular, White privilege refers to the concept and reality that in the United States and other countries, those considered to be White (an arbitrary distinction which has changed throughout the years) have societal advantages over people of color (Andersen, Taylor, & Logio, 2014). As McIntosh (1988) states:

> I have come to see white privilege as an invisible package of unearned assets that I can count on cashing in each day, but about which I was 'meant' to remain oblivious. White privilege is like an invisible weightless knapsack of special provisions, maps, passports, codebooks, visas, clothes, tools, and blank checks. (pp.1-2)

This privilege manifests itself in many ways, but at heart, it means that I am able to enjoy many privileges that are not as accessible to people of color, and often I am ignorant of what these privileges are at all.

White privilege can also show itself in society and culture in myriad ways. For example, there are some values that are arguably inherently White, yet are typically perceived to be values for society as a whole. These include perfectionism, a sense of urgency, defensiveness, valuing quantity over quality, worship of the written word, paternalism, either/or thinking, power hoarding, fear of open conflict, individualism, and the belief in objectivity (Jones & Okun, 2001).

There are also many other sets of privileges and structures that dictate what is a preferred identity over an oppressed or subordinated identity. For example, males are privileged over females, heterosexuals are privileged over members of the LGBTQ+ community, able-bodied individuals are privileged over individuals with disabilities, and so forth.

In this project, I have done my best to think about my own social identities and how they affect how I interact with the world in general and this project in particular. I carry with me an enormous amount of privilege. Unpacking that is a lifelong venture, but working on my awareness has meant several things for this project. First, it meant that a community-based approach was essential for my own academic and personal self. Such an approach (described in later chapters) has allowed me to work against the traditional, positivist academic view. Second, I have tried to manage my privilege by stepping back whenever possible, which also follows with the community-based approach. This makes space for other voices into conversations and helps bring awareness to situations in which I might take up too much space. Third, I have tried to be open and authentic in how I present myself so that I may share my own vulnerabilities and remove some of the power

from my own position. Finally, I have worked to remain nonjudgmental and open to differences in my work with BIN citizens.

These are far from perfect attempts to understand and mitigate my own privilege. However, I feel this is a piece of the research process that is not necessarily discussed openly, and I am working to be as transparent as possible in this project. In this research, I hope I can use these resources to make space for someone else to have a chance to speak; to work toward equity, social justice, and humanity; and to step back so that others have room to step forward and be heard.

Chapter 2: The Brothertown Indian Nation

The history of the Brothertown Indian Nation (BIN) as a distinct nation goes back to 1785, but the Brothertown people had come together in years earlier, in large part due to their shared Christian beliefs (Jarvis, 2010; Ottery & Ottery, 1989). The BIN was formed by members of several different nations located in the Northeastern United States – Pequot at Groton, Massachusetts; Pequot at Stonington, Connecticut; Narragansett; Montauk; Eastern and Western Niantic; Mohegan; and Tunxis (Jarvis, 2010). The nation formed largely due to three leaders: Samson Occom, Joseph Johnson (Samson's son-in-law), and David Fowler (Samson's brother-in-law) (Jarvis, 2010; Ottery & Ottery, 1989). Occom was considered to be a great Christian preacher and teacher, acting as a missionary to other tribes. At the end of 1765, he was sent to England by Eleazar Wheelock, a European settler and missionary (Ottery & Ottery, 1989). There, he delivered sermons and raised funds for the purposes of starting a school for American Indians back in his home territory. However, Wheelock used the funds Occom had collected to start Dartmouth College, which is not a school for American Indians (Jarvis, 2010; Ottery & Ottery, 1989).

After this event, Occom, Johnson, and Fowler determined that if their people were to survive and flourish, they would need to move away from the colonized population to different lands. By moving, the Brothertown believed they would have the necessary land to support themselves through agriculture, as well as hunting and gathering. They would also be able to establish a solid Christian community. In other words, their people would be able to survive.

When the tribes of the Brothertown came together officially in 1785, it was in part because of their shared Christianity, which had been introduced to them through European settlers and missionaries (Jarvis, 2010). Although historians have interpreted the Brothertown's commitment to Christianity in various ways, it can be viewed as a mechanism meant to keep the community strong and to maintain a foothold in a changing world, which was increasingly unfriendly to Indigenous peoples. As Jarvis (2010) states:

> Bonds of kinship and common history united this diverse community, and its residents constructed a cohesive identity upon the basis of Christian themes of brotherhood. The melding of aspects of Anglo-American culture with traditional Algonquian cultural mores did not signal assimilation. Rather such accommodation functioned to ensure Brothertown survival amid the forces of colonialism. (p. 233)

The Brothertown people organized several moves at various times during and after their formation as a nation. First, they moved to Oneida land in New York, as they had good relations with the Oneida, who also had land reserved for them in New York (Ottery & Ottery, 1989; Jarvis, 2010). Occom believed it was necessary "to hold land which could not be alienated. This was because when problems arose these Indians were tempted to sell themselves out of house and home to solve them" (Ottery & Ottery, 1989, p. 43). This move to New York started in 1774 due to a treaty with the Oneida, but it would not be their last relocation. Although by 1813, they had a thriving agricultural-based community, forces beyond their control (e.g. federal prompts, the encroachment of European settlers, etc.) were still pushing them westward. Their settlement in New York had decreased in size for many years at the insistence of White settlers and many BIN citizens were concerned about maintaining their lands (Ottery & Ottery, 1989). Their leadership also suffered during this time; Occom died in 1792 and Fowler died in 1807 (Love, 1894). Joseph Johnson died sometime between 1775 and 1776. He had been an

important negotiating figure in the Brothertown's dealings with the Oneida, and his loss was undoubtedly very detrimental to the leadership of the new nation (Ottery & Ottery, 1989). In addition, the Revolutionary War had devastated many of the Indian nations in the Northeast. Although the Brothertown offered a declaration of neutrality, they ultimately showed more loyalty to the revolutionaries and were repaid with the ransacking, burning, and destroying of their settlements by British forces, as well as with the death of many of their young men through warfare (Ottery & Ottery, 1989).

After Occom's death in 1792, the Brothertown leadership struggled. Several more moves were imminent. A planned move to the White River in Indiana, encouraged by the government and agreed upon by the Miami and Delaware, was stalled at the 11th hour when the U.S. government bought the land from underneath the Brothertown (Silverman, 2010). Ultimately, in 1822, they secured a plot of land eight miles wide and thirty miles long along Lake Winnebago in what would become Wisconsin through a treaty with the U.S. government and began moving to Wisconsin in the 1830s (Ottery & Ottery, 1989). However, after significant negotiations and signing five treaties with the U.S. government, the Ho-Chunk, and the Menominee, when all was said and done, the Brothertown received a plot of 23,040 acres (Ottery & Ottery, 1989). They moved slowly to their new land, but upon their arrival, the U.S. government wanted them to relocate almost immediately; it appears the U.S. government learned the Brothertown had acquired fertile farmland. Under the Indian Removal Act, the U.S. government sought to relocate the Brothertown to Kansas (Jarvis, 2010). To resist that move, in 1834 Brothertown petitioned to receive U.S. citizenship, which would allow individual citizens

to own land (Jarvis, 2010). In 1839, their requests were granted (Ottery & Ottery, 1989; Jarvis, 2010).

Although ultimately all citizens of Indian nations would receive U.S. citizenship and thus dual citizen status (Jarvis, 2010), the Brothertown were unique – and indeed some of the first American Indians to receive U.S. citizenship – in their acceptance at this time. Accepting U.S. citizenship along with their land acquisition was seen as a way to ensure they could not be removed West (particularly to Kansas), as was occurring to many other Indian nations (Jarvis, 2010). Although perhaps counterintuitive and certainly argued against, owning land and accepting citizenship can be viewed as a way to hold onto their cultural and religious values and traditions. At the time, many outsiders saw the Brothertown's history and existence as the ultimate American Indian assimilation (Commuck, 1859). However, that is not how the Brothertown see their history and themselves, and more modern historians have offered differing views. For example, Jarvis (2010) states:

> Brothertown emerged as a response to colonialism and consequently it constituted a movement away from English physical and political encroachment. But the town also developed within, and reflected many elements of, the broader colonial world surrounding it…Although the residents were Christians, the men did the farming and the government resembled that of a New England town, yet Brothertown also retained traditional emphases on communal land ownership, a sharing of political authority, and the importance of kinship. Thus Brothertown seemed to meld many aspects of Native and English cultural traditions. (p.121)

In other words, accepting citizenship and binding themselves to land in Wisconsin may have been seen by the Brothertown as a way to strengthen their cultural heritage, economic viability, and stability as a nation. Historians from within the Brothertown community, as well as those outside the BIN, argue that accepting citizenship was a way to gain a foothold in this new, hostile world; it was a way to ensure their survival and

protect their assets. Taking this view, accepting citizenship was not seen as relinquishing their status as a sovereign nation, nor did those moves deny their "Indianness" (Cipolla, 2013; Jarvis, 2010; Ottery & Ottery, 1989). If anything, these actions were meant to bring together the Brothertown people and strengthen their community and sovereignty.

Yet this strength of community would be continually challenged in Wisconsin. In 1839, the Wisconsin Enquirer stated "the red man is doomed to be exterminated! – and the white man will not cease to follow in his footsteps until the last Indian will have trod to the shores of the Pacific!" (Wisconsin Enquirer, 1839, p. 3, col.1). Nevertheless, although their land was eventually bought by non-Brothertown individuals through a variety of often-unscrupulous means, the BIN continued to operate as a sovereign nation,. As U.S. citizens, Brothertown citizens were now subject to taxation and foreclosure, with which many previously had little or no experience. This was compounded by the difficulty in some areas for Brothertown citizens to find economically sustaining employment, especially during financial crises of the 1850s and 1890s (Brothertown Indian Nation, 2012). The inability to pay taxes could lead to foreclosure and confiscation of the plat and its purchase by settlers, who were rapidly emigrating to Wisconsin. Adding to this challenge, land speculators could illegitimately force sale of property. Historically, the Brothertown (and many of their fellow Indian nations) operated through communalism and interdependence (Silverman, 2010). They were undoubtedly not wholly sophisticated landowners – indeed, they did not come to Wisconsin to engage in the property market, but instead were typically devoted farmers, hunters, and gatherers. As their population grew, it became challenging for young people to farm and live off the original land, which also led to the scattering of BIN citizens. It

seems that a guiding desire behind the Brothertown's quest for citizenship was not necessarily so they could further assimilate, but rather so its people could be left alone. These challenges ultimately meant that the Brothertown's original land settlement was filled with European settlers (Silverman, 2010; Jarvis, 2010).

Throughout these struggles, their government remained generally intact and they interacted with the U.S. government as a sovereign nation (Cipolla, 2013). In the 1940s through the 1960s, the U.S. government targeted many nations across the country for official termination (Getches, Wilkinson, & Williams, 2005). Although the U.S. government had actually terminated the BIN in 1839, they still interacted with the BIN during this period of termination.

In 1954, the Department of the Interior released a memo stating: "about 3,600 members of the Oneida Tribe residing in Wisconsin" would be affected by an upcoming termination bill (Department of the Interior, 1954). Although that memo only discusses the Oneida, it may also have been referring to other tribes, including the BIN, as evidenced by litigation that the Oneida, Stockbridge-Munsee, and Brothertown began in the 1950s for land claims and to fight termination. They ultimately were rewarded some $38.5 million. In this proceeding, the Department of the Interior stated that the "Indian Claims Commission Awards Over $38.5 Million to Indian Tribes in 1964," going on to say that the Emigrant Indians of New York are "now known as the Oneidas, Stockbridge-Munsee, and Brotherton Indians of Wisconsin" (Department of the Interior, 1965). This judgment did not state that the Brothertown were indeed terminated in the eyes of the federal government at that time, although interestingly, Brothertown citizens did not have to pay federal taxes on these monies. The U.S. government did ask at this time that the

BIN update their rolls, another indication that the BIN was not necessarily seen as an unrecognized tribe at this time.

In 1978, the Department of the Interior released official guidelines for tribes seeking federal recognition. Many recommendations have been made to change these criteria and the Office of Acknowledgment itself has acknowledged that the system needs major changes (Department of the Interior, 2016). At one senate hearing, John Norwood, a tribal leader of the Nanticoke Lenni-Lenape Tribe of New Jersey, said, "Increasingly, indigenous and American Indian are being redefined as 'federally recognized' based upon a history and process that is known to be hostile, unreasonable, unfair, racially biased, and demeaning to nonfederally recognized historically documented tribes.…This increasing denial of identity equates to a process of administrative genocide, in which nonfederally recognized citizens are being systematically wiped from the political landscape," (Toensing, 2012).

At present, the criteria for recognition include these criteria:

1. The tribe has operated continuously since 1900
2. The tribe has operated and continues to operate as a distinct community
3. There is a political structure that has influence over citizens
4. Evidence of membership and government procedures
5. Members descend from a group that historically functioned as a single political entity
6. Members are primarily not also enrolled in other tribes
7. The group has not been expressly terminated (Department of the Interior, 2016).

Robert Fowler, a BIN citizen and lawyer, began putting together the tribal roll in the 1970s (Indian Country Wisconsin, n.d.). In 1980, the BIN submitted its letter of intent to petition for federal recognition, one of 332 tribes who would do so by 2008 (Lambert, 2010). In 1990, the Department of the Interior released a judgment stating that accepting citizenship was not equivalent to termination, which seems to relate directly to the BIN's

case (Lambert, 2010). In 1996, the BIN submitted a complete petition to the Bureau of Indian Affairs (Lambert, 2010). In 2012, the Department of the Interior finally stated that the BIN cannot seek federal recognition from the Department of the Interior. Following the seventh criterion for acknowledgement, it stated that because the BIN was terminated by an Act of Congress in 1839, only an Act of Congress can reinstate their federal recognition, (Brothertown Indian Nation, 2012).

Despite the federal government's unwillingness to acknowledge that the BIN as a sovereign nation, other Indian nations and the state of Wisconsin do formally recognize the BIN as a sovereign nation (Proposed finding against acknowledgement of the Brothertown Indian Nation, 2009; Ottery & Ottery, 1989). Throughout their history in Wisconsin, the Brothertown have acted as a sovereign nation, even without the recognition of the United States government. At this juncture, however, it would take an Act of Congress to reinstate their federal recognition.

Regaining federal recognition is important to the Brothertown community. Federal recognition would not only further legitimize the Brothertown's identity, it could provide them with access to federal resources and services that could have significant impacts on the community and its citizens (Department of the Interior, 2014).

Recognition

At this juncture, I find it prudent to discuss what it means to be a federally recognized tribe. A federally recognized tribe has a right to self-government, tribal sovereignty, and self-determination as recognized by the United States government (Tribal nations of the United States, 2015). This means that these tribes can form and enact their own government, laws, taxes, and regulations. They have the same limitations

as states. Often, the relationships between tribes and the US government were defined by treaties, which typically described land boundaries, hunting and fishing rights, US protection, and the provision of economic assistance for tribes from the US government for provisions such as housing, education, and health care. As sovereign nations, tribes have entered into trust relationships with the US government, which means the US provides protection for the tribe's right to self-govern and protects tribal assets.

Despite the relationship between tribal governments and the US government, the US government is frequently seen as not fulfilling its obligations. For example, the US is obligated to provide free health care through Indian Health Service (IHS) as part of its treaty obligations (Tribal Nations of the United States, 2015). Indian Health Service operates through hospitals and clinics nationwide, and care at IHS-funded facilities is free for those eligible for care. Those eligible for care include one who:

A. Is of Indian and/or Alaska Native descent as evidenced by one or more of the following factors:
    1. Is regarded by the community in which he lives as an Indian OR Alaska Native;
    2. Is a member, enrolled or otherwise, of an Indian or Alaska Native Tribe or Group under Federal supervision;
    3. Resides on tax-exempt land or owns restricted property;
    4. Actively participates in tribal affairs;
    5. Any other reasonable factor indicative of Indian descent; or
B. Is an Indian of Canadian or Mexican origin, recognized by any Indian tribe or group as a member of an Indian community served by the Indian Health program; or
C. Is a non-Indian woman pregnant with an eligible Indian's child for the duration of her pregnancy through postpartum (usually 6 weeks); or
D. Is a non-Indian member of an eligible Indian's household and the medical officer in charge determines that services are necessary to control a public health hazard or an acute infectious disease which constitutes a public health hazard.
(Indian health manual, 2016).

As a federal program, the IHS is funded through the federal government. In 2013, IHS received 0.12% of the federal budget. In 2014, IHS spent $3,107 per person on healthcare expenses, compared to $8,097 nationally (Fiscal year 2017 Indian Country budget request, 2016). In contrast, in 2011 the median amount spent per person on

prisoner health care costs was over $5,000 (State prison health care spending, 2014). Therefore, many argue that the IHS is very underfunded and its budget needs to be broadly expanded. The National Congress of American Indians estimates that American Indians have effectively lost $6.2 billion during the last 30 years because the IHS budget has not increased with need and inflation (Fiscal year 2017 Indian Country budget request, 2016). Each tribe manages the funds it receives from IHS, but due to this chronic underfunding, facilities often have to limit the care they can provide. This underfunding pattern has gone on for decades – and some argue, since the program's inception (U.S. Commission on Civil Rights, 2003).

Although it is clear that programs, especially health services, are not funded to the needed levels, these are still resources that federally-recognized tribes have access to that nonrecognized tribes do not. In 2015, around $20 billion was slated for expenditures for American Indian programs and services, which would come to around $35,273,368 per tribe (Fogarty, 2015). Clearly, there are significant negative financial implications for the BIN's lack of federal recognition.

Although the rules of membership in recognized tribes have changed through the years, currently, recognized tribes are able to self-determine their membership rules. This policy began under President Richard Nixon, who said "to strengthen the Indian's sense of autonomy without threatening his sense of community. And we must make it clear that Indians can become independent of Federal control without being cut off from Federal concern and Federal support" (Brownell, 2001, p. 277).

There are presently an unknown number of federally unrecognized tribes in the United States. To date, there are 33 tribal nations that have been denied recognition by

the Office of Federal Acknowledgement (Office of Federal Acknowledgement, 2017b). However, there are many other tribes who have not gone through the acknowledgement process. There are also many individuals who self-identify as American Indians, far more than can be accounted for by births (Kohn, 2014). Additionally, there are people who have American Indian heritage but cannot belong to a recognized tribe because they do not qualify under blood quantum rules (Schmidt, 2011). Through these means – belonging to an unrecognized tribe, self-identifying as American Indian for some reason, or having clear American Indian heritage yet having too little blood quantum for enrollment – there are 5.4 million people in the United States who identify as American Indian, yet around 1.9 million citizens of recognized tribes (United States Census Bureau, 2014; Bureau of Indian Affairs, 2017).

Adaptation strategies

Regardless, the process for federal recognition is cumbersome, challenging, and has critics on all sides. As Miller (2004) states:

> During the 1970s, however, the BIA and recognized tribes rejected more liberal and inclusive modes of acknowledging Indian entities, instead insisting upon prodigious amounts of written proof of ancestry, political leadership, community functioning, and outside verification of Indianness. The BIA dismissed self-identification, oral testimonials, and a people's own unique sense of community and social organization as proof of tribal identity. Instead, the bureaucracy designed a comprehensive template for federal tribalism. (p. 257)

The struggle to obtain federal recognition has not stopped BIN and other unrecognized tribes from continuing to operate and preserving their culture. Some tribes have embraced their non-recognition. The chief of the Bear Clan of the Avogel tribe, John Mayeux, said, "Once you start taking money from the government, they want to tell you how to run the tribe, and we want to stay with our traditions, our language, our

culture," (Talamo, 2016). From this viewpoint, not having federal recognition could offer a tribe the freedom to not abide by federal rules. There could be concern that once recognition is received, the federal government could take it away again, which means that the work put into receiving recognition was for naught and the tribe's structure and programs would change once again (Talamo, 2016).

Unrecognized tribal members also often describe their knowledge of their own identity, although this has not been explored at great length in the academic literature. Citizens of unrecognized tribes have described how they have always known of their "Indian-ness" as evidenced by Albert Naquin, the chief of the Isle de Jean Charles band of the Biloxi-Chitimacha-Choctaw in Louisiana, who said simply "When I was a child, I was an Indian" (Talamo, 2016). These citizens of unrecognized tribes, like the BIN, often have histories of political governance, cultural traditions, and community cohesion (Miller, 2004). Regardless of whether or not they receive recognition, they will continue to operate to the best of their abilities as a sovereign nation.

The BIN, like many other nations, continues to struggle through the acknowledgement process, which is costly and time-consuming. It functions as a nation and a community, keeping government appointments, holding events, with its members supporting one another. The Brothertown government, although it has evolved to reflect the changing needs of the world and the nation itself, focuses on consensus, rather than a winner-takes-all policy (Brothertown Indian Nation, 2012b). The nation's government includes a Tribal Council, elected by the membership to perform specific tasks and come together to help lead the nation. The government also includes Peacemakers, who are also elected and must be 55 years of age. This office dates back to 1796, when the BIN was

first granted land in New York by the Oneida (Brothertown Indian Nation, 2012c). At that time, the Peacemakers were given the task of dividing up the land in a fair, honest, and compassionate fashion. Throughout history, Peacemakers have been called upon to act on judicial matters, interpret the BIN Constitution, and settle appeals and controversies. This sovereign history and unique political structure, along with the history that is still in the making today, describes a resilient, dedicated people committed to revitalization and to each other. These factors are undoubtedly important pieces of their cultural identity. Christianity is still present in their culture today, as well, as prayers are part of celebrations and meetings (Cipolla, 2013).

Family is also an important part of cultural identity for many Brothertown people. At the Council meetings of the BIN that I've attended, meetings begin by stating who you are and your family history. Three men –Samson Occom, Joseph Johnson, and David Fowler – founded the Brothertown and extensive genealogy work has allowed many Brothertown to trace their lineage back to the origins of their ancestors (Jarvis, 2010; Cipolla, 2013; Ottery & Ottery, 1989). This strong sense of family and lineage is an important part of their culture; it helps ground members in remembering who they are, from whom they came, and what is important to them.

Colonialism

In discussing the specific history and characteristics of the BIN, I wish also to give a brief overview of some larger American Indian history, as well. Native Americans had a rich and long history before the arrival of European settlers. Although it is not appropriate for me to discuss the creation stories of different Indian tribes, many (if not all) American Indian nations know they existed on Turtle Island (North America) since

the beginning of time. They formed many hundreds of distinctive cultural units that had their own practices, beliefs, traditions, and relationships with other nations. Although population estimates are uncertain, they range from 2.1 million to 18 million around 10,000 years ago (Kennedy, Cohen, & Bailey, 2006). However, this history and existence was not appreciated by European settlers, who initially arrived in L'Anse aux Meadows in Newfoundland in the year 1000 and began arriving in 1492 for the purpose of colonization, or taking of the land and resources by force (McManamon, Cordell, Lightfoot, & Milner, 2009). That marked the beginning of colonization of American Indians, which some scholars argue continues today through laws and policies, such as mass incarceration (Morgensen, 2011; Alexander, 2010).

This period marked the beginning of intentional harm done to Native communities across what would become the United States. As Legters (1988) states, these harms include:

> ...coerced abandonment of religious and cultural underpinnings of the subject society, preemption or destruction of resources necessary to native survival... transmittal of disease and addiction against which native populations have inadequate immunity, disruption of kinship and familial relations basic to the native social structure, treatment based on modes of definition that obliterate a group's identity, and finally, outright extermination of native populations. (pp. 771-772)

As colonizers encroached onto lands where Native people were living, conflict arose on a number of fronts, and Native peoples were subject to a variety of hostile policies from the United States government, which generally tried to obtain Native lands for its own sale or use. For many or most Native people, ownership was not a utilized or well-understood concept. "For American Indians, land, plants, and animals are considered sacred relatives, far beyond a concept of property. Their loss became a source of grief," (Yellow Horse Brave Heart & DeBruyn, 1998, p. 62). Native nations entered

into treaty agreements regarding land and resource use and rights with the United States, yet these treaties were often poorly understood due to the differing ideological constructions of Native peoples and the U.S. Additionally, these treaties were often not upheld by the U.S., and legal battles continue today regarding treaty rights (e.g. Hersher, 2017). As European colonizers spread throughout North America, conflict was inevitable, whether in named military conflicts (such as the Creek War), in government-sanctioned militia battles, or in interpersonal interactions between Native peoples and colonizers. Although many conflicts between the United States and American Indians occurred during named conflicts, others received less historical attention. For example, Madley (2016) describes government-sanctioned acts of violence against American Indians in California during the mid-1800s. While these were sometimes perpetrated by civilians individually or in groups, other acts of violence were carried out by military forces. During an 1850 incident, prompted by the killing of two slaveowners by American Indians, the federal infantry and cavalry attacked a village in Clear Lake and took an estimated 800 lives.

Colonization extended beyond military maneuvering. George Washington developed a plan to "civilize" Native peoples, as he believed their societies were inferior (Remini, 2010). This effort encouraged organizations (often religious in nature) to work to convert American Indians to Christianity and provide European-style education. The Indian Removal Act of 1830 legalized the forcible and violent removal of Native peoples from their ancestral lands and homes to reservations (Library of Congress, 2017). This policy would be influential for decades, prompting military conflicts as Indians resisted their removal and fought to stay on their ancestral lands. Theodore Roosevelt said, "I

don't go so far as to think that the only good Indians are dead Indians, but I believe nine out of ten are, and I shouldn't like to inquire too closely into the case of the tenth" (Carney, 1999, pp. 65-66). American Indians did not only face military and political threats; they also faced threats to their own mortality through the introduction of European diseases for which Indians lacked immunity, such as smallpox (Kohn, 2007). At times, these diseases were purposely introduced into Native communities as a kind of biological warfare. Between military conflicts, removal, and disease, Native populations declined precipitously. In 1800, 600,000 Indians remained in the US, and that number declined to 250,000 by 1890 (Thornton, 1990).

As part of attempts to "civilize" Indians, the US established boarding schools to "acculturate" Indian children so they could be part of mainstream American society. This involved removing (often forcibly) children from their homes and families at young ages and sending them to (often Christian) boarding schools where they were supposed to shed their Native identities (including language and customs) to become "American." The model for these schools was the Carlisle Indian Industrial School, at which educators were encouraged to "Kill the Indian, save the child" (Hultgren, 1989).

Native peoples were further encouraged to assimilate into mainstream society in the 20th century. In 1956, the Indian Relocation Act encouraged Indians to leave their reservations to seek employment in designated urban areas (Robbins, 1992). This act gave funds for moving expenses and some educational expenses. As a result, those who left their reservations were socially and physically isolated from their communities, often faced discrimination and reduced opportunity due to race (such as redlining policies that drastically limited their housing potential), and often lived in areas targeted for urban

renewal, which made their housing situations precarious. Tribal communities often saw their populations decrease, which led to instability of tribal governments.

Although we may think of colonization as a government policy of the past, the repercussions of the European colonization of the United States reverberate today in myriad ways. As described above, Native peoples have been subject to genocide, forced acculturation, removal, discrimination, abuse, and disenfranchisement.

What's more, citizens of federally recognized tribes have several communication challenges around the past and present of colonization. Despite these myriad injustices, federally recognized tribes have been unable to effectively communicate about them to mainstream America. As a result, these issues, and their resulting health disparities (to be discussed in the next chapter), are of little relevance to the majority of Americans. This challenge is compounded for citizens of unrecognized nations, such as the Brothertown. In reality, then, American Indians face a twofold challenge: colonization and its aftereffects, and the inability to communicate effectively about them.

Chapter 3: Health disparities and health communication

Now that I have discussed some of the history of the Brothertown Indian Nation, I can begin to contextualize the health of and healthcare for American Indians in general and the Brothertown Indian Nation in particular. However, this can only be done with a clear understanding of the state of healthcare and an explanation of health disparities in the United States. In this chapter, I will go into greater detail about health disparities and inequities, health disparities in American Indians, the role of culture in health, and a framework for health equity.

The average cost of healthcare in the United States was $10,345 per person in 2016, a total of $3.35 trillion (Alonso-Zaldivar, 2016). This cost is thousands of dollars more than any other developed country, yet the United States lags behind similar countries in measures of quality of care, access to care, efficiency, and equity (Davis, Stremikis, Squires, & Schoen, 2014). Davis et al's (2014) report showed that access to care is dependent on several factors, including one's income and the fact that patients were likely to go without care because of cost. The report also showed that the U.S. is lagging behind on important indicators of healthy lives: infant mortality, mortality amenable to medical care, and healthy life expectancy at age 60.

Compounding these issues, these poor health outcomes are not equally distributed among all individuals in the United States. Racial and ethnic minorities, hereafter described as people of color, consistently have worse health outcomes than their White peers; the gap between these outcomes is called a health disparity (Smedley, Stith, & Nelson, 2003). In 2003, a committee of medical professionals, researchers, and scientists

released *Unequal treatment: Confronting racial and ethnic disparities in health care*, a detailed report about health disparities in the United States edited by Smedley, Stith, and Nelson. They found that:

> Racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities, even when access-related factors, such as patients' insurance status and income, are controlled. The sources of these disparities are complex, are rooted in historic and contemporary inequities, and involve many participants at several levels, including health systems, their administrative and bureaucratic processes, utilization managers, healthcare professionals, and patients. (p. 1)

This report details several reasons for the persistence of these disparities. At the macro level, health disparities are created and affected by the healthcare system and other institutions, while at the micro level, they are affected by individuals interacting with their own health and those influencing their health. Additionally, these disparities develop from deeper root causes. The healthcare system may put in place cultural and linguistic barriers, decrease incentives to offer affordable care to patients of color, and limit the physical locations where people of color can receive care. Disparities may also persist because of negative clinical interactions stemming from prejudice against people of color, stereotypes relating to behavior and health behavior, and increased uncertainty in interactions with patients of color.

Health disparities in American Indians

In the American Indian (AI) population, health disparities are particularly prevalent. According to the Indian Health Service (IHS), AIs are expected to live 4.2 fewer years than all races in the U.S. population (Indian Health Service, 2015). They also are affected at higher rates with chronic liver disease, diabetes, unintentional injuries, assault, suicide, and chronic lower respiratory diseases. The Centers for Disease Control and Prevention point out that AIs also have worse mental health outcomes, higher infant

mortality, higher rates of alcohol and tobacco use, and higher teen pregnancy rates than the average American citizen (American Indian and Alaska Native Populations, 2014).

The Great Lakes Intertribal Epidemiology Center has also examined health outcomes specifically for AIs in the Great Lakes area (Michigan, Minnesota, and Wisconsin) (Great Lakes Inter-Tribal Epidemiology Center, 2010). In their report, they found that AIs are less likely to have attained a high school or college degree, earn less money, and face higher rates of unemployment when compared to all races. AI families are more likely to be single-parent households, as well. Similar to national AI health disparities, AIs in the Great Lakes region have higher rates of all cancers, liver disease, diseases of the heart, influenza, pneumonia, suicide, unintentional injury, diabetes, and diseases of the kidney. They also had higher infant mortality rates, higher teen births, and far higher rates of Sudden Infant Death Syndrome than all other races.

Culture and health disparities

One's culture can – and often does – affect health disparities. Although there are many definitions of culture, scholars typically agree that culture is what people learn from and share with each other, often from generation to generation (Kreuter & McClure, 2004). Culture can encompass values, norms, social roles, communication styles, rules, patterns of social interactions, and belief systems, among other things (Kreuter & McClure, 2004; Larkey & Hecht, 2011). Culture can be thought of as "the way we do things around here," (Martin, 2006, p.1). Culture is more complicated than proxies that are often used in place of culture, such as socioeconomic status, race, ethnicity, gender, and so on (Kreuter & McClure, 2004). Singer (2012) uses several sources to craft a definition of culture, stating that it is:

> the blueprint or guiding framework behind a population group's conscious and unconscious actions, or the 'toolkit' for living life, solving problems, and informing decisions…Culture is 1) learned from birth through the processes of language acquisition and socialization, 2) shared by all members of the same cultural group, 3) an adaptation to specific environmental and technical conditions, and therefore, 4) a dynamic, ever-changing process. (p. 357)

Individuals, therefore, are part of several cultures, and these cultures and cultural identities have implications for health disparities. For BIN citizens, there may be additional cultural factors at play, especially given their federally unrecognized status.

Macro level

At the macro level, policies, institutions, and organizations may not be culturally sensitive to people of color or those in less privileged social positions (e.g. LGBTQ individuals, the homeless, ethnic groups). At a societal level, one's social determinants of health are important factors in health disparities. These determinants encompass the social factors that can influence an individual's health: relationships, positions occupied in social and economic structures, ethnicity, race, gender, and so forth (Link & Phelan, 1995; Marmot, 2005). These social factors are extremely important in determining one's access to resources, be they health insurance, paid sick days, time, energy, and money to eat well and exercise, social support, or money to pay for treatments. Because our access to these resources is far from equal, it follows that we will have differential health and healthcare outcomes, as well. Although resource access may initially seem to be less related to health, in fact, it can play an important role in one's health. At the macro level, one's social determinants of health vary depending on the culture one identifies with and is a part of.

In the context of the Brothertown Indian Nation, a hugely influential macro level social determinant of health is their unrecognized federal status, which means they do not

have access to health services and structures that are available to federally recognized tribes, such as the Indian Health Service, the ability to apply for many federal grants, and other resources and grants specifically for federally recognized tribes. This is in addition to the health implications of their American Indian identity, which will be described in a later chapter.

Additionally, organizations, institutions, and policies tend to be culturally responsive to some groups and not others, continuing to lead to health disparities. Some of these system-level barriers to equitable care include complicated healthcare reimbursement and other systems, which may present difficulty for those with low English literacy levels (Smedley et al, 2003). Other healthcare materials may not be presented in patients' native languages, or in understandable language, presenting a significant barrier (Smedley et al, 2003). As someone with multiple advanced degrees, I can attest – healthcare communications are often difficult to understand. Given that the Brothertown Indians share English as a common language, English language barriers do not exist as they do for other Indian nations such as the Navajo, but they may still experience difficulty understanding complicated health communications.

Patients of color may also not have geographic access to high quality healthcare facilities and practitioners, yet another structural barrier (Smedley et al, 2003). For other American Indians besides BIN citizens, this can mean that Indian Health Service clinics are geographically inaccessible – or they may be limited in what they can provide due to fluctuating budgets. Individuals may also simply not be able to afford quality insurance, which further limits the care they receive (Smedley et al, 2003). Although citizens of federally recognized nations have access to care and clinics through Indian Health

Service, BIN citizens do not, and must rely on other sources of insurance for their healthcare; however, they may face the same geographic challenges of other people of color when accessing care. At a systemic level, these barriers present significant challenges for patients of color who are part of other cultures, resulting in health disparities.

People of color are also underrepresented in the healthcare fields. Nine percent of physicians in the United States are African American, Asian American, Hispanic, or American Indian (Smedley et al, 2003). Nurses fare slightly better – around 12.3% of nurses are people of color (Smedley et al, 2003). This lack of diversity in the healthcare field has historical roots that are still affecting people today; during the 20th century, medical schools were not desegregated until the late 1960s (Byrd & Clayton, 2003). People of color report higher satisfaction when they interact with other people of color in the healthcare setting, which can lead to better patient adherence to medical protocols and a higher likelihood of seeking medical assistance (Smedley et al, 2003). These data show the importance of including people of color in the healthcare system, yet still today people of color are underrepresented or excluded at many levels of the healthcare system and infrastructure. These disparities are especially grim when American Indians specifically are considered. Although American Indians make up 1.7% of the U.S. population, they represent only 0.4% of the nursing workforce and less than 0.4% of physicians (Weintraub et al, 2015).

People of color may also face additional structural difficulties in accessing care. People of color report difficulty in accessing even basic care, whether due to lack of insurance, lack of transportation, or lack of healthcare facilities in their geographic area,

among others (Lillie-Blanton, Martinez, & Salganicoff, 2001). They also report difficulty in accessing specialist care for different diseases and illnesses (e.g. visiting an odolaryngologist for ear, nose, and throat issues). Eight percent of Whites report having difficulty accessing a specialist for health problems, while 16%, 22%, and 26% of African Americans, Hispanics, and Asian Americans respectively report the same challenge (Collins, Hall, & Neuhaus, 1999).

Micro level

Culture also plays a role at the micro, or individual level of health and healthcare. A patient of color may be subject to discrimination, stereotypes, and biases (both implicit and explicit) at the interpersonal level, resulting in worse care. Although many people believe they are not prejudiced and do not hold stereotypes about people of color, that is simply not true. All people have implicit biases, and those biases have significant implications for health disparities (Dovidio, Hewstone, Glick, & Esses, 2010; Dovidio, Penner, Albrecht, Norton, Gaertner, & Shelton, 2008). For example, if a physician implicitly assumes that an American Indian patient will be less compliant with medical instructions, she may treat that patient in a more condescending or patronizing way. In turn, this may activate the patient's defense mechanisms, increasing her distrust for her physician, which then makes her less likely to comply with her physician's instructions. In essence, a self-fulfilling prophecy is created and carried out.

Other cultural factors can influence health at the micro level. Members of different cultures may have specific histories that contribute to individual-level health effects. Many people of color, including American Indians, experience historical or intergenerational trauma. Consider one example of intergenerational trauma: AIs have a

long, generally negative history with the United States, often involving genocide, forced enculturation, disrespect, segregation, forced removal, and prohibition of spiritual and cultural practices (Stannard, 1992; Thornton, 1987). This history, and the resulting historical trauma, can result in the adoption of negative health behaviors as coping mechanisms, such as increased tobacco and alcohol use, sedentary lifestyles, and obesity (Burhansstipanov, 2012). It may also contribute to poor standards of living for many AIs, including increased poverty rates, unsafe work environments, and a lack of adequate water supplies and waste disposal facilities (Burhansstipanov, 2012). As such, historical trauma is passed down intergenerationally, contributing to poor health outcomes.

Additionally, differences in cultural values between many American Indian nations and values typically held by majority citizens of the United States may lead to stress and poor health outcomes (Yellow Horse Brave Heart, 1999; Whitbeck, McMorris, Hoyt, Stubben, & La Fromboise, 2002). The stress of holding and communicating cultural beliefs that are not accepted or valued in a society in which one lives can cause depressive symptoms, psychological distress, and possibly self-destructive or antisocial behaviors (Duran & Duran, 1995; Beauvais, 1998; Whitbeck et al, 2002). This stress is compounded by discrimination.

Culture interacts with health disparities in a variety of ways at the macro and micro levels. Ultimately, many of these factors come down to discrimination against groups that are not in the majority, a cultural group's access to resources, and the assumption that all people will interact with the healthcare system in the same way. Therefore, as we work to eliminate these health disparities, we must be aware of their roots and how they are connected. Rather than looking at a health disparity and assuming

there is one root cause, addressing the interplay between these systems means assuming there are multiple factors at work and responding as such.

Chronic stress

Chronic stress adds another layer of complication on health disparities. Stress is the body's response to a demand (National Institute of Mental Health, 2017). This demand on the body can be positive (e.g. feeling motivated for a job interview) or negative (e.g. the death of a spouse). At a basic level, stress creates predictable physiological changes. These include increased muscle tension, rapid breathing, increased heart rate, increased blood pressure, an increase in the stress hormones adrenaline, noradrenaline and cortisol, gastrointestinal changes, and an aroused sympathetic nervous system (American Psychological Association, 2017). This is often known as the "fight or flight" response, as a stress response occurs when the body is under direct threat, such as a threat from an attacker which would require a person to fight or flee for their own safety. Adrenaline helps airways to dilate, redirects blood towards the heart and lungs, decreases the pain response, heightens awareness, and sends glucose into the bloodstream (Hormone Health Network, 2017). Noradrenaline helps to increase the heart rate, dilates the eyes, and helps redirect blood flow to the heart and brain (Net Doctor, 2014). Cortisol increases blood glucose, suppresses the digestive and reproductive systems, inhibits growth, and reduces inflammation (Mayo Clinic, 2016). These physiological changes occur so the person would have the best chance of survival in the situation. In the short term, the stress response is very important for the survival of threatening situations.

However, the stress response does not limit itself to only life or death situations. We experience stress in a variety of other situations. Stress can come from mental challenges (worrying about problems or challenges); noisy, crowded, or unsanitary living conditions; isolation (mentally or physically, and for any number of reasons, such as physical/mental health conditions, discrimination, or lack of a social support system); and other kinds of displeasure and discomfort in everyday living situations (Academic Success Center, n.d.). Although in the short term, stress effects are similar to those listed above, if one regularly and routinely experiences stress responses, it is considered chronic stress. Chronic stress manifests itself in a multitude of ways, including but not limited to changes in appetite, fatigue, chronic pain, mood and personality changes, changes in sleep patterns, decreased mental capabilities, and an ineffective immune response (Academic Success Center, n.d.).

This exposure to stress has serious health implications. Chronic stress can shorten one's telomeres (protective casing on DNA), which can accelerate the aging process and increase risk of heart disease, cancer, and diabetes (Lu, 2014). Therefore, chronic stress contributes to the onset and progression of many chronic diseases affecting a multitude of bodily systems. The effects of stress can even change the type of food we crave, further contributing to poor health outcomes. Dallman et al (2003) found that people who are exposed to stress are more driven to eat food that is typically considered comfort food (foods containing sucrose and/or fat) food that is very palatable, which can lead to obesity. The effects of repetitive, constant stress can be more detrimental than the effect a single challenge. According to Braveman, Egerter, and Williams (2011):

> The accumulated strain from trying, with inadequate resources, to cope with daily challenges may, over time, lead to more physiological damage than would a single dramatically stressful event. A recent collection of papers summarizes current knowledge

> of pathways and biological mechanisms likely to be involved in the health effects of stress and other psychosocial factors—including perceived control, subjective social status, and social support. (p. 388)

In short, chronic stress is incredibly damaging. Its physiological responses affect virtually all systems of the body negatively. Chronic stress is not always produced by singular events that we often associate with stress, such as the death of a loved one. Instead, stress can occur from the daily grind of life, the myriad of problems that are out of one's control, and the social structures that make up the fabric of our lives.

And as with other health problems and diseases, chronic stress does not affect all people equally. Chronic stress is hugely influenced by the social determinants of health (Figure 1). The stress of coping with decreased resources, whether they are financial, social, or otherwise, is immense. This is compounded by the stress of discrimination, racism, and living within systems of oppression. This damage often begins in childhood and its effects are lifelong. As Notterman and Mitchell (2015) state:

> Recent evidence demonstrates that the chronic stress of social disadvantage, socioeconomic inequality, and racial discrimination act through a variety of biological pathways to influence health, including: neuroendocrine, developmental, immunologic, and vascular mechanisms. In response to stressful events cortisol, cytokines, and other intermediates are released, and if there is long-term, repetitive or chronic exposure, these substances may damage key physiologic systems. (p. 1228)

In other words, stress does not simply affect individuals in the short-term; it can affect a number of systems longitudinally. Additionally, the effects of stress can physiologically affect an individual long after the source of the stress as gone, as Notterman and Mitchell (2015) describe:

> One of the largest and most consistently replicated literatures demonstrates the negative effects of social disadvantage in childhood on later child and adult health, socio-emotional wellbeing, and cognitive ability. This literature shows that childhood social disadvantage works through a variety of complex mechanisms to result in dramatically different developmental outcomes, which are often apparent even in childhood, but which are typically more fully manifest in adulthood. Indeed, there is evidence that early

> childhood disadvantage appears to leave a "biological residue" which in turn has effects on development, health and wellbeing. (p. 1228)

The stress we encounter as children can manifest throughout the life course. If children do not transition into better circumstances as adults, they are not able to escape the cycles of chronic stress, ultimately leading to increased risk of injury, disease, and death.

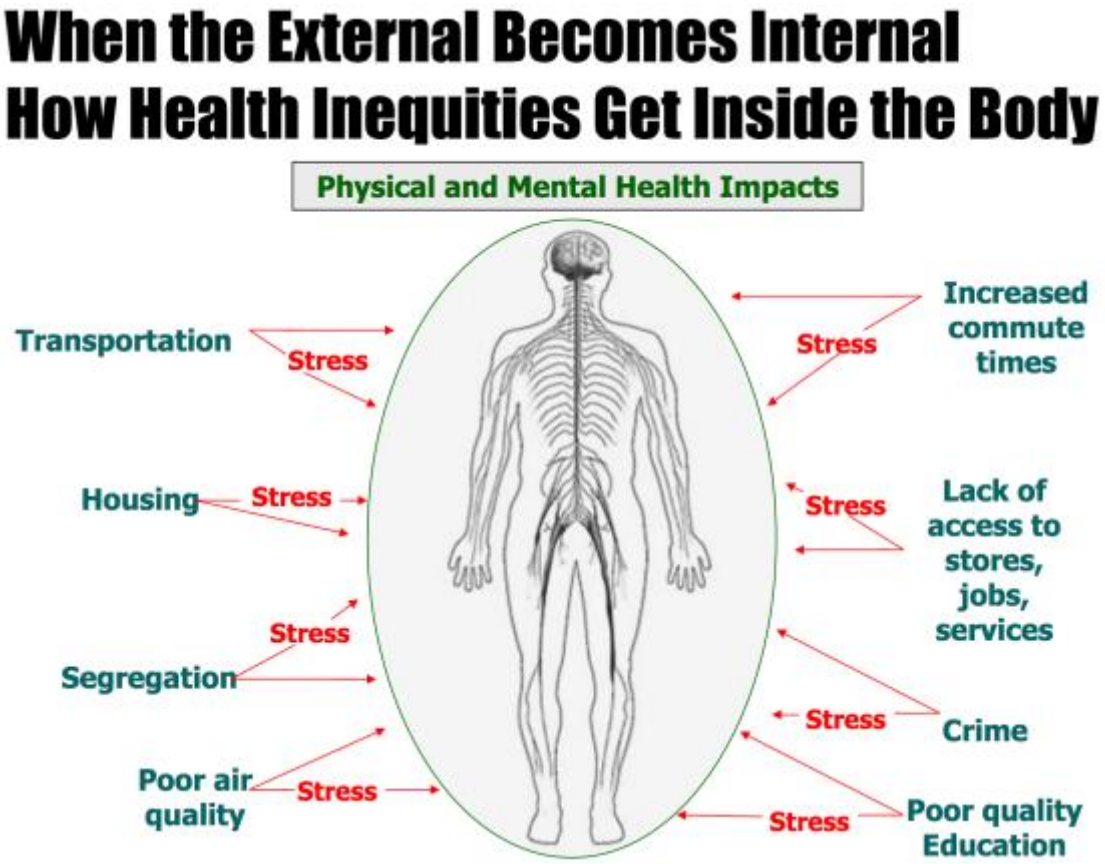


Figure 1 The effects of chronic stress (Alameda County Department of Public Health, 2016)

Addressing root causes

Health is not merely the absence of disease, but "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 2006, p.1). Although health disparities are unequal health outcomes, they have complex root causes, which in turn affect one's social determinants of health. Social determinants of health "are the structural determinants and conditions in which

people are born, grow, live, and age. They include factors like socioeconomic status, education, the physical environment, employment, and social support networks, as well as access to health care" (Heiman & Artiga, 2015). In other words, health outcomes are the symptoms of underlying upstream problems (see Figure 1). These upstream problems include differential treatment at the ideological, institutional, interpersonal, and internal levels based on class, race/ethnicity, immigration status, gender, and sexual orientation, among other kinds of social identity. Social inequities based on these categorizations affect one's social determinants of health

The root causes of health disparities can be understood as follows: one's social identities are tied to institutional power (or lack thereof) in some way, through the government, educational systems, financial systems, and so on. These institutional powers affect how one is able to live during daily life. Those daily living conditions in turn affect one's risk behaviors, prevalence of disease and injury, and ultimately morbidity and mortality.

For example, American Indians have a complex history in the United States, out of which developed ideologies about what it is to be an American Indian, such as the perception of Indians as savages who were less than White people. This is oppression at the ideological level. These ideologies led those in political power (e.g. the federal U.S. government) to create policies and institutions that interacted with AIs in specific ways. For instance, through specific policies like the Indian Appropriations Act of 1851, the U.S. government created reservations and forced Native peoples to live on small tracts of land, often far away from the lands on which they originally lived (Bennett, 2008). This is oppression at the institutional level.

In turn, these policies affected how AIs went through daily life. Many were unable to live on the lands they were used to. Often, they were unable to hunt, fish, and gather as they had been. They were geographically isolated from other kinds of economic opportunity. The government provided food for them, which was often unhealthy and highly processed (e.g. white flour, sugar). These changes had huge ramifications for their everyday living conditions. For many AIs, their diets were less nutritious and contained more sugar, fats, and calories than their traditional diets, directly leading to health problems. Unable to partake in many traditional ways of life and expected to become part of the new economic society, they were now isolated from many economic opportunities on reservations, leading to poverty and financial hardship. This means people had fewer resources with which to care for themselves and their families. All of these changes also were stressful, contributing to poor health outcomes. These are examples of how this oppression manifests at the interpersonal level.

Finally, all of these changes can lead to the development of internalized oppression, or the internal struggle one experiencing oppression has with the oppressor's beliefs. In this scenario, an American Indian individual may internalize messages of being "less than" or necessary of isolation. This can lead to poor self-concept, depression, or other mental health problems, which one might self-medicate with drugs, alcohol, or other risky behaviors.

From the above example, it is clear that there are root causes to the social determinants of health. In considering health, we are often more familiar and comfortable with the downstream outcomes, such as diseases, illnesses, and injuries. Many health promotion programs focus on curing or preventing a disease. For example, health

education specialists may promote increased consumption of fruits and vegetables to help prevent many diseases. However, if people live in a "food desert" or a location where healthy foods are difficult to access, they may not have easy access to produce (Story, Kaphingst, Robinson-o'Brien, & Glanz, 2008*)*. If their living arrangements do not include a large refrigerator, they may not be able to store produce efficiently. To solve these intermediary problems, we have to consider why they are occurring – what are the root causes? That may be because a city's planning committee has not considered the health needs of lower-income people when planning new grocery stores or developing low-income housing. Individuals may need access to low-income housing because their family members are incarcerated at disproportionate levels, limiting the family's income potential – for example, American Indians are incarcerated at higher rates than Whites, and Native men are incarcerated at four times the rate of White men (Greenfeld & Smith, 1999; Nakota Lives Matter, 2015). Therefore, one root cause of this problem might therefore be that a racial or ethnic minority is systematically targeted for criminal behavior and incarceration. Addressing this problem may therefore increase the consumption of fruits and vegetables through this long, convoluted chain.

This is known as a health equity approach (Figure 2) (American Public Health Association, 2017). This may seem, and often is, more complicated than treating diseases and illnesses as they arise. However, the health equity approach targets problems upstream, rather than downstream. It focuses on creating meaningful equity in those places and spaces where inequity has festered and caused these gaps and disparities.

Health equity also focuses on empowerment, which can be defined as "the capacity of individuals, groups, and/or communities to take control of their

circumstances, exercise power and achieve their own goals, and the process by which, individually and collectively, they are able to help themselves and others to maximize the quality of their lives" (Adams, 2008). In order for equity to flourish, those who have been disempowered must be empowered. This also means that they need to have access to and control over the resources they need (Perkins & Zimmerman, 1995).

When we use a health equity approach that acknowledges the root causes of health disparities in the context of American Indians in general and the Brothertown Indian Nation in particular, we are left with several questions that focus on both the policy level and the individual level.

At the policy level, what policies are in place to ensure that a certain tribe or nation and its individuals have equal access to care, such as the current funding of the Indian Health Service? How are these issues being communicated to the broader public, policymakers, and American Indians themselves? What communication strategies are at play to improve the health of American Indians? What is being done to empower American Indians at an institutional level and address historical, intergenerational trauma?

At the individual level, we are left with different questions: can citizens of a tribe easily access a quality clinic? If the care they need is unavailable at a clinic, can they easily access specialty services? At that clinic, can they interact with someone who has received cultural sensitivity training to increase the positivity of the interaction and attempt to decrease implicit bias? Can they interact with a fellow AI? What other historical factors, such as intergenerational trauma, may be adding to this individual's poor health outcomes? What sort of resource access does this individual have? How have

history and institutional discrimination influenced this resource access? How does that resource access affect the available food choices, time spent exercising, social support, and stress levels? These questions help show the interplay between the different systems and illuminate some of the challenges of health disparities, as well as the importance of utilizing a health equity framework.

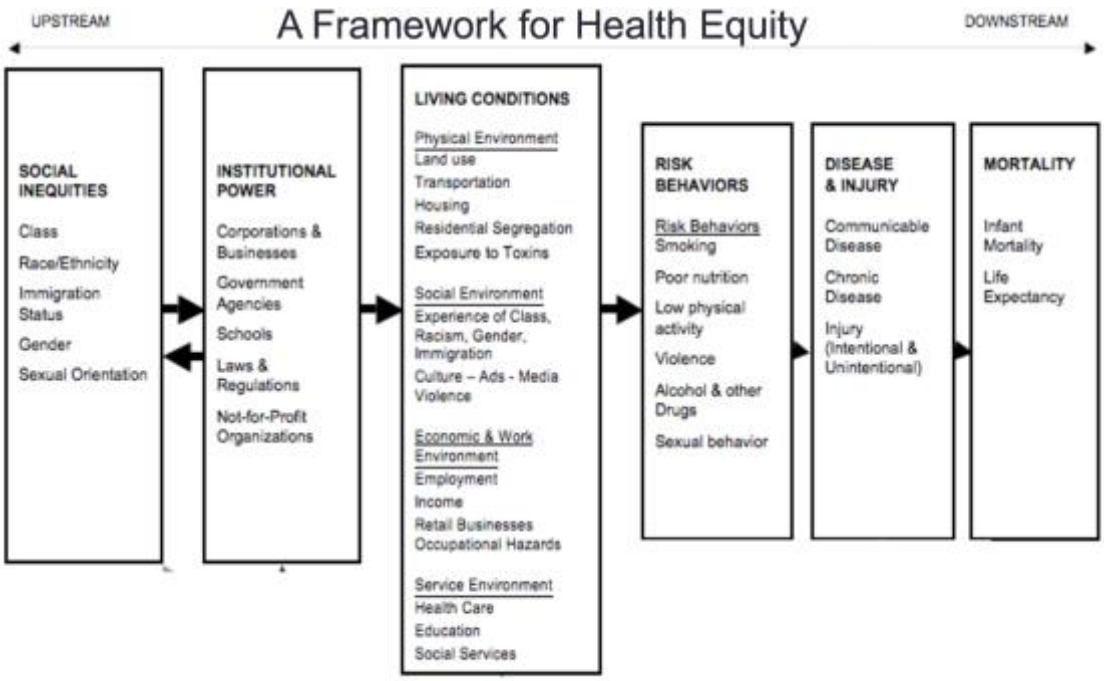


Figure 2 A Framework for Health Equity (Bay Area Regional Health Inequities Initiative, 2015)

Health promotion research

The existence of health disparities in people of color is starting to be addressed by researchers and practitioners, and there are several solutions that have been put forth in the health communication literature. First, it is important to consider the role of culture in understanding and addressing health behaviors. Second, increasing patient trust can have

several positive effects on patient health. Third, those working in healthcare should be aware of their own prejudices and biases and actively work against them through cultural competence and other training. Fourth, policy-level changes can affect health disparities, such as the Affordable Care Act.

Using a culturally responsive approach

One important way to decrease health disparities is work toward a system of healthcare and health communication that is culturally competent or culturally responsive. Betancourt, Green, Carillo, and Ananeh-Firempong (2003) describe a culturally competent health care system "as one that acknowledges and incorporates – at all levels – the importance of culture, assessment of cross-cultural relations, vigilance toward the dynamics that result from cultural differences, expansion of cultural knowledge, and adaptation of services to meet culturally unique needs" (p. 34).

This may mean developing individual-level health behavioral and communication interventions that put culture at the front of the program. Indeed, health disparities are often presented as a result of individual-level behaviors rather than a result of social determinants (Niederdeppe, Bigman, Gonzalez & Gollust, 2013). When the focus is on individual-level behaviors, scholars have tried to include culture into a behavioral intervention in several ways. Barrera, Castro, Strycker, and Toobert (2013) describe several different ways of including culture in an already established behavioral intervention. Often, this means working with communities to incorporate culture into an intervention in some way, whether that means the community itself develops an intervention or adds cultural elements to an existing program. These authors stress that

culture should be considered at all phases of the research and may mean using different presentation or content strategies in the intervention itself.

There are many examples in which American Indian nations incorporate cultural elements into their health and wellness practices. The Navajo bring in spiritual leaders to perform Blessing Way ceremonies to emphasize healing, creation, harmony, and peace (McCloskey, 2007). Different tribes may also use the placenta for ceremonial purposes after childbirth (Independent Placenta Encapsulation Network, 2017). Many Native cultures, including the Brothertown, use smudging as a way to cultivate healing and wellness during specific ceremonies, or simply as a part of other gatherings (Schultz, 2017). Developing a sense of cultural awareness can extend beyond special interactions and into everyday practices and interactions, as well. Healthcare professionals can develop an understanding of the customs and traditions of different cultures, and then work to be respectful of those traditions in interactions. For example, many Indigenous people prefer interpersonal interactions instead of phone or written exchanges (Hodge, Pasqua, Marquez, & Geishirt-Cantrell, 2002). As such, healthcare professionals can be sensitive to this by prioritizing face-to-face interactions for healthcare conversations, rather than communicating by phone or email. With the BIN, then, this literature indicates that community members should be involved throughout the research process and culture should be continually considered.

Culture can also be considered when creating and distributing health information. Many American Indians prefer visual information as opposed to large blocks of text (Geana, Greiner, Cully, Talawyma, & Daley, 2012). Therefore, information crafted for an American Indian audience might look different than information designed for a White

audience. Such information can be tailored so it resonates with and is appealing to members of a culture. Cultural targeting can include several strategies, including peripheral, or using packaging to appeal to a given group (e.g. colors, images, titles); evidential, or enhancing the relevance of a topic for a cultural group; linguistic, or using the group's dominant language; constituent-involving, or drawing on the experience of the cultural group; and sociocultural, or discussing health issues in terms of the sociocultural values held by the cultural group (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2002). These strategies can make messages more relevant, appealing, and informative for a cultural group.

However, it is important to keep in mind that culture is not a simple variable to incorporate into a research plan. All too often, culture is boiled down as a risk factor for a disease or health condition, and may be considered as a dichotomous variable, resulting in a view of culture that is lacking in substance, does not consider culture holistically, and is often patronizing to members of that culture (Singer, 2012).

Using a culture-centered approach generally also means using a participatory research approach. To truly include culture in a meaningful way, experts recommend using participatory methods, coconstructive data gathering and analysis, and producing community-driven results that are meaningful to the community (Dutta, Anaele, & Jones, 2013; Dutta, 2008). Ultimately, community members are experts in their own culture, and in order for a research approach to incorporate culture, community members must be involved in the research process.

Addressing culture through specific communication strategies

There are many ways to successfully integrate culture into health communication plans and messaging to address health disparities through health promotion strategies, as well. Barrera, Castro, and Holleran Steiker (2011) outline four approaches for integrating culture into health campaigns: a research-driven process that uses formative research to understand a specific cultural group's risk factors and then designs an intervention, an approach in which community members add cultural elements to a theory-based intervention, an indigenous framework in which the intervention is driven by members of the cultural group, and an evidence-based intervention that is adapted for a specific cultural group. In other words, there are several ways to include culture and cultural elements to a health communication strategy. Regardless of the strategy applied, health communication theory can provide insight into strategy development.

The culture itself may guide the use of a communication theory with a community. For example, framing theory can be used to better understand how to work with the cultural values of individualism and collectivism (Sherman, Uskul, & Updegraff, 2011; Uskul & Oyserman, 2010; Uskul, Sherman, & Fitzgibbon, 2009). Typically, cultures that are high in individualistic cultures tend to value personal autonomy, self-expression, and agency, and tend to believe that individuals can (and should) causally determine decisions and actions, pursue opportunities, and focus on positive outcomes (Han & Shavitt, 1994). Alternatively, collectivistic cultures, tend to believe that the self is more so defined by social relationships and is thus embedded in social context. Collectivist cultures tend to focus on group decision-making, social harmony, responsibilities, and preventing mistakes (Han & Shavitt, 1994). Research looking at health message framing has found that people in individualistic cultures tend to focus

more on health promotion and respond better to gain-framed messages (e.g. you will gain a healthy life by exercising regularly), while people in collectivist cultures tend to be more prevention focused and respond better to loss-framed messages (e.g. you could lose your happy lifestyle if you don't exercise) (Uskul, Sherman, & Fitzgibbon, 2009). This cultural framing has proven to be effective in health messaging; individuals can even be primed with identity-specific messages to help them further identify with a specific culture and elicit a stronger response to collectivism or individualism.

The Theory of Planned Behavior states that one's attitudes, social norms, perceived self-efficacy, and barriers toward a behavior influence one's intentions to perform a behavior, which is a strong predictor of actually performing the behavior (Ajzen, 1985). These variables may be affected by culture, and so considering culture when assessing them can help with the development of appropriate health communication materials. Self-efficacy, or one's belief that they can accomplish a behavior, may be affected by a culture's sense of individualism or collectivism. Individualistic cultures and societies put higher weight on an individual's sense of self-efficacy, meaning that an individual is responsible for their own decisions and should make decisions for their own benefit, rather than for the benefit of the larger group (Hofstede, 2001). One's sense of self-efficacy may have important health implications. If one does not believe they are in control of their own fate, then they may not believe they have the power to change behaviors affecting their health. If one is part of a collectivist culture, on the other hand, one may believe they must make decisions that will benefit the group, increasing their self-efficacy in behaviors that positively affect the larger group. Self-efficacy may also be affected by an individual's feeling of empowerment, which is related to one's cultural

identity. A member of a disenfranchised, marginalized minority group may have lower feelings of self-efficacy for a variety of behaviors because they feel an overall sense of disempowerment. Taylor (2000) explored this in the context of alcohol use among American Indians, finding that individuals who felt culturally disempowered also had lower self-efficacy in resisting alcohol abuse. Scott and Dearing (2012) also examined the role of self-efficacy in American Indian youths battling depression, looking at how one's cultural identity either enhanced or detracted from one's sense of self-efficacy.

Culture may interact with other Theory of Planned Behavior variables, as well. Kostick, Schensul, Singh, Pelto, and Saggurti (2011) point out that it's crucial to think about community and cultural norms when considering health promotion, as doing so can lead to "better absorption and institutionalization of intervention activities and principles by implementing organizations, increased capacity of community members and organizations to mobilize resources, technical assistance, researcher involvement, and public support for existing or developing programs" (p. 2). Kulis, Napoli, and Marsiglia (2002) also examined how cultural factors affect behavioral norms, finding that ethnic pride and biculturalism were able to enhance positive behavioral norms. In other words, drawing on cultural pride can help community members build on positive behaviors they are already doing. Culture may strongly affect behavioral norms if one is part of a collectivist culture, as well, as members of collectivist cultures put a lot of weight on what others around them are doing and what others expect them to do (Lee et al, 2006). These examples help show that when utilizing social norms in health communication strategies, looking toward specific cultural information can give a deeper understanding of normative behavior.

Attitudes, another piece of the Theory of Planned Behavior, may also be affected by culture. Attitudes comprise the evaluation of a behavior, or whether one believes there will be a positive or negative outcome from performing a behavior (Ajzen, 1985). Different cultures may have different beliefs about the benefits or disadvantages about a certain behavior, thus affecting an individual's attitudes. For example, Blanchard, Rhodes, Nehl, Fisher, Sparling, and Courneya, (2003) examined how different ethnic groups thought about exercise, using the Theory of Planned Behavior as a guiding framework. Indeed, these authors found that culture affected one's attitudinal beliefs about exercise, including whether exercise would relieve stress, give one energy, help one lose weight, or increase fitness. Individualistic and collectivistic cultural models may also affect one's attitudes toward a specific behavior, as well. In collectivist cultures, one's attitudes about a behavior may simply have less importance than social norms, so attitudes may not contribute to behavior in a meaningful way (Lee, Hubbard, O'Riordan, & Kim, 2006).

Culture can also be incorporated directly into messaging strategies. Kreuter & McClure (2004) recommend that culture be taken into consideration at each juncture of the communication process: source, message, channel, receiver, and destination, although the first three points are most easily modified by communicators. These authors recommend thinking about expertise, trustworthiness, and similarity of the source, message approaches, formats, order, balance, and framing, along with metaphor usage and call to action specificity in the message, and the most used channels by the audience when considering the channel. Providing culturally sensitive message sources, messages, and channels has proven to be effective in many instances (Herek et al, 1998).

Narrative communication strategies lend themselves well to cultural tailoring. For example, Larkey and Hecht (2011) suggest integrating culture throughout the creation of narrative messaging by providing engaging characters in messages, providing cultural elements in a message, allowing for transportation and identification to occur, encouraging diffusion through social interactions, and affecting social norms by changing the perceived social norms. In this way, one:

> starts with the culture to create messages rather than adding it to existing messages. Here, narratives are obtained and shaped into messages that keep much of the original content and form intact, with the intent to represent the culture and give voice to those who have participated in creating the content by sharing their stories. Members of the group even may be involved in message construction. (p. 116)

Many different intervention and outreach efforts have successfully incorporated cultural tailoring with positive effects (Barrerra et al, 2013). Some studies use cultural tailoring to influence holistic behavioral interventions that address both health information and health behaviors. For example, A 2011 study by Osuna et al modified an evidence-based diabetes intervention for Latinas in several ways. In this intervention, all materials were communicated in English and Spanish. The women in the study were encouraged to modify their traditional staple recipes to make them healthier, while maintaining the customary flavors and foods they were used to. To incorporate more physical activity into the women's lives, they were given the choice to take part in a salsa-based aerobics class. Importantly, throughout the intervention, researchers regularly sought feedback from the participants to modify the information the women received and the activities offered so they would resonate more strongly with the women.

Another successful example of cultural tailoring is the Strengthening Families Program, which focuses on substance abuse prevention for families. This program has been culturally tailored for use with many different cultural groups in the United States,

as well as in 17 other countries (Kumpfer, Pinyuchon, Melo, & Whiteside, 2008). This program's success in a wide range of cultures and spaces has been due to careful cultural tailoring, using pilot testing to guide the process of adaptation. In this intervention, researchers tailored elements such as stories, examples, pictures, and videos used in messaging, along with behavioral componentns, including songs, dances, and exercises implemented during the intervention itself.

There has been some cultural tailoring specifically with Native populations, as well. For instance, Jackson and Hodge (2010) reviewed 11 studies that culturally tailored interventions with Native youth around substance abuse and mental health behaviors. Studies that found positive results from cultural tailoring used the following approaches: local and tribal message sources; incorporating culture-specific values, beliefs, behaviors, and legends into the messages; and focusing on cooperation rather than competition.

Other studies have focused specifically on culturally tailoring health communication pieces. Kreuter et al (2004) culturally tailored cancer-focused messages for African American women using religiosity, collectivism, racial pride, present time orientation, and future time orientation. They found that these health messages were more memorable, relevant, and likable, and women were more likely to share that information with their friends than non-tailored messages. A meta-analysis examining culturally tailored diabetes information in health education sessions showed that these messages sustainably improved glycemic control and diabetes knowledge among participants (Hawthorne, Robles, Cannings-John, & Edwards, 2010). These interventions occurred with a variety of different cultural groups, including African American women (including several age groups), Mexican Americans, Puerto Ricans, South Asian British, and

Pakistani British. Health information was tailored in a variety of ways, including: adapting to literacy levels, adapting to cultural dietary customs, delivering messages from fellow community members, and adapting to cultural norms of the specific group.

Increasing patient trust

One influential cultural factor in health disparities is patient trust. People of color may bring their cultural and ethnic history with them to healthcare encounters, as well as their personal history. For instance, American Indians have a long history of negative health effects at the hands of colonizers and ultimately other Americans (e.g. alcoholism, succumbing to New World diseases, political stances, and conflicts have historically killed up to 95% of AIs), which can contribute to healthcare provider and system mistrust (Smedley et al, 2003). Additionally, the very system of the Indian Health Service, from which many AIs receive care, can be seen as paternalistic and culturally insensitive, leading to further mistrust. People of color may also experience actual or perceived mistreatment or discrimination in healthcare encounters, which contributes to a negative patient experience, poor compliance with medical directions, decreased likelihood of seeking medical attention, and ultimately, decreased trust in the healthcare system and the healthcare provider (Smedley et al, 2003). As such, patient trust is a factor in the health experience of many American Indians; overall, AIs have lower trust in their healthcare providers and the healthcare system than Whites (Simonds, Goins, Krantz, & Garroutte, 2013). In particular, AIs have lower institutional trust in the healthcare system, which may make them less likely to seek out healthcare and medical assistance. It is unknown whether this is true for the BIN, who have experienced unpredictable and unfair treatment from the federal government, which has an active hand in healthcare. Patient mistrust can

negatively affect the healthcare *provider*, as well, who is then less likely to provide vigorous treatment (Smedley et al, 2003).

Patient trust can be built in several ways. Having a consistent relationship with a healthcare provider is linked to increased trust, as well as the use of preventative care services (Smedley et al, 2003). Additionally, community health workers (such as health advisors), can improve access to care, build trust in the healthcare system and biomedicine, and educate providers about the community with whom they're working (Smedley et al, 2003). Healthcare providers themselves should receive cultural training so they can learn about and understand the complex culture of groups they're working with, as well (Smedley et al, 2003). This individual-level training should also address information about institutional factors inhibiting health equity, so that healthcare providers can see how their interactions are contributing to larger inequities. Healthcare systems should work to increase institutional trust, too, through increasing diversity in their organizations, being transparent in their policies and regulations, acknowledging health disparities and their causes and working to ameliorate them, and working to be culturally sensitive and responsive as institutions (Smedley et al, 2003; Simonds et al, 2013).

Addressing prejudice and discrimination

Although the social science literature tells us that more highly educated individuals (such as nurses and physicians) are less likely to hold prejudiced views of people of color than their uneducated counterparts, discrimination and stereotypes still affect healthcare encounters (Smedley et al, 2003). Dovidio & Fiske (2012) created a classification of different biases against groups of people, which result in certain

healthcare outcomes. In this classification system, different racial and ethnic groups are associated with various personality and behavioral traits. For example, according to this classification, poor African Americans may be considered to be low in warmth (friendliness) and low in competence (skill or ability to comply), which can elicit feelings of disgust and contempt from those with whom they interact. In the healthcare setting, this might result in passive harm, such as neglect, isolation, and treatment as though the patient is actually incompetent, and active harm, such as unnecessarily aggressive treatment. Although American Indians were not included in this particular classification, it is clear that even if healthcare professionals have warmth toward American Indians, they may still be discriminating against them in their treatment regiments. However, healthcare providers may not see their behavior as racially or ethnically motivated; they may be acting due to implicit bias.

All humans have implicit biases. These are formed socially, through our cultures, social trends in regard to race and ethnicity, and personal experiences (Smedley et al, 2003; Dovidio & Fiske, 2012; Staats, 2014). We are not aware of implicit biases, as these are deeply held biases that are formed starting at a very young age through messages we receive, but they can influence our behavior by promoting certain views of different races or ethnicities (Staats, 2014). Therefore, these implicit biases may shape a healthcare provider's behavior – sometimes in very small, yet influential ways – even if the healthcare provider is unaware of holding any prejudices. Patients of color feel the results of these biases, saying that they feel their race has negatively affected their health care (Dovidio & Fiske, 2012). We can work against these implicit biases in several ways,

including specific training, exposure to counter-stereotypical individuals, intergroup contact, deliberative processing, and taking the perspective of others (Staats, 2014).

Acknowledging these implicit biases also means acknowledging that they are a part of systems and institutional structures, as well. After all, human beings are behind the creation of these systems and institutions, and determine their policies (both in the public and private realm), their structures, and how they will operate. Acknowledging our individual-level implicit bias can allow us to recognize how these biases are played out in the operations of systems and policies, as I've discussed earlier in this chapter, and push us to make them more equitable whenever possible. Individual or micro-level biases can be played out in the structural and institutional (macro) barriers to healthcare; if these are not addressed concurrently, positive effects from changes may not be seen.

Policy-level interventions

As we know, health disparities have myriad causes, including policy-level causes. For example, in 2000, the Department of Health and Human Services (DHHS) released standards for culturally and linguistically appropriate health services (U.S. DHHS, 2000). These include ensuring that patients receive care that is understandable and respectful of cultural beliefs, imploring the recruitment of diverse staff members, and ensuring that staff receive training in culturally appropriate healthcare delivery, among others. In 2011, the DHHS released the *HHS Action Plan to Reduce Racial and Ethnic Health Disparities, an update showing that the DHHS is still committed to these goals* (National Partnership for Action, 2011).

However, another recent piece of legislation is having a large effect on healthcare in the United States: the Affordable Care Act (ACA) of 2010 – and its potential repeal in

2017. Some of its goals are increasing access to affordable, reasonable health insurance and public programs for all Americans, increasing the number and availability of community health clinics, diversifying the healthcare workforce, and providing funding for prevention and education initiatives (Kimbrough-Melton, 2013). It is also establishing federal infrastructures to reduce health disparities (National Conference of State Legislatures, 2014). There are also specific implications for American Indians. Citizens of federally recognized tribes can enroll at any time and can change plans up to once per month (U.S. Centers for Medicare and Medicaid Services, 2017). They can also qualify more easily for Medicaid and CHIP and do not have to pay a penalty for not having health insurance. These benefits would be offered to BIN citizens if BIN was federally recognized.

Although many see the ACA as a step in the right direction, there are still formidable challenges in its goals and the larger goal of reducing health disparities. About 40% of Americans don't know details of the law, how it will affect them, or how they can get coverage, and there is less overall awareness of the aspects of the law focusing on prevention and primary care (Kimbrough-Melton, 2013). Additionally, the ACA does not address the environmental and socioeconomic factors that prevent people from accessing quality health care and leading healthy lives, and it does not address all the structural barriers to accessing care. However, the ACA may provide more opportunities for BIN citizens to obtain affordable health insurance and receive adequate healthcare. By March 2012, 29,000 AIs had gained health insurance (Kimbrough-Melton, 2013). Overall, 8.8 million people have signed up for health insurance and 16.5 million more have access to care through ACA policies (Affordable Care Act by the Numbers,

2014; Gaba, 2017). Policy solutions like the ACA are far from perfect, but they may be a good start to holistically improving the system and decreasing health disparities.

However, the future of the ACA is uncertain at this time. In 2017, it has faced clear opposition from the Trump administration, the Republican-held Senate, and the Republican-held House of Representatives (Kaplan, 2017). Although the Senate and the House have put forth plans to repeal and replace (or just repeal) the ACA, they have not yet been successful (Kaplan, 2017). This may signal future attempts to repeal and replace the ACA, which will have significant impacts on the access to healthcare for many Americans.

Chapter 4: Identity and health

Of the many factors that influence health and well-being, identity should not be excluded. Just as one's race and ethnicity often impact one's health by affecting access to resources, ability to carry out a healthy lifestyle, and discrimination faced during health encounters, one's identity can also play a role in health in a variety of ways, both positively and negatively.

Identity is not determined by any one structure. Instead, identity refers to a host of criteria, including the attributes, ideologies, values, and feelings of moral worth that a person assumes to be their own (Charmaz, 1999). Identity can include group affiliations, as well (e.g. race or ethnicity), and may be considered in different lights, such as a social or public identity and a personal identity (Kely & Millward, 2004). In many social settings, individuals define themselves in terms of their group membership. This shared social identity can be seen as the basis for many forms of productive social behavior, including leadership, cooperation, trust, communication, and organization (Haslam, Jetten, Postmes, & Haslam, 2009).

Identity is therefore fluid and influenced by social structures. It can change as group membership becomes more or less central to self-definition and as an individual changes her level of readiness to use that identity (Oakes, Haslam, & Turner, 1994; Kelleher & Leavey, 2004; Haslam et al, 2009). For example, if an individual has recently learned about her Brothertown heritage, she may not be ready to incorporate the Brothertown identity into her self-concept. One's social identity for any given group is influenced by the perceived permeability of group boundaries (i.e. how easy it is to enter a group), as well as the perceived stability and legitimacy of the group's position relative

to other groups (i.e. how the group fares compared to others) (Haslam et al, 2009). The importance of group membership changes in various situations. Different group memberships may become more or less salient depending on the social situation at hand and the perceived strength of membership (Oakes, Haslam, & Turner, 1994). For instance, during a Brothertown Annual Picnic, an individual's Brothertown identity may become more salient than it would be at the workplace.

Some individuals are more influenced by their group membership and group identity than others, and may see group membership as central to who they are, take pride in their group membership, and act while thinking about that identity (Harwood & Sparks, 2003). However, if one's social identity is changed or compromised by forces outside their control, this can have negative psychological consequences (Haslam et al, 2009).

Identity and health are comingled in several ways. Group membership can be very beneficial, both for health and for other aspects of life. It can provide social companionship, bonding, security, and help us to achieve goals (Haslam et al, 2009). Groups that give people a sense of purpose and belonging can also have psychological benefits by enhancing one's self-esteem and sense of worth, in addition to acting as a buffer to well-being when it is compromised (Haslam et al, 2009). Some scholars argue that merely participating in group life can help us to be healthy and well (Putnam, 2000).

The salience of one's identity can have other consequences for health, as well. When part of one's identity becomes more salient, one may be more likely to engage in perceived normative behavior for that group. For example, teenagers are less likely to smoke when they are reminded of their identity as members of a *family* versus members

of a *teenage peer group* (Kobus, 2003). This has also been shown to be true with ethnic identities, as well. Oyserman, Fryberg, and Yoder (2007) showed that when American Indians were exposed to messages about dieting from White sources, they saw positive health behavior as something that was non-normative for American Indians and were less likely to make positive health choices. Therefore, seeing pro-health messages from members of groups one is a part of tapping into group identity and promoting better health choices, since the pro-health behavior will then be seen as normative for the group. This is supported in literature on targeting and tailoring, as well. Health messages given by people who are demographically similar to the targeted individual are more trusted and seen as more relevant (Campbell, Bernhardt, Waldmiller, Jackson, Potenziani, Weathers, et al, 1999; Kalichman & Coley, 1995). Messages given from sources similar to the target audience can be seen as more credible and may make that part of the audience's identity more salient at that time (Rimer & Kreuter, 2006).

People can also use their group membership as an unconscious heuristic when thinking about their own health. For example, Clair & He (2009) found that when older adults were encouraged to think of themselves as elderly, they were more likely to believe they had hearing loss, even if physiologically they did not have hearing loss. This can relate to an individual internalizing stereotypes of a part of their identity. For example, some research shows that African Americans and other students of color are discouraged to succeed academically in part due to internal stereotypes dissociating academic achievement and Black identity, as well as from external feedback about academic success as a White value (Fordham & Ogbu, 1986). These students may have to

contend with accusations of "acting White" from peers as well as educators (Bergin & Cooks, 2002).

Such group identity salience also has impact for the weight one gives to social norms around health, or the behaviors that are typical and acceptable for a group. For example, if one strongly identifies as a smoker, then it follows that it will be harder to change the negative health behavior of smoking than it is for one who does not identify strongly as a smoker (Harwood & Sparks, 2003). However, the strength of identification, and how one identifies, can have more positive implications, too. Harwood and Sparks (2003) found that those who identify as cancer patients displayed more positive health behaviors, such as information-seeking and compliance with medical regimens.

Additionally, identity can both be a *source* of stress and a *buffer* from stress for people of color. People of color often experience stress from the oppression and discrimination they face at many levels (institutional, interpersonal, internalized) because of their racial and ethnic identities (Williams & House, 1991; Williams, Spencer, & Jackson, 1999). It can feel stressful to be living in a culture that is different from your own (Nevid & Rathus, 2003). This is known as acculturative stress, and it can have negative health effects, including increasing hypertension (Kaholokula, Iwane, & Nacapoy, 2010), depression (Jang, & Chiriboga, 2010), and substance abuse and anxiety (Ehlers, Gilder, Criado, & Caetano, 2009).

Simultaneously, one's group identity can act as a psychosocial resource or buffer for people of color experiencing discriminatory stress, bolstering health and increasing one's sense of self-esteem and well-being (Phinney, 1990; Smith & Silva, 2011). Members of a disadvantaged group can use their shared social identity to help one

another through social support and sharing the emotional and intellectual resources to overcome oppression and discrimination (Blaine & Crocker, 1995; Branscombe, Schmitt, & Harvey, 1999). Social identity may affect health through one's knowledge of racial and ethnic health disparities, as well. People of color may be aware of the rates of disease incidence for their social group (e.g. increased rates of sickle cell disease in African Americans) and take preventive measures to address potential health problems (Harwood & Sparks, 2003).

American Indian identity

There is no monolithic American Indian person, and so there is no monolithic American Indian identity (Mihesuah, 2003). With over 600 federally recognized American Indian tribes and hundreds more unrecognized nations, American Indian identity will mean different things to individuals depending on their situation, experience, and life. Different tribes – and even individuals within those tribes – may have different understandings of American Indian identity. American Indian identity has many layers, and like other identities, can shift over time. However, the academic literature can tell us several things about the intersection of American Indian identity and health.

Regardless of how identity is conceptualized for the individual, American Indian identity can be positive for one's health. Canales (2004) argues that Native identity can contribute positively to one's physical, psychological, and spiritual health. Through a qualitative grounded theory approach, Canales (2004) found that individually and collectively connecting to one's Native identity had positive health implications for women, although it was clear that identity changed over time. This connection can lead individuals to incorporate Native traditions around health and healing into their daily

lives, with positive health consequences and richer social outcomes. Some studies have shown that biculturalism can be beneficial for one's health, in which an individual feels competent in two cultures (e.g. tribal culture and mainstream American culture) without having to choose one culture over another or lose a cultural identity (LaFromboise et al, 1993).

However, American Indian identity can have fuzzy boundaries depending upon an individual's situation, and one's legal claim to American Indian identity is not solely in the hands of American Indians, as is especially true for a non-recognized tribe like the Brothertown. As Schmidt (2011) notes, "To obtain federal recognition and protection, American Indians, unlike any other American ethnic group, must constantly prove their identity, which in turn, forces them to adopt whatever Indian histories or identities are needed to convince themselves and others of their Indian identity, and thus their unique cultural heritage" (p. 1). Indeed, American Indian identity was historically created by colonizers who developed racial classification systems in order to control, exploit, and oppress racialized others (Schmidt, 2011). The creation of blood quantum identification systems has had tremendous implications for Native peoples and is in stark contrast to other historical "blood" identification systems, such as the African American "one drop" principle.

Yet how does American Indian identity change with external influence? Indeed, American Indians are not in complete control of whether they are considered Indian by outsiders or in the legal system. One's identity can change because of the United States government, since the federal government has the power to determine which Indian nations can be federally recognized and thus considered as sovereign nations in the eyes

of the law. In federally recognized tribes, blood quantum is often used to determine one's Indian status in many circumstances (Barrios & Egan, 2002). A tribe itself can also change its own policies for recognition of its citizens, resulting in identity shifts (Burhansstipanov & Satter, 2000). These changes not only impact one's self-identity, they can influence one's access to federal or tribal resources, such as housing funds, trust or gaming profits, or access to health care through Indian Health Service. Thus, unlike other racial and ethnic groups, American Indian identity can be seen at least in some ways as out of control of the individual, as well as unstable and changing.

Little is known about the conceptualization of identity for the Brothertown Indian Nation. To start, its citizens may have different ideas about their own American Indian identity due to their unrecognized federal status. This unrecognized status is largely due to the BIN accepting citizenship for its people in 1839. Yet the Brothertown were not the first American Indians to accept citizenship, nor would they be the last. In 1830, the Choctaw accepted citizenship as part of a treaty with the U.S. government (Treaty with the Choctaw, 1830). In 1919, President Warren Harding offered citizenship to all Native men who served in World War I (Landry, 2016). In 1924, President Calvin Coolidge extended citizenship to those Native Americans who were not yet citizens (Indian Citizenship, 1924). Today, all American Indians are dual citizens – they are citizens of the United States and citizens of their Native nation.

Further complicating Native identity, in the 1940s through the 1960s, the federal government adopted a policy of termination, which was enacted by many pieces of legislation designed to dismantle and erase the sovereign status of many tribes (Getches, Wilkinson, & Williams, 2005). This resulted in the termination of over 100 tribes and the

dismantling of tribes' self-determination. In the 1960s, the U.S. moved its policy stance away from a termination policy due in large part to activists and tribal leadership, as well as some federal support (including from Presidents Lyndon Johnson and Richard Nixon), and many tribes were able to regain recognition and their status as sovereign nations, including the Wisconsin Menominee (Peroff, 2006). However, there are still many tribes (such as the BIN) who have not been able to reclaim their sovereign status with the federal government. This unrecognized status can have reverberations for unrecognized peoples in the realms of self-identity, public or social identity, and access to resources as a result of identity. BIN citizens recognize themselves as a sovereign nation and enjoy that view from other tribes, but cannot claim that identity in the eyes of the federal government. This adds yet another layer on top of the complicated tangle that is Native identity.

Today, there are 1.9 million American Indians enrolled in a federally recognized tribe, yet an additional 3.5 million people in the United States who claim American Indian ethnicity (Bragi, 2005). These people may be citizens of unrecognized tribes, not qualify to enroll in a recognized tribe, or have some other awareness of their Native ancestry. In Bragi's (2005) collection of experiences of people who consider themselves to be American Indian yet are not enrolled in a recognized tribe, he was able to document some of the experiences and ways of being for the so-called "invisible Indians." Some individuals he interviewed had no interest in becoming federally recognized citizens, as they felt it was disingenuous to let someone else determine their own heritage and ethnicity. Others are citizens of tribes that are no longer pursuing recognition, but are continuing their Native heritage independently.

In Bragi's collection of stories, many people describe the pain they feel with their American Indian identity. Some describe hearing comments that denigrate their claims to American Indian identity: "The most painful incident involved an encounter with an older, very drunk Indian on a commuter train…He let me know that I should never have been born and that he would bury me," (p. 139). Some feel as though they do not fit into any group: "I'm not quite white and not quite Indian. I have never felt like I belonged anywhere," (p. 124). Others are worried that if they discuss their American Indian heritage, they will be seen as "wannabes" and frauds, or they feel that delving into their Native identity will be too painful and uncertain.

Others are more determined to take pride and joy in their own sense of identity, regardless of the official groups to which they may (or may not) belong. They may focus on cultural traditions and customs that resonate with them, or find groups that welcome people with some Native ancestry. For some, their sense of identity remains very personal: "I just live my life in the most sacred manner that I am able…I am a daughter of indigenous ancestors. No one can take that away from me," (Bragi, 2005, p. 208). These individuals may work on their own genealogy and focus on knowing about the cultures of their ancestors. Bragi (2005) describes how unrecognized individuals often focus on what they can control—their cultural traditions, the groups to which they belong, passing on knowledge, their spiritual practices—and create their own sense of identity. Often, however, this means they feel like they are not really a part of a specific group. As one interviewee said, "I'm always outside looking in. This is not always a bad thing. I think it gives me a unique perspective. Sometimes I feel like this objective U.N. observer" (p. 139).

Community health approach

To address some of the health issues related to identity, as well as issues specific to American Indian identity, it can be helpful to utilize a community health approach. This approach considers community as both a group of people sharing characteristics or similarities and as people in a geographic space (Community Health, n.d.). This approach recognizes that health is not determined solely by individual choices, but is strongly affected by the circumstance in which we live and the people surrounding us. By addressing some of the root causes of disparities, the health and well-being of an entire area can be enhanced. To be healthy is not a solitary act; it is dependent on the systems and people surrounding an individual. That also means that communication strategies to improve health outcomes should acknowledge the interconnectedness of the community and the systems operating within a group.

In practical terms, this has several implications. First, this means revisiting the health equity approach and acknowledging there may be several entry points to affect health that can and should be considered. Many health promotion and social marketing campaigns work to influence individual-level risk behaviors that directly affect incidence of disease and illness. Often, these interventions are desired by communities and are seen as essential in improving health outcomes. To expand this viewpoint to include a community health approach, a health intervention can work backwards through the health equity model to look at the systems affecting living conditions, as well. Influencing upstream causes may be done through channels like lobbying, political policy, and advocacy, providing other ways of influencing health beyond individual-level behavior change.There can be an inherent tension in determining which part of the model to focus

on: downstream outcomes or upstream causes. While there is perhaps no easy answer, a community health approach acknowledges this tension and presents information to the community about health influences both upstream and downstream, incorporating community wisdom to determine the areas of focus. Although different strategies may focus solely on downstream results or upstream causes, the community health approach may help both integrate into a communication and health promotion strategy by recognizing the importance of the entire health equity model.

Second, health communication strategies can include information that is targeted directly to a community and its specific challenges and strengths. This means that health issues are discussed in a linguistically appropriate manner, including relevant social and cultural information from the specific community (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003). In this way, "a group's cultural values, beliefs, and behaviors are recognized, reinforced, and built upon to provide context and meaning to information and messages about a given health problem or behavior" (Kreuter et al, 2003, p. 136). Some values to consider may include religiosity, collectivism vs. individualism, perceptions of constructs such as time, and community-identified strengths (Kreuter et al, 2003).

Third, this means using narrative communication directly from the community itself. Narratives can capture unique, rich information about the community in question and help deliver health promotion communications *to* the community that are also *by* the community (Larkey & Hecht, 2010). These narrative communications can also be a way of enacting an identity, pulling together multiple elements from a community that may otherwise be inaccessible or difficult to incorporate, such as cultural practices and norms

(Hecht, Warren, Jung, & Krieger, 2004). Narrative communication also addresses the importance of social interactions in understanding the self. Additionally, narrative communication has an important role in Native cultures, which have strong oral traditions.

Fourth, social norms may feature prominently in a community health approach. These social norms can incorporate both descriptive and injunctive norms (Cialdini, 2003). Descriptive norms focus on the actual behavior of others, while injuctive or subjective norms focus on the beliefs of others. For example, descriptive norms around eating in a community would focus on what others are actually eating (e.g. others are eating healthy food), while injunctive norms focus on the beliefs that others have around eating (e.g. others believe it is good to eat healthy food). Norms are especially important in a community setting, as it is inherently a group situation.

Last, a community health communication approach can also recognize the differences within the community itself, and adjust accordingly. Communities are not homogenous, and although their members often share characteristics, it is important to recognize the differences within the community and develop communications strategies appropriately. These differences include, but are not limited to: age, gender, leadership position, beliefs, and level of involvement. Acknowledging these differences can help any interventions better resonate with individuals within the community (Kostick, Schensul, Singh, Pelto, & Saggurti, 2011). This approach also utilizes the strengths of the community wisely and appropriately to maximize effects.

Chapter 5: Research approach

There is no question that a great deal of research conducted in the past – and some still conducted today – has been exploitive, extractive, disrespectful, and harmful to American Indians. The late Vine Deloria, Jr. has written extensively on the academic treatment of Native peoples, including the damaging and disrespectful nature of scientific inquiry, as he discusses in his 1995 book *Red Earth, White Lies*:

> Regardless of what Indians have said concerning their origins, their migrations, their experiences with birds, animals, lands, waters, mountains, and other peoples, the scientists have maintained a stranglehold on the definitions of what respectable and reliable human experiences are. The Indian explanation is always cast aside as a superstition, precluding Indians from having an acceptable status as human beings, and reducing them in the eyes of educated people to a prehuman level of ignorance. Indians must simply take whatever status they have been granted by scientists at that point at which they have become acceptable to science. There was a terrible reaction in 1969 when I accused anthropologists of treating Indians like scientific specimens. Now, after a quarter of a century, Indians are no longer 'informants'; they are now seen quite often as colleagues. (p. 7)

This negative history reverberates today and must be considered in doing any research with Native peoples. Additionally, Indigenous scholars argue that the nature of academic research is often at odds with Native protocols, creating tension and putting unnecessary strain on Indian nations. Traditional academic research may ignore Indigenous protocols and knowledge, perpetuate stereotypes, and do harm to Indigenous communities (Chilisa, 2012). For example, traditional research has appropriated Indigenous knowledge for the profit of outside entities, such as the case of an African cactus which was used to create diet pills without the consent of or remuneration toward the community that initially found and utilized the plant (Chilisa & Preece, 2005).

The mere history of many Native peoples could be enough to inspire mistrust of academic researchers, but unfortunately, many Indian nations have suffered at the hands of academics, as well. Research has been conducted *on* (as opposed to *with*) American

Indian communities since the 1800s (Caldwell et al, 2005). The majority of the time, this research was paternalistic, exploitive, and extractive (Caldwell et al, 2005; Manson, Garrouette, Goins, & Henderson, 2004). Many studies went beyond academics simply seizing the information they wanted from the community, ignoring the needs of the community, and taking any research benefits along with them; some research was actively harmful to Indian communities. For example, the results of some research have led to the stigmatization of communities and a subsequent loss of economic viability (Manson et al, 2004; Caldwell et al, 2005; Manson, 1989). Other research was performed without the knowledge and consent of community members, leading to unethical studies (Shaffer, 2004; Hodge, Weinmann, & Robideaux, 2000). This history may unsurprisingly leave many Indian nations suspicious and mistrustful of researchers, and must be kept in mind when pursuing any research with Indian communities. As I recently heard in a workshop on justice and equity – what is done **for** us and not **with** us is done **to** us. This led me to a specific research approach: community-based participatory research. It helped me to overcome these challenges and conduct meaningful, collaborative research with the Brothertown Indian Nation.

Community-based participatory research

All research is done within an epistemological framework that clarifies how one understands knowledge and knowing. Community-based participatory research (CBPR) methods trace their origin to participatory methods used by Kurt Lewin, Orlando Fals Borda, and Paulo Freire, as outlined by Wallerstein & Duran (2008) in *Community-based Participatory Research for Health*. The paradigms of feminism, poststructuralism, and postcolonialism led to new research goals in the academy, which included examining the

structures that control people's lives, using a strengths-based approach to problem-solving and learning, and working for social justice. This approach forces the researcher to acknowledge and confront the power structures present in our everyday interactions, including those in academia, for the purpose of redesigning these structures for a more just and equitable world. CBPR identifies the act of research as political, which means that research should be used for justice.

There are several important principles of CBPR that make this methodology so extraordinary. These include: a community-identified research topic, a research process that includes equitable collaboration on behalf of academics and community members, recognition that both academics and community members have unique and important knowledge that should be included, an outcome that works for social action, change, and justice, and an end result that is meaningful, sustainable, and useful for the communities (Wallerstein & Duran, 2008).

First, the community that is involved with the research should identify the topic at hand as important and a topic they would also like to research (Wallerstein & Duran, 2006). In other words, the community members themselves identify a topic, question, or problem that they would like to further explore using some sort of research. This may mean the community has identified a potential problem or risk they would like to solve or know more about (Cashman et al, 2008). It may also mean that the community suspects there may be a problem, but they need outside assistance to determine exactly what is occurring (Wing, Cole, & Grant, 2000). This approach to research is often at odds with traditional research in the academic world. Traditional research typically starts with the university and its faculty, staff, and/or students, and may or may not move out into

different communities, depending on the topic (Minkler & Wallerstein, 2008). For example, a researcher may focus specifically on a topic, idea, or theory, thereby only doing research on her specific focus. Unless a community request is in line with that topic area – and community members can connect with an interested university partner, which tends to be unlikely – all research ideas will come from the researcher. A researcher may also be limited in what she studies based on the types of funding available. This may put further constraints on the topics the academic is willing to pursue. Lastly, there are not always avenues for persons outside of academia to contact researchers, decreasing the likelihood that a community idea could be used in an academic research project.

In my health communication work with the BIN, I used several methods of gathering input to develop the research questions. I spoke with BIN citizens at several events and gatherings informally. I developed a short email survey which was shared with members. I solicited ideas at Tribal Council meetings. Throughout this process, I shared what my own interests were: health, health equity, and how to communicate about health. Community members then shared their own thoughts and ideas until we were able to develop some general research topics, which I then reflected back to the community at a Tribal Council meeting. Throughout the process, I tried to ensure that BIN citizens knew I wanted our work on health communication to be collaborative and useful to the community at large.

Second, community-based research methods work to equitably recognize and utilize the contributions of both academic and community members. In traditional academic research, the academic partner is responsible for bringing knowledge into the research (Wallerstein & Duran, 2008). Academics are seen as holding all the knowledge,

which they can dispense to members of communities if they wish, such as in traditional health interventions. Community members may benefit from said knowledge, but are not contributing meaningfully to the equation, and the researcher's time, energy, and knowledge may not be wanted, needed, or well-utilized by the community. In CBPR, community members are crucial parts of a partnership with academic researchers. They are active partners in the research, making valuable contributions at any and/or all junctures (Green & Mercer, 2001). Members of a community are encouraged to participate during any part of the research process, from research questions/hypotheses development, developing methods of data collection, data collection, data analysis, and dissemination of results (Minkler & Wallerstein, 2008).

This is done for several reasons. First, it helps build capacity within the community itself – members may gain valuable skills that will be useful after the research project is finished, which contributes to the CBPR goal of social change. Second, encouraging participation at different parts of the research process helps to ensure that the project partnership is equitable and truly acknowledges the viewpoints and contributions of community members. Third, this method of contribution gives community members ownership over the research, and is a way for those of the dominant culture (academics) to create space for voices that may not traditionally be heard in the research process (community members) (Chavez, Duran, Baker, Avila, & Wallerstein, 2008).

This kind of collaboration is not always done in traditional research. Some academic researchers may believe that they are the sole keepers and creators of knowledge and that community members don't have meaningful input to contribute. Involving community members also means that academics will have to yield some

control of the research project, which may be unsettling. Additionally, graduate students doing research often have to take control of research to get credit for their degrees, which discourages collaboration (Stoecker, 2008). However, such collaboration has many clear benefits for both academics and community members, which will be described later in this chapter.

An important piece of this collaboration is recognizing that academics and community members both have valuable knowledge to contribute. This is a very important piece of the CBPR puzzle, and is also valuable to consider when thinking about achieving true social change. In society today, there are many ways for different communities to be oppressed – gender, race, ethnicity, class, sexuality, socioeconomic status, and so forth (Chilisa, 2012). These different types of oppression empower some groups of people and oppress others (Chavez et al, 2008). Chavez et al (2008) describe productive power, which creates or reproduces structural inequalities that normalize or mask repressive relationships, such as the relationships in which university researchers are the only entities that can conduct research. CBPR works against these types of privilege and oppression by breaking down traditional relationships and making space for more individuals at the table. Bradbury & Reason (2008) argue that instead of traditional research:

> the primary purpose of action research is not to produce academic theories based on action, nor is it to produce theories about action, nor is it to produce theoretical or empirical knowledge that can be applied in action; it is to reweave knowing and doing so as to liberate the human body, mind, and spirit in the search for a better, freer world. (p. 228)

Not only is the research quality better because the process itself is based in the perspectives of those concerned with the topic, doing so moves us away from a positivist

view of the world and allows for a much broader understanding of the world and the issues we're interested in (Bradbury & Reason, 2008).

In this project, I continually stressed that my role was to gather participants' thoughts, ideas, and opinions about health, and reflect and communicate them back to the community. I was happy to share my own analysis and recommendations, as requested by the community, but also worked to highlight the thoughts of community members. Their knowledge was just as important as mine – if not more so – and that was reflected throughout this process. I also worked on data analysis in collaboration with the research liaison for the tribe.

One of the most important pieces of CBPR is that an end goal is some sort of social action and/or social change. There are myriad studies that show how social change is brought about by CBPR methods (e.g. Cashman et al, 2008; Green & Mercer, 2001; Wallerstein & Duran, 2006). However, it can seem like doing research is not the best vehicle for social change when compared to political action or political organizing (Auerbach & Wallerstein, 2004). However, good policy design is based on sound knowledge and research, and such research must be produced somewhere. If community-based methods can produce information that is high quality, relevant to the community, and has implications for policy change, then CBPR is an excellent research tool. Using CBPR can ensure that community-level policy decisions are driven by community-produced knowledge and data (Wallerstein & Duran, 2006; Themba-Nixon, Minkler, & Freudenberg, 2008).

Although this project may not directly result in social change, my hope is that it provides a health communication structure, adds further evidence for the case of the Brothertown's sovereignty, and helps them continue to work towards federal recognition.

Lastly, it is crucial that CBPR produces information that is useful for the community, as seems sensible after discussing the goal of broader social change. The typical product of academic research is an academic article that is written for and eventually published in a peer-reviewed academic journal. This type of product may hold little or no use for someone outside that academic discipline; it is often convoluted, filled with jargon, and confusing. Although such an article may still be a product of CBPR, there should also by additional products that will be of use to the community (O'Fallon & Deary, 2002; Minkler & Baden, 2008). These products may take any number of communication forms, from community presentations, short journalistic style articles, and posters, to interventions that act on the research findings themselves. Minkler and Baden (2008) describe a variety of dissemination ways, from local artistic performances to mass media to press releases. These different dissemination methods all share one thing in common: they come from the community and work toward the community's goals. Although this may put the university researcher in a new (and sometimes uncomfortable) position of being an advocate, which may bring up other concerns, academics must determine how to navigate these spaces while respecting community members and their own interests.

From this project, I am creating several other deliverables that will be of use to the BIN community, which will be described in the discussion.

Asset-based approach

CBPR typically uses an asset-based approach (Minkler & Wallerstein, 2008), which is especially important when workings with Indigenous populations. Native communities, just like other communities, have many assets, often based on customary ways of living and thinking. Although I am certainly unable to discuss these in an exhaustible fashion, I will touch on several important points.

In many Native communities, the definition of family is extended far beyond the Euro-American view of the nuclear family (Cummings, Ireland, Resnick, & Blum, 1999). Instead, the family reaches beyond the nuclear family to encompass extended family, and perhaps even citizens of one's tribe (Caldwell et al, 2005). This has implications for raising and guiding children, social support, and the transmission of culture and values. In the Brothertown community, family is an important piece of their culture, as is evidenced in their writing and community events (Ottery & Ottery, 1989).

There is also a strong sense of resilience in many Indian nations. Simply to be have survived their tumultuous histories means Native peoples have had to overcome seemingly insurmountable obstacles. Many Indian nations have not only done so, but are thriving, as well (McCubbin, Thompson, Thompson, & Fromer, 1998). This sense of resilience often stems from one's own culture and sense of cultural identity, where the nature of one's culture supports resilience (Stumblingbear-Riddle & Romans, 2012).

Finally, sovereignty and self-determination are important pieces of many (if not all) Native cultures. Sovereignty means that Indian nations can adopt their own forms of government and govern themselves in domestic matters (Wilkins, 1997). Native peoples have the right to self-govern, as was agreed upon in treaties Indian nations signed with the United States government (Limb, Hodge, & Panos, 2008). Sovereignty sets apart

American Indian nations as separate, unique, and important. This is especially important for the Brothertown as they work to regain their own federal recognition and sovereignty as recognized by the U.S. government.

Community-based health research

Community-based participatory (CBPR) research approaches have a wide variety of uses, but one of their most robust uses is in the field of health and health communication. The Institute of Medicine recently stated that public health schools should offer training in CBPR (Gebbie, Rosenstock, & Hernandez, 2003). Minkler and Wallerstein (2008) point out in the introduction of their book that participatory methods have long been used in nursing, as that field recognizes that combining the perspectives of all interested parties can lead to better health outcomes for patients. Additionally, the authors point out that there is increased funding available for participatory research approaches. In Indian Country, where resources may be limited, the availability of funding can be an important piece for success.

CBPR is also appropriate for research specifically relating to communication about health disparities. It has been used to address many American Indian health issues, including tobacco use, cancer prevention, youth wellness, environmental exposures, and mental health issues (e.g. Arcury, Quandty, & Dearry, 2001; English, Fairbanks, Finster, Rafelito, Luna, & Kennedy, 2008; Horn, McCracken, Dino, & Brayboy, 2006; Teufel-Shone, Siyuja, Watahomigie, & Irwin, 2006; Letiecq & Bailey, 2004). For example, LaRowe, Wubben, Cronin, Vannatter, and Adams (2007) used CBPR approaches in with Wisconsin tribal communities around youth obesity in the *Healthy Children, Strong Families* project. By focusing on specific communities and involving community

members throughout the process, this project was able to develop and communicate meaningful materials and interventions that were relevant to each community. Rather than taking outside interventions and trying to force them to fit a community's specific needs, intervention materials came from the community itself. In the *Healthy Children, Strong Families* project, some of the intervention materials were designed by academic researchers, tribal researchers, child development specialists, dieticians who worked with AI children, and a home visiting specialist who had experience working with communities that were under-served. Along the way, community mentors, community members, and tribal wellness staff provided feedback to help ensure the materials would be successful in the communities themselves. As this example illustrates, involving community members in the research gives community members a voice and power over the process, and projects also benefit from the added insight community members bring (Chavez et al, 2008). In the context of health, this means that projects may be more likely to succeed because they are shaped using the values, norms, and beliefs held by community members, and any intervention, prevention, or health promotion materials that come out of the project will be shaped using the community's own resources and perspectives. In Indigenous communities, these values may include trust, respect, sovereignty, reciprocity, and collective benefit (Manson et al, 2004). Including these values throughout the research process can produce more rigorous and successful results by increasing participation, creating interventions with accurate cultural information, and interpreting results accurately from the perspectives of those being studied (Cashman et al, 2008; LaRowe, Wubben, Cronin, Vannatter, & Adams, 2007).

As Manson, Garroutte, Goins, and Henderson (2004) point out, "The costs of doing business as usual with respect to research in this special population have proven to be enormous. They range from stigmatizing communities to undermining their economic viability" (p. 59S). Community-based methods are one way to work against traditional academic research that has hurt and exploited AI communities, as well as approach research in a way that is suitable for the community at hand. Because CBPR methods are tailored holistically to the specific community, projects are able to address the specific community needs. The CBPR approach has successfully been used to study and communicate health topics in Native communities due to its community-tailored approach, ability to empower communities through the research process, goal of sustainability, ability to be culturally responsive, and capacity to involve Indigenous peoples in processes and realms from which they have been historically excluded.

The very process of CBPR can positively affect the health outcomes of community members. Wallerstein & Duran (2006) point out that there is some literature published on the health benefits of participating in a CBPR project. These health benefits can come from increased buy-in to the project itself (resulting in more participation and healthier outcomes), or from effects that come from participating, including increased self-efficacy and group bonding. Even though the research outcomes should contribute to positive outcomes for community members, the process by which they get to the outcomes can also be beneficial. This empowerment can be very important for those who have been – and continue to be – disenfranchised in many ways.

Culturally responsive results

CBPR approaches are used with individual communities to find information or solutions that are appropriate for that individual community, which allows them to be culturally responsive. This means that the information discovered in the research process should be very relevant to the community in question, which can be crucial when developing an intervention or other source of support for the community. Looking again at the *Healthy Children, Strong Families* initiative, Adams et al (2012) took a community-based approach that allowed them to be culturally responsive. In this obesity intervention with American Indian youth, a large part of the program's success was due to community members, who championed subject recruitment, study promotion, data collection, and result dissemination. The study also included active participation of tribal citizens as program mentors, who played an essential role in the program itself. This allowed for cultural elements of each community to have a large part in each intervention.

Embracing elements of a community's culture can also mean acknowledging, understanding, and respecting its history, including negative events that occurred between AI communities and the U.S. government and academic researchers. Historically, researchers working with American Indian communities conducted research *on* community members (Christopher, Watts, Knows His Gun McCormick, & Young, 2008). This resulted in projects that were carried out in AI communities without true consent, results that led to the (often costly) stigmatization of AI tribes, and data that were taken from AI communities and used in ways that did not benefit the tribes (Christopher et al, 2008; Caldwell et al, 2005). CBPR works to move away from the historically paternalistic and harmful research approach that has been used with Native communities

and seek an equitable relationship among all collaborators (Chilisa, 2012). Such cultural and historical acknowledgement is often absent in traditional research, which may not necessarily value the cultural background of a community and build upon that culture's strengths (Christopher et al, 2008). Including community members throughout the research process not only has the potential to empower them in situations where researchers used to disempower them, it can work to ensure the community's culture is accurately represented, understood, and respected throughout the entire process (Caldwell et al, 2005). In this research project, each step of the process was guided by the needs and desires of the BIN community, and each step received feedback and approval from the Tribal Council before proceeding.

Increased sustainability

Giving the community ownership over the project and the outcomes also helps create projects that are sustainable in the community even after academic partners may no longer be involved. In many research projects, an intervention or project may come to end when the academic partner's grant funding runs out, often meaning the community benefit ends there once the academics withdraw. In CBPR, the community members are working alongside the researchers on the project and a clear end goal is to create some kind of social action and change. This resulting community capacity could mean several things – increasing the community's infrastructure around an issue, the transfer of skills from academic partners to community partners and vice versa, augmenting the community's ability to address health issues, or continuing a community-academic partnership indefinitely (Hacker et al, 2012). This focus on increasing community capacity and sustainability, in whatever form is appropriate for the partners involved,

means that CBPR research has a much longer life than typical research. In my project, I am working with community members to create health communication products and processes that will live on into the future.

Involvement of American Indians in research and health

Finally, CBPR in the health field can provide opportunities for community members to become involved in research, which can help develop opportunities for them to become further involved in the health and medical professions. People of color, those people who are most affected by health disparities, are also underrepresented in academia and the health care professions, and American Indians are no exception. There is some evidence that women and people of color are discriminated against before even entering the academic system, as was shown in a study where fictional prospective doctoral students with racially indicative names reached out to university professors for mentoring (Milkman, Akinola, & Chugh, 2014). People of color are underrepresented in academia in the fields of the life sciences, computer science, mathematics, physical sciences, and engineering (Frehill & Ivie, 2013). African Americans, American Indians, Alaska Natives, and Hispanics account for 36% of the United States population of 18- to 24-year-olds, but represented 22% or less of the degrees awarded in the STEM fields in 2009 (National Action Council for Minorities in Engineering, 2011). What's more, they represent about nine percent of nurses, six percent of physicians, and five percent of dentists despite representing 28% of the population (Sullivan Commission, 2004).

This underrepresentation of people of color in general and American Indians in particular in the academic and health care fields is detrimental to Indigenous peoples in a variety of ways, but CBPR can push back against these negative forces. In CBPR health

projects, Indigenous peoples have a chance to get involved in research and in their own health and health care, which can present many opportunities for community members and further open professional opportunities in academia and the health care industry.

Chapter 6: Methodology

Indigenous research

To further strengthen this community-based participatory research approach, I added another element to my research approach: the inclusion of Indigenous research methodologies. Although CBPR methodologies have shown themselves to be very appropriate for use in Indigenous communities, and are often more useful than traditional academic research approaches, the inclusion of specific Indigenous ideologies can further strengthen the CBPR approach.

At their heart, Indigenous methodologies are compatible with CBPR. Some principles associated with Indigenous methodologies include involving Indigenous peoples at all stages of the research project, using a needs-based approach to any research, Indigenous ownership of the data, disseminating the results for the benefit of the community, and working toward social change, which I have done in this project (Henry, Dunbar, Arnott, Scrimgeour, Matthews, Murakami-Gold, & Chamberlain, 2002). Kovach (2009) outlines other Indigenous research principles that are similar to CBPR methodologies: "(a) that the research methodology be in line with Indigenous values; (b) that there is some form of community accountability; (c) that the research gives back to and benefits the community in some manner; and (d) that the researcher is an ally and will not do harm" (p.48).

Using an Indigenous perspective adds to CBPR principles in several ways, as well. Rigney (1999) outlines three principles that should be integrated into Indigenous research: resistance (to colonized ways of thinking), political integrity, and the privileging of Indigenous voices. Kovach (2009) further adds to these, stating that

Indigenous research methods should use a tribal epistemology, have a goal of decolonization, involve researcher preparation using cultural protocols, use tribal ethics, and focus on making meaning of the knowledge gathered. Using Indigenous methods also:

> involves the restoration and development of cultural practices, thinking patterns, beliefs, and values that were suppressed but are still relevant and necessary to the survival and birth of new ideas, thinking, techniques, and lifestyles that contribute to the advancement and empowerment of the historically oppressed and former colonized non-Western societies." (Chilisa, 2012, p. 14)

The Brothertown Indian Nation I am working with bears many scars of the colonized mindset. Samson Occom, one of the founders of the Brothertown Indian Nation, was also a Mohegan Christian missionary who worked in England to raise funds for a school for his tribe (Jarvis, 2010). Upon his return to the United States, the funds Occom raised were used to start Dartmouth College rather than benefit his own people. This, among many other actions, contributed to the silencing of the Native Brothertown voice while privileging the colonized voice. This project worked instead to privilege the Native voice to chip away at the colonized mindset.

Incorporating Indigenous methodologies means different things for different cultures and peoples, but there are some characteristics that these methods tend to share (Chilisa, 2012).

As it stands today, the academic research paradigm is inherently Western. Our academic institutions reflect imperialism, colonization, and globalization, and these structures have privileged certain knowledge and research systems over others (Chilisa, 2012). As a result, Indigenous ways of thinking and knowing are not always reflected in traditional academic research, but using Indigenous methodologies can help ameliorate this problem. By incorporating Indigenous methodologies into a research project,

academic researchers can help ensure the research participants' voices are heard, give power to those who have been historically oppressed and abused, privilege Indigenous knowledge throughout the process, interpret results from an Indigenous perspective, and use whatever specific methods resonate with the community and the problem at hand (Kovach, 2009; Chilisa, 2012).

There are several important principles that I followed when incorporating Indigenous methodologies into this research. First, these methods involve giving the oppressed a full seat at the table. In the history of research, there is a clear hierarchy of whose voices are privileged and get a seat at the table, and from whom knowledge is extracted, leaving the researched disenfranchised (Kovach, 2009). In some instances, non-Westerners have had their voices oppressed, subordinated, and marginalized by the forces of colonization and colonized methodologies in which benefits only go to the researchers, and sometimes clear harm comes to those being researched (Davis & Reid, 1999). Indigenous methods seek to give these voices back to the oppressed by including and empowering their voice in the research itself (Chilisa, 2012). This means that research participants are also researchers, and vice versa, similar to community-based participatory research and the approach I outlined above.

In this project, I have made it clear from the beginning that this work should benefit the community. Data is owned and directed by the Tribal Council. End products will benefit the community. I have asked for community input at all stages of the research, and community members provided guidance as they were able to do so. My intent is to capture the voices of the community and reflect them in a way that is useful to them.

Second, these voices present an alternative worldview. Colonialist and imperialist forces have historically influenced academic research, which privileges certain ways of thinking above others (Chilisa, 2012). Decolonized methods attempt to introduce new narratives and ways of thinking into the academic dialogue, privileging Indigenous knowledge. This knowledge may be embodied in music, rituals, stories, and cultural experiences, and may have been previously ignored. Privileging this knowledge allows for the reclamation of heritage and helps Indigenous peoples work against their colonized history. For example, the Western paradigm focuses on an individualistic view of knowledge in which knowledge is gained and can be owned. On the other hand, Indigenous paradigms focus on constructivism and a relational view of knowledge (Chilisa, 2012). In this view, knowledge is not so black and white, but is very much dependent on those involved. Under this paradigm, those involved in the research have the opportunity to present their own viewpoint and way of thinking, and those who have been oppressed are empowered. The Indigenous way of thinking opens up the realm of knowledge to those beyond a small group of typically White people. In this way of thinking, everyone has a sense of worth, and the values of interconnectedness, relationship, and holism are maintained (Kovach, 2009). I utilized this Indigenous value by honoring the voices of those who participated in this project and focusing on relationships throughout this project.

Third, Indigenous methodologies view research as a moral and political activity, rather than a value-free activity. Unlike positivism, which asserts that there is a singular truth and an objective reality, Indigenous paradigms view reality as socially and politically constructed. It is important to note that there are research paradigms outside

Indigenous research that similarily view the construction of reality. Research, then, has the power to further social justice, human rights, and cultural respect (Chilisa, 2012). It moves out of a sterile environment and into the real world, where there is awareness of the forces at work and where those involved can move toward justice. These methods work to improve the lives of people, rather than just generate knowledge for the sake of generating knowledge (Poupart, Baker, & Red Horse, 2009). With the Brothertown, this means that I am a full ally to and accomplice with the Brothertown people and will collaborate with them in their social change goal: regaining federal recognition. In this project, I have interacted with the Brothertown Indian Nation as a sovereign nation that has self-determination. I made a political choice by choosing to focus on this research topic with this community, and I am not an objective bystander. Instead, I want to be seen as an accomplice who is committed to working with the tribe to move forward with their goals.

Fourth, Indigenous methods embrace different ways of knowing and recording knowledge. Many Indigenous peoples have used oral traditions, shared activities, and cultural acts to keep and share their knowledge (Kovach, 2009; Chilsa, 2012). In the Western paradigm, these have not been considered legitimate ways of keeping knowledge. Indigenous methodologies then look outside the traditional places for knowledge. Knowledge might be found in storytelling, proverbs, songs, or spiritual rituals. These Indigenous methodologies allow for the construction of reality in decolonized ways, which may not be accepted in traditional academic research. For instance, these methods may have an I/We relationship focus instead of a focus on the I/You relationship. As such, these methodologies focus on relational ways of knowing

instead of individual ways of knowing. They may also embrace a reality in which interconnectedness is stressed, such as in relationships between living and nonliving beings (e.g. Mother Earth). This is no way delegitimizes the knowledge or decreases its value.

Fifth, these methodologies will differ based on the Indigenous culture involved in the research and should be responsive to the needs of the community. For example, AI communities may wish to use a methodology that draws from the American Indian Medicine Wheel, which "encompasses a holistic integration of humans and the natural world, including all beings, processes and creations" (Walker, 2001, p. 19). This means incorporating elements from the East, or the spiritual aspects of experience; the South, or the natural world; the West, or the bodily aspects of knowledge; and the North, or the cognitive process of incorporating wisdom and knowledge (Chilisa, 2012). In a research project, these principles would guide the entire project and inform both the time of each piece of the research and the process of the project. As I have worked with the Brothertown, this means that I am mindful of the methodologies they choose to use – and choose not to employ.

Sixth, Indigenous research is done based on the community's need and want for the research (Kovach, 2009). Rather than the researcher setting an agenda, deciding on the research questions, and imposing them upon a community, Indigenous methods implore research to be done as the community itself needs and requests it. This gives a stronger voice to those who have been historically without power. Because the participants are also the researchers, they can ensure that their voice is accurately represented in the research, as well. I have embraced this principle by adjusting my

research plans so they align with those of the Brothertown and have been doing so ever since I began working on this project.

Seventh, in an Indigenous research perspective, the researcher is not an objective or absent part of the process (Kovach, 2009; Chilisa, 2012; Smith, 2012). The researcher should state where she is coming from, her worldview, and her connections to the problem and people, which I did in the introduction of this research. This allows the researcher to identify her voice and privilege, locates the researcher and the research in a specific place and time, and shows that the researcher is part of the meaning-making process, not a neutral bystander. This also helps to ensure that the researcher is a transparent ally to the community participating in the research.

Finally, these methods may require a different way of thinking about confidentiality and anonymity, as participants may wish to be named and stand by their knowledge (Chilisa, 2012). This process of "naming" where knowledge comes from also applies to the academic researcher, who often grounds herself by explaining where her perspective comes from as part of the research, too (Chilisa, 2012; Kovach, 2009). Throughout the research process, I have paid close attention to participants' desires for confidentiality, as well as their desires about how these data will be shared within the tribe and in other ways.

Ethical standards of Indigenous research

When using Indigenous methods, there are certain ethical standards that should be upheld. Although this is not an exhaustive discussion of ethical principles, I would like to discuss some important values that I took with me into my research. Ethical principles of Indigenous research include reciprocity, respect, empowering those from whom power

has been stripped, and focusing on relationships (Smith, 2012). Another way of looking at these ethical standards is the four R's: respect, relevance, reciprocity, and responsibility (Kirkness & Barnhardt, 2001).

First, the research should be in line with the Indigenous values of the community participating in the research. These values may be different in various communities, but are typically founded on respectful relationships in which all parties are honored (Kirkness & Barnhardt, 2001). While I cannot attempt to discover the many values of the Brothertown Indian Nation, nor is that the focus of this project, my work with them has showed me that some important values in the Brothertown community include reciprocity, respect for others and the earth, a shared Christian faith, a dedication to communalism, and a deep reverence for one's ancestors. I have tried to respect these values throughout this project in several ways, including making space for these topics during data collection and participating in events, even when I may feel uncomfortable.

Second, researchers should be aware of Indigenous protocols in the community (Kovach, 2009). Each Indigenous community may have different ways of doing things, and they should be respected. This may affect how community members participate, consent, and interact with the data. For example, the community may wish to have ownership over the data, and this wish should be respected. This is something I am respecting in this project. I have utilized methods that community members felt comfortable with and included participants in whatever way they wished. I have also respected the timeline the Brothertown wanted to use.

Additionally, the research should give back to the community in some way, or be relevant to the community (Chilisa, 2012; Kovach, 2009). This means that findings

should be disseminated to all parties, ideally in ways that are understandable and accessible (Thomas et al, 2011). This also means that the researcher is held responsible to the community for all actions. For the Brothertown, this means producing several different end products and continuing my work with them beyond the scope of this project. As a part of giving back to the community, it is expected that the researcher build reciprocal relationships, and that all work completed gives back to all who are involved.

Using community-based methods is a start to completing meaningful work for AI communities, but this research approach can be enhanced by incorporating an Indigenous worldview and methodologies. Incorporating Indigenous methodologies can work against unequal power paradigms, give credence to the Indigenous way of knowing and researching, and further empower Native peoples.

Grounded theory

Using a community-based participatory research approach means that part of the research will involve constructivist grounded theory. This means that rather than starting with assumptions about the outcomes of the research, the researcher asks research questions, collects data, and draws the resulting theories out of the data itself (Martin & Turner, 1986). The end results, data, and knowledge are co-constructed by the researcher and the research participants. One overriding principle of constructivist grounded theory is that while there may be a "real" reality, it can only be imperfectly perceived, as it is always perceived by humans (Mills et al, 2006). Humans view the world through their own lenses, which are results of what they've experienced, and these lenses are constantly present. Therefore, the researcher is a part of the research and any products of the research are co-constructed by the researcher and all others involved in the research.

The constructivist approach also stresses trying to shift the balance of power during the research itself. Traditionally, the researcher has a higher status than the research participant (Fontana, 1994). However, in order to build a reciprocal and equal relationship in which to co-construct data and knowledge, the parties should work to achieve a more equitable relationship (Mills et al, 2006). This means the researcher should work to reduce her power; strategies to do so include constant self-checking (Seibold, 1992), refraining from valuating participant responses (Holloway & Fulbrook, 2001), yielding control of the conversation, sharing information reciprocally, and using unstructured methods (O'Connor, 2001). These principles are also in line with a community-based participatory research approach (Minkler & Wallerstein, 2008).

Research questions

In traditional academic research, research questions come from the review of the literature. In this project, the development of research questions was informed by the literature, but they were co-created with tribal citizens. Therefore, this process may look quite different from traditional academic research.

Development of research questions started with my initial meeting with citizens of the Brothertown Indian Nation. Initially, I met with my advisor and a Tribal Council member to discuss my research interests and determine if there was any overlap with research topics the BIN was interested in. This initial meeting helped us determine that the BIN was potentially interested in collaborating with me, and we discussed strategies for moving forward.

I then attended a Brothertown annual picnic alongside my advisor, which allowed me the opportunity to get to know many other Brothertown citizens. At this event as I

met people, I let them know who I was and that I was interested in working with them to answer questions they might have around health, health promotion, and health communication. I shared my skill set and interests, and let them know that I was interested in working on a research project in collaboration with them.

As I was talking with people, I did encounter some skepticism and questions. Many people wondered why I did not *already* have a research agenda, with questions already laid out and ready for implementation. Contrary to what I might have thought, some people thought that would be the easiest way to move forward. They expected me to be an expert on these topics and some were in disbelief that I did not want to study them in some way. For some individuals, it was quite confusing that I did not have a clear plan in place. I explained my research approach and research goals, but it seemed to be initially difficult for people to think about research in this way. Eventually, people I spoke with started to talk about their health concerns, questions, and ideas. After initially meeting with people, I advertised in their newsletter that I would like to hear ideas about what research topics the tribe would like me to pursue, and continued to have conversations with tribal citizens. These meetings occurred informally, as well as at Tribal Council meetings and other BIN events.

During this time of relationship-building, I did not encounter much (if any) skepticism or mistrust about my role as a researcher. I believe this is in no small part due to the role of my advisor and the initial Tribal Council member I worked with. They both had strong relationships with many individuals within the BIN and are seen as trustworthy, competent, and valued people. Because my interactions with other BIN citizens were initially through these mentors, I was able to more efficiently and

effectively build relationships. People used my relationship with these mentors as a heuristic for trustworthiness, and I was able to speak with people more freely and quickly than I may have otherwise been able to do.

This was especially important for me as a graduate student. This project was not funded and, as a graduate student, I was on a more limited timeline than other researchers may have been. Although I ultimately spent a year finalizing research plans before collecting data, I did not have the luxury of taking several years solely for relationship-building. Relationship-building and developing trust relationships is a crucial part of community-based research, yet for my situation (and undoubtedly for other graduate students), time was an important consideration. Thus, these mentors, or cultural navigators, were an essential part of this project.

After several conversations with BIN citizens and Tribal Council at other meetings and events, our research questions began to take shape. One of many unique aspects of the BIN is their federally unrecognized status. This means they do not have access to many of the same resources that other tribes do, including clear and direct access to the Indian Health Service. This left the people I talked to wondering – how are citizens accessing health care? What channels are they going through? How do they receive information about health?

Once we had developed some of these ideas, I fleshed them out into broader research questions and a general research plan (Appendix A). I shared this at a Tribal Council meeting and received approval from Tribal Council. From there, I developed a more extensive research plan, which went through the approval process of both the University of Wisconsin-Madison Institutional Review Board and the BIN Tribal

Council. This study, which explored health communication in the Brothertown Indian Nation, was approved by both entities (Appendix B). The BIN does not have a formal IRB committee in place. To receive approval from Tribal Council, all research plans, methods, and research questions were shared with Tribal Council, who was able to make any needed changes or edits.

After going through IRB approval, the Tribal Research Liaison introduced herself to me by phone. Although I had met her several times, I did not know about her role; if I had, I would have encouraged her to be part of the research plan development. She is a doctoral candidate in Anthropology at the University of Michigan and was appointed by the Tribal Council to work with all researchers conducting research with the BIN. She played an active role in data analysis and dissemination, and her role will be discussed throughout the remaining sections.

The research questions were as follows:

1. What is the experience of being a BIN citizen?
2. How do BIN citizens access healthcare?
3. How do BIN citizens access health information?
    a. What are the strengths of these different access methods?
    b. What are the challenges of these different access methods?
4. How does the current healthcare system meet the needs of BIN citizens?
    a. What can it improve?
5. What are the personal health concerns of BIN citizens?
    a. What are the biggest health concerns for the BIN?
6. What do BIN citizens believe the BIN can do to promote health and wellness for its people?
7. What do BIN citizens believe are the strengths of the BIN?

It was important to approach lines of questioning from a strengths-based approach, yet remain flexible in the conversation topics and let the flow of the conversation be guided by the participants. If participants chose to discuss what they perceived to be challenges, I explored that topic area with them.

A hallmark of community-based participatory research is participation in the full research process by community members. However, this participation is guided by the desires of the community, and the extent to which they can and would like to participate. Although I invited many community members personally through in-person conversations and through advertisements in the BIN newsletter, posted at the community center, and online to participate in different ways in the study, I did not receive interest in participating in the actual research process from any citizens. I believe that many citizens were already overstretched in their capacities by their day-to-day lives and their volunteer duties for the BIN; they could not and would not add the role of researcher to their collective plate. Instead, they wished me to pursue this research with their oversight and input. My role in this project is to respect the needs and wants of the community, which means I pursued this research without collaboration around the actual research implementation.

This is certainly an instance in which community-based participatory methodologies were unable to fulfill their desired intention: to give the community more control over the research. This may also speak to a failing on my part, as I was the initiator of this research process, not the BIN. Although this research looked at community-identified questions, its impetus was not the community itself. It should be noted that this challenge may arise when doing CBPR that is initiated by the researcher, not the community.

It is important to note that along the research process, I developed several community-facing outputs, namely two Health and Wellness Fairs. For these Fairs, I worked with another BIN citizen, contacted local entities related to health and wellbeing,

and invited them to have a booth at the Fair. These included a local college that had a free dental clinic, the YMCA, a tobacco use cessation expert, several nurses, and other community health programs offered at local medical institutions, such as a grief counseling program and a diabetes program. These Fairs were held in conjunction with other community events, which helped draw people to participate in them. BIN citizens were able to talk with people at different booths, learn new health information, explore programs they could participate in, and engage in broader health discussions. For example, we held larger question-and-answer sessions at each Fair where different BIN community members could discuss their health questions with the local experts for the benefit of the greater BIN community. These discussions seemed to be very valuable, as evidenced by the comments I received from several people in attendance.

Interviews

Given the nature of my dissertation project, qualitative methods are the most appropriate, and this was confirmed by citizens of the BIN. During the construction of the research plan, BIN citizens stressed that it was important to focus on interpersonal interactions to learn people's stories. However, to cast a wide geographic net, it was necessary to use telephone interviews instead of in-person interviews.

I advertised participation in the health communication study in several ways. I advertised in the BIN newsletter during several newsletter cycles. I posted an advertisement at the BIN Community Center (Appendix C). I also had a standing advertisement on the BIN website. I attended Tribal Council meetings, as well as other tribal events, and asked people if they would like to participate in interviews. When talking with people, I asked if they might be able to direct me to other participants.

It is important to note that I spent a great deal of time interacting with BIN citizens (and ultimately interview participants) in person at community events. Typically, by the time I talked with an interview participant, I had met them several times at various community events and had developed a relationship with them. I attended many meetings and other community events (walks, Homecomings, events in the greater Fond du Lac community) with the sole purpose of getting to know more BIN citizens. These interpersonal interactions helped me to develop trust relationships with the people I would interview. I got to know them, and more importantly, they got to know me. Through these conversations, they understood my motivations, interests, and background. In short, we got to know each other as people beyond a research relationship. Although I could have asked participants to complete their interviews with me during these community events, to do so would have been disrespectful. Many of these individuals had traveled a long distance to be at the community event and had limited time to be there. There were many other people they wanted to talk to and events in which they wanted to participate. I felt I could not ask them to give up an hour of this precious time to talk with me. Additionally, this would have identified them as interview participants to other memebers of their community. Therefore, when I talked to them on the phone for their interview, it was a continuation of a relationship that had already been established.

It was not easy to work with participants to have them sign up for interviews. The individuals I had the privilege of speaking to were eager and happy to talk. However, getting them to that stage was more difficult. It seemed as though many participants felt they would not have very much to contribute to the study. They seemed to feel that their views were not interesting enough to discuss in an official interview, asking, “What do I

have to contribute?" when I encouraged them to participate. I tried to stress that I was looking to talk with a wide variety of people and would welcome input from anyone who was willing to speak with me. I utilized some snowball sampling, asking interviewees to direct me towards others who may be interested in speaking with me (Biernacki & Waldorf, 1981).

Ultimately, I completed semi-structured telephone interviews with 20 citizens of the Brothertown Indian Nation. In keeping with Indigenous methodologies and being aware of the Brothertown traditions of oral history, these interviews were semi-structured and focused on narratives, while following a guide of questions (Appendix D). This allowed for the free flow of information and for the interview to be conducted like a conversation, rather than a power-laden interview (Chilisa, 2012). This also helped address the power imbalance between participants and myself.

Although I have undoubtedly made mistakes throughout this research, I am committed to doing my best to use Indigenous methods and be as culturally sensitive as I can be. This means that I tried to focus on narratives and storytelling throughout the interviews, as these are traditional ways to share knowledge and are important in the Brothertown community (Poupart et al, 2009). During these sharing sessions, it was important for me to be an attentive, patient, and non-interfering listener. It was also important that I respect and acknowledge silence as a method of communication that allows time for reflection and the generation of thoughts, rather than a void that needs to be filled. For example, Covarrubius (2007) shares this narrative to demonstrate the importance of silence in Native conversations:

> When I was a little girl at my grandma's house, I remember Grandma, Uncle, and a visitor sat in the living room, I was in the room too, two and a half hours later, they're still sitting there in silence and finally the old man guest spoke, ''Well,

> I'm going home,'' and he got up and left, and that's the world I grew up in . . . and I was just being, and you were just being and that was OK. . . . we remind our young people that this is how our grandmas and grandpas were, they were prayerful people, they didn't move so fast and wanna achieve so much and get somewhere that wasn't Indian, that wasn't separate from who we are now, that we're products of those people who had great peace and great perseverance. (p. 265)

By respecting different cultural ways of sharing knowledge, checking my own privilege, and remaining open to wherever the conversation may take us, I largely had positive, helpful interview experiences.

Interviews lasted between 30 and 80 minutes, with most averaging between 50 and 60 minutes. Interview participants ranged in their demographic characteristics and experiences within the tribe. Ages ranged from 22 to over 80, with most participants between the ages of 45 and 65.

Demographic characteristic	**Number of participants**	**Percentage**
Age 18-34	3	15%
35-54	8	40%
55+	9	45%
Gender Male	8	40%
Female	12	60%
Location Within 100 mile radius of Fond du Lac	13	65%
Beyond 100 mile radius of Fond du Lac	7	35%
Leadership position Currently/formerly in formal leadership role	8	40%
Not currently/formerly in leadership role	12	60%

Table 1 Demographic characteristics

I spoke with many individuals who have been very active or had been active in the leadership of BIN, as well as those who have not had leadership roles. I spoke with 12 women and 8 men. I recorded the interviews and transcribed them. I also wrote analytic memos to record my own thoughts and feelings after interviews, which helped to further contextualize each interview. These notes included information about my feelings about the interview, interesting and unexpected points of conversation, and anything that would be useful when later transcribing, coding, and analyzing these interviews.

Talking Circles

To provide additional opportunities for BIN citizens to participate in this project, I initially wanted to facilitate Talking Circles, which are similar to focus groups but are based on traditional Indigenous ways of sharing information and healing. In discussing Talking Circles with the Brothertown, citizens expressed interest and enthusiasm in participating with this methodology.

Other CBPR health research has successfully used Talking Circles or focus groups (Daley et al, 2010; Struthers, Hodge, Geishirt-Cantrell, & De Cora, 2003; Running Wolf & Pickard, 2003). This is a culturally traditional way of sharing, teaching, and learning for many Native peoples, which means it is a format that BIN citizens may already be comfortable with (Struthers et al, 2003). It is similar to a focus group in that there is a facilitator who leads the conversation as necessary, but it may include additional cultural elements and has a different history. For instance, in the Talking Circle, everyone is given an equal chance to share and discuss. A symbolic object can be used and passed around to each speaker. Sometimes, a prayer is offered at the beginning. Careful attention is paid to each speaker, and citizens are asked to support each speaker

by being present and attending to their words. The facilitator might also be a citizen of the community to encourage open sharing. Talking Circles are thought to have been developed in the Midwest tribes and used in tribal governments, where the circle represented the interconnectedness of all things (Running Wolf & Rickard, 2003).

In addition to being a tool of sharing, the Talking Circle itself is seen to have health and healing benefits. It has been used for alcohol and drug addictions, physical and mental health issues, and as a prevention tool. Talking Circles are thought to foster respect, promote attentive listening, strengthen self-esteem, and work out problems (Running Wolf & Rickard, 2003).

I scheduled several Talking Circles at different Brothertown events, including their Homecoming celebration, during a Health Fair, and after a Tribal Council meeting. These Talking Circles were framed as a way to discuss the health and well being of those who belonged to the BIN as a group while respecting each individual's story and privacy. They were advertised as modified focus groups that adhered to Native protocols. However, I did not have sufficient interest to actually host a Talking Circle. The opportunity to have Talking Circles was advertised at the event, yet no one came to the designated space to participate. When I approached individuals about participating in Talking Circles, they said they would prefer to speak to be privately. Brothertown citizens preferred to speak with me personally through interviews. Although I believe Talking Circles could have been a useful methodology, it was imperative that I respect citizens' wishes, and so ultimately I did not utilize Talking Circles.

I coded the data from the interviews using Saldaña's (2009) *Coding Manual for Qualitative Research*. Initially, I reread interview transcripts to better understand the

topic and content of each interview. Then, I coded by hand, taking notes of themes that emerged, noting quotes, and allowing categories to emerge. I read through each transcript, noting whatever topics emerged. I was not concerned about splitting each line and digging out detailed analyses at this time. During this initial coding, I focused on Holistic coding to develop familiarity with the data and the general ideas being expressed. I used this method to prepare to develop finer-grained sub-themes. Because I had defined research questions, I was able to use Holistic coding to see what themes emerged around them, such as "Access to care" and "Health issues of concern." I also utilized Grounded Theory during Holistic coding to allow for other (perhaps unexpected) themes to emerge. In this way, I was not solely limited to information that directly related to my research questions. Instead, I was able to see what other topics came up during conversations, such as "My Brothertown experience" and "Volunteers". This allowed me to both follow my general research plans and allow for the inclusion of new themes.

During second cycle coding, I utilized Descriptive coding to understand some of the broader themes occurring. Using Descriptive coding, I was able to summarize a passage or statement into a basic theme. This helped to develop the initial codes into more concrete themes and subthemes. For example, under the initial code of "Accessing care," I was able to break this down further into "Private insurance," and "Federal program". Descriptive coding in particular helped answer the concrete research questions the interviews were based upon, as it allowed for the simple organization of themes into subthemes. It also helped me to understand what people were doing, such as in regards to health behaviors.

I also utilized Values coding to draw out participants' ideas around what they valued individually and as a tribe, and to understand how participants evaluated their experiences in the tribe itself. This coding helped me to understand participant's values, beliefs, and attitudes. This gave me a better understanding of the BIN's cultural values and what activities were perceived to embody those values, such as the value of higher education. It also clarified the perceived valence of different activities, such as accessing health information online.

Additionally, I used Versus coding whenever conflict arose in the transcripts. Versus coding helps to organize binary values or activities that are in conflict with one another. This was especially helpful in understanding perceived conflicts of identity expression. This conflict was identified by the participant and presented in some binary fashion. For example, some participants felt that one form of expressing their Brothertown identity (such as following a Christian religion) was in conflict or at odds with other forms of spirituality.

During the final third cycle coding, I used Focused coding to develop appropriate subthemes. This allowed for the refinement of categories appropriately and to see which codes hung together. Ultimately, this developed into a list of themes, with subthemes under each. During this process, I organized final codes into excel sheets, noting each code, giving exemplars of each, and providing space to denote where an interview could utilize each code. This represented a codebook, which was used to test intercoder reliability. I tested my coding for reliability with the help of another graduate student, who coded 10% of the interviews with intercoder agreement of 94%. This graduate student was also a white female who had experience with qualitative research. While

testing for coder agreement with the codebook I had developed, I asked her to note places where relevant information had not been captured in the codebook, but she did not have additional codes to add to the codebook.

During the coding process, I organized the main themes into a short summary of preliminary results and shared this with the BIN's Tribal Research Liaison. She was able to reflect on these themes, send me her thoughts and ideas for further analysis, and suggest further readings. She did not have the time to read through individual transcripts, and so preferred that I send her data that was already in the analysis process. We went through three iterations of this analysis. At that point, we developed materials for Tribal Council and other citizens of the BIN in order to share the results.

At this time, it would have been helpful to do member checking, in which I reflect my data and results back to the original participants. I did not pursue member checking, largely because I did not want to impose an additional time burden on my research participants, who had previously stated (either explicitly or implicitly) that they did not have the capacity to be more involved with the research process. Providing an interview was the contribution with which they felt comfortable.

Chapter 7: Results

In this section, I will discuss the major themes that developed in this health communication study from data analysis and coding. Findings clustered into five main categories: family, Brothertown Indian Nation (BIN) identity, BIN strengths, BIN challenges, and health. Although many of my structured questions focused on health, participants also desired to talk about the experience of being a BIN citizen, as well as the experience of being a citizen of a federally unrecognized tribe. This section goes over the themes of our conversations, which will later be analyzed in the discussion.

To better conceptualize these themes, the following chart may be helpful:

Family	Brothertown Indian Nation (BIN) identity	Strengths	Challenges	Health
Family connections	Being a BIN citizen and White	Education	Exclusion	Health issues
Family challenges	Language use	Dedication	Geographic distance	Healthcare coverage
Including younger generations	Conceptualization of BIN identity	Being in community	Leadership	Accessing health information
		Strengths in disagreements	Sustainability	Improving the health of the BIN

Table 2 Results

Family

Almost every interviewee discussed the importance of family, and specifically the importance of family in relation to being Brothertown. In other words, family connections were important for their BIN citizenship. Many interviewees said they were involved with the BIN because of family, and that a family member encouraged them to get involved with the tribe. As one participant said, “We didn't really get into doing Native cultural things until my mom's younger brother and sister started getting into it.”

Family connections

Often, participants spoke about the closeness they felt with their Brothertown family, regardless of their exact connection to other members. These connections, regardless of whether they were with immediate family members, were familial in nature and carried great importance. One participant described that feeling by saying, "I like to say that I'm everybody's cousin." These family connections can indicate a sense of belonging, and may have important health implications, which will be developed in the discussion.

Family challenges

While many participants became involved with the tribe because of their family, they had challenges encouraging their own younger family members to be active within the nation. One participant shared, "I wish that we could get younger people involved, because if we don't, as we pass on, there will be no one there." Although her son was initially very excited about being involved, his involvement has since dropped off. Other participants also noted that it was difficult to involve younger people. They noted this was perhaps due to the general busyness of people's everyday lives, or due to geographic constraints that made it difficult to participate regularly in tribal activities. This may be especially relevant when considering that there is limited tribal infrastructure for activities and that the BIN must conduct most tribal business on a volunteer basis.

The experience of being a Brothertown Indian Nation citizen

One area of conversation I focused on with participants was the conceptualization of what it means to be a citizen of the BIN. As discussed in the literature review, members of the BIN face particular challenges related to their self-identity, which can

have implications for health. During my conversations, I tried to gain a better understanding of what it meant for each participant to be a Brothertown citizen in the hopes that this information could be useful for the BIN to further understand and strengthen citizens' sense of belonging and identification.

Almost all the interview participants I spoke with have always known they were American Indian, if not Brothertown specifically. As one participant said, "There was never a time when I didn't know that I was Brothertown." This knowledge typically began in childhood, even if participants were not entirely sure what it meant.

This sense of identity, whether Native in general or Brothertown in specific, was seen as critically important by many participants. One participant said, "I was raised with the culture. It's not only who I am, but it's what I am." Another person stated, "It's been an everyday, everyday part of my life."

For some interviewees, this sense of identity had shifted through the years. Although identifying as American Indian is now seen as a point of pride by many, that was not always the case, and some participants spoke of working through issues of shame during childhood. "As a kid, I used to get picked on all the time, so it kind of scarred me in a way to be Indian," shared one participant. Another shared the struggle of feeling like she didn't fit in either the Indian world or the mainstream world. "I went to an elementary school near the Rez and got made fun of for not being Native enough," this participant shared. "And then I went to a very White, very homogenous high school and got made fun of for not being White enough." Things changed for this participant during college, when she realized that: "Native isn't something you have to define, you don't have to look Native." For many, these negative childhood interactions improved into adulthood

as participants (and perhaps the culture, world, and people around them) embraced this part of their identity and developed more nuanced understandings of what it means to be American Indian.

Being Brothertown and White

Some participants understood their Brothertown identity in a different way, explaining that they often felt similar to White people. One participant said, "I've grown up just like any other non-Native person in the community" while another noted "I never considered myself any different from anybody else." This suggests that although being Brothertown is an important piece of self-identity for many members, they may also strongly identify with non-Indians and White culture – or they feel it is necessary to tell a White researcher this. One participant described their understanding of identification with White culture:

> That maybe is the difference between someone who's always, some tribe that's always been treated as a tribe and another tribe that is maybe forced to assimilate a little bit more because their tribal membership is taken away for citizenship.... their role in America has been given that choice of you know, giving up and become a citizen or go, leave. And nobody else has had to go through that.

This was also understood in another way: that BIN members could move more easily between the White world and the Indian world. One participant described this by saying:

> They're…I think their strength, they're kind of, it's not a strength I know, they have the ability to play on both sides of the line, Native American, non-Native American. I've done it my entire career, you know…it's an advantage, but it's also a disadvantage. That's one of their…you can call it a strength, but I can also make the case for a weakness, or a threat.

One participant described the ability for BIN members to move between different cultures in this way:

> **Participant**: And I don't think we are looked upon, the Brothertown people, as the Menomonee and the Stockbridge are. They're kind of ostracized right here in our area, although they're Indians, people will talk about it, it's the Indian, where people don't seem to think of us as being Indian. So…
> **Interviewer**: Do you find that has a psychological impact on you or your fellow members?
> **Participant:** I don't think so. I don't think so. You could tell a distinction, could you not, when you were there at the Homecoming, between us and the Stockbridge? You could tell by looks, identify who was who?

In this instance, the interviewee was simply describing the differences they saw between BIN citizens and citizens of other Indian nations in the area. BIN citizens were not necessarily treated as Indians, which in this scenario was seen as negative, in this interviewee's view. BIN citizens also had different physical appearances from other American Indians, according to the interviewee.

Language use

Different conceptualizations of being Brothertown were also expressed in participants' language use. Some participants used "I" and "we" when talking about the nation, while others said "they" instead. This could connote different conceptualizations of identity and belonging.

Some participants used "I/we" and "they" interchangeably with no discernible pattern or change in use. This could indicate several things. They may have been unsure about whether the phrasing of the question was asking about them personally or about the nation as a whole. They may also feel somewhat less connected to the BIN than other participants at times.

Other participants consistently used the first person, which could indicate that they identify more strongly as a BIN citizen or that they feel more connected to the nation. Others consistently used the third person throughout the conversation, which may indicate that they feel somewhat apart from the nation.

In some instances, participants seemed to switch from using the first person to the third person in specific contexts. For example, some people used the third person when discussing what they viewed as some challenges of the nation:

> I really can't see them succeeding in what it is, and if it does, if they do get federal recognition, that's great, but I can't see where they can maintain what they get because they don't have ways to raise funds, how are you going to maintain buildings and stuff when you don't have the ability to raise the money and all this stuff.

In contrast, participants almost always discussed the strengths of the BIN in the first plural person. This method of switching between first and third person could indicate that participants felt more distant from their nation when discussing its perceived challenges, and felt closer to it as they discussed its strengths.

Conceptualizations of BIN identity

In my conversations, I heard other indications that there were several conceptualizations of what it means to be a citizen of the BIN. I asked participants what it meant to be a citizen of the BIN and heard a variety of answers. Some participants felt that the founding citizens of the nation had meant for all Brothertown citizens to give up the traditions and cultural heritage of their founding tribes. To be Brothertown with this mindset meant fully embracing Christianity, letting go of older Native ways, and becoming more like European settlers. One participant said:

> There's no other Indian tribe like us. When you look at our history as an Indian tribe, when we got to Wisconsin, we built the first church in the state of Wisconsin. Between us and the Stockbridge, we had the first public school teachers in the state of Wisconsin, we had the first postmaster in the state of Wisconsin, we were even pioneers in the state of Wisconsin. We weren't savages like people think of Indians. When people think of Indians, it's just like …when they petitioned us to become US citizens, representative Doty, in Congress, he said the Brothertown, as a tribe of Indians, you'd be better off to refer to them as a community of Indians because they're more civilized than the white people coming from Europe who were settling they because they had homes, they had schools, they had houses, they had communities. They were just more civilized than the people that were coming over from Europe.

For this participant, it seemed very important that the BIN and its citizens were seen in a particular, "civilized" way, with emphasis put on some forms of public life such as education. They seem to be stressing that the BIN had customs and ways that were similar to the White population, and that should be a point of pride for the tribe. The participant continued to say:

> I don't think our Brothertown brothers and sisters today in our tribe know our history. They don't know our history when they do their drumming and dancing around the drums and stuff, that's not Brothertown history. That's Mohican history and that's Naragansett history and that's the history of the tribes that we came out of, but Samson Occom, our founder, would have never allowed that. If he were here he wouldn't allow it.

Here, the participant is pointing out that not only are the BIN citizens taking traditions from their founding tribes, they are also taking traditions from other tribes, such as the Mohican, with whom they have a relationship but which is not one of their founding tribes.

Another participant tried to describe the different identities of their fellow citizens. From this viewpoint, there are several different ways of conceptualizing what it means to be Brothertown, and these different identities are at times conflicting, although they may also be seen as relational or fluid:

> There are certain people, they don't want to be associated with the Brothertown. There are people who act and think Indian and they don't want them. What they want are church-going Christians. And they're still some people in the office and on the council and most of the Peacemakers that think that way.

This viewpoint describes several identity challenges: first, those individuals who wish to focus on the Christian faith and not other aspects of the BIN; and second, those who are trying to become involved in the BIN, but cannot due to either enrollment challenges or individual bias. This conflict between different ways of identifying as

Brothertown was noted by several people. Another participant describe the struggle as such:

> There's a very small faction that of people who have grown up on one reservation or another and been a part of an Indian community their entire life and some [sic] has their family ahead of them and we understand what it is to be Native...we understand the customs and traditions and that kind of thing are actually traditional. There's another faction that's held onto the Christianity of the Brothertown tribe and are staunch against anything outside of that and discourage anyone who is not following that direction, and it's a very large faction, and the thing is that it's dying out fast, but three quarters of those don't want to be identified as Indian, but they're the largest, largest group in our membership. They don't want to be associated with Indian, they don't want anyone to know that they're Indian, they're still ashamed of the fact that they're Indian...Then the third part are the ones who've discovered they're part-Native, they've discovered through genealogy or something...They jump in with both feet and then they start to realize how deep the water is and they get confused, lost, and they don't understand where they're going or how they're getting there. They adopt cultures, you know, little bits of culture of every different tribe, they don't try to understand who they are or who they come from.

From this perspective, the Christian identity is again reiterated, and two more identities are included: those who have strong historic Native ties and have embraced Native culture, and those who have recently discovered their Native identity and might not fully understand what it means. One participant shared about their experience discovering the Brothertown identity:

> It [identity] means that it is part of my heritage and because it is something that is relatively new to me, I feel like I'm just discovering it and learning about it and I feel that there's so much, there's so much for me to learn. It's like any other person who's doing their genealogy or learning about their heritage. So I'm trying to educate myself, just trying to learn more.

Although these identities were sometimes discussed as being in clear conflict with one another, not all interviewees shared that view. Some described being able to move among different identities when it may be expedient, advantageous, or to avoid unpleasantness, which speaks to a more fluid understanding of identity. One participant described the back-and-forth between Christianity and honoring the traditions of the Brothertown's parent tribes in a more positive and unified way:

> When I first started becoming Brothertown in the 90s, we were Christians, don't give me any of this pagan stuff, we were Christians and Council let you know we were Christians. And because [laughing] always the first one to call me a pagan and it was a Brothertown elder and I said I guess I am, thank you. They wanted none of that, none of that drumming and none of that pagan stuff, and now that it's being brought back to the front with such significance and confidence, I like that, and I like that it hasn't usurped the position of Christianity, the traditionalness hasn't gone overboard to say you're excluded, like the Christian movement excluded us. So yeah, I like the foundation coming back and not being hidden. I like that.

In addition to being mentioned in a descriptive sense, these different conceptualizations of identity were seen as a source of emotional distress for some participants. They described their frustrations with in-group disagreements and different factions: "What I think is missing is we need to come together more as people. And it's not so much as meetings, it's just getting together and discussing some of this stuff." This view expressed the desire for tribal citizens to come together to work through these differences and come to more positive understandings of one another. This participant reiterated that thought:

> I did see more of that, so they're trying to pull it together in that way I think the cultural aspect is like, one aspect, it's kind of a little bit like a membership club and maybe some people look at it that way, and maybe some people look at it in a heritage way so I know that my mom and my dad and my grandma and grandpa were Native and I'm proud to be Native as well, so it's like right then and there, it's like three different ways of looking at it. I still think they need to pull that all together, they haven't reached that sweet spot quite yet and who knows what that sweet spot is going to be.

From these conversations, it seems clear that there are several ideas about what it means to be a citizen of the Brothertown Indian Nation.

Strengths

Participants commented on many strengths they felt the BIN and its people have. These discussions coalesced around the following themes: a high number of very educated people among the BIN, dedicated volunteers, a strong sense of community and

being in community with other BIN citizens, and the ability to disagree to bring in new perspectives.

Education

Several participants mentioned that the high number of educated members was a strength for the nation. They saw each other as a resource that could be tapped into: "We got a lot of educated people in the tribe. We have an awful lot of attorneys, a lot of educated people. I have a lot of cousins who are educated in Indian law."

One participant thought that although there is a large number of educated individuals, the nation was struggling to tap into them as resources: "We have a great deal of highly educated, experienced professionals within the tribe, so if we were a little more attuned to that, if we were in a situation where we were able to use those talents, [we would] have a fair share of opportunities we could venture off into." This individual felt that Tribal leadership was not utilizing the talents of Tribal citizens, and as such, the educational attainment citizens brought with them was not being put to good use internally.

Dedication

Overwhelmingly, dedication to the nation was the strength mentioned most often. One participant said, "Well, there's a few dedicated people that…have been there for quite a few years. I guess our biggest strengths [sic] is that we have a group of people who are willing to volunteer and spend a lot of time, a really long time working at it." Nearly every interviewee noted that the tribe has a number of incredibly dedicated volunteers who contribute their time, energy, and resources to the tribe.

These volunteers run programming, complete projects, sit in leadership roles, and help move the nation towards its goals. “I think that a strength is that there are a core group of people who are very dedicated to the present and the future of the tribe and are working very hard for recognition and just to move forward.” The vast, vast majority of work done with and for BIN is done on a volunteer basis, as there is little income with which to pay individuals. One participant noted:

> The other strengths or the other…are the other members that dedicate their lives or have dedicated to put the BIN up where we are today for getting recognized. There’s a lot of people that stuck a lot of time into this and other people don’t realize what it took, what they did for us. And they should be up on the platform or should be recognized for things that they’ve achieved to get us where we are today.

It was noted that there is typically a small number of volunteers who are really dedicated. One participant said, “I feel like, it’s tough because there’s a lot of stuff that’s gotta get done and there’s a small number of really dedicated volunteers and tribal council, they get bombarded with so many things.” Participants noted that it is difficult to get citizens involved in volunteer positions. Challenges to involvement participants discussed included geographic distance, family commitments, political disagreements with Tribal leadership, and the lack of monetary compensation. One regular volunteer expressed burnout with their volunteer role: “It seems like it’s always the same people volunteering all the time and that gets old fast.”

Being in community

Some participants also mentioned the joy and pride they feel in working with and for the BIN. One participant said, “I sort of felt times more fulfilled than I had doing anything else in my life” to describe times she spent doing activities with the tribe. Another said, describing her path into doing cultural activities with the tribe:

> So we didn't, we didn't really get into doing Native cultural things until my mom's younger brother and sister started getting into it and started to research and participating and enjoying the cultural events and studying and things like that. And we just kind of fell into it with them. And now it's so much a part of my life, it's like everything.

It is clear that time spent working with the tribe was very important for some participants.

The importance of being in community with other BIN citizens and what that can inspire was also mentioned. One participant said:

> Well, I think, I think most of our people have been very independent, had to be very independent, and we've not been pushed into a reserve and so we don't have that same community that has been on reservations, but we've maintained that community from afar, there's distances between us, yet there's closeness.

This participant seemed to be looking at their current situation with some optimism, framing their current lack of land as a positive outcome because they were not removed from their land to a place they did not wish to go. Instead, the Brothertown had some autonomy in deciding to come to Wisconsin, even though they had significant challenges in remaining in Wisconsin. They continued to say:

> And part of that value that we all have is that we're, I don't know what you call it, energetic or positive thinking, you know I haven't seen anybody just hopeless feeling or not active because there's nothing they can do, we haven't been beaten down in that way.

BIN members are located in all 50 states, even though half of them do live within about four hours of Fond du Lac, Wisconsin.

Strength in disagreements and diverse opinions

Lastly, some people felt that the ability to disagree and bring in new perspectives is a strength. One member articulated, "I think that one of the strengths is the disagreements that we have. It brings about new ideas. So I think that's a strength." Another described how the diversity of opinions was helpful for the nation:

> I like that when there are hard decisions to be made, they don't make them spur of the moment. We talk to lots and lots of people, lots of people, elders and new people and young people and say, what do you say, and then making the decision.

Challenges

I did not specifically ask about challenges, as this project used a strengths-based approach. However, as I was talking with people, many interviewees voluntarily brought up the challenges they perceived in their nation. I feel these can be constructive and can help BIN build upon its strengths, which is why I am mentioning them. I find it important to note at this juncture that I will spend time in the discussion exploring how to re-frame these challenges as exciting opportunities, as well as explore how the nation can make sense of this information. I will also attempt to contextualize these perceived challenges in the broader context of American Indians living in the United States today.

Exclusion

One of the major themes coding uncovered was exclusion. Some BIN citizens felt strongly as though they had been excluded or had witnessed others be excluded from the nation both intentionally and unintentionally. In this context, exclusion meant several things.

For some people, it meant that they were frustrated at what they saw as intentional exclusion from the nation itself. Several people described difficulty in getting their fellow Brothertown citizens enrolled due to procedural or political issues. One interviewee noted, "[It's] mainly to try to get my family, my extended family all enrolled and that's very difficult, because we're missing this or that or that paper or that information."

One interviewee who had extensive leadership history in the BIN described the difficulty they'd experienced getting others enrolled:

> We were at the meeting up in Minnesota at the [redacted] reunion and this lady, this is a big issue, we have more Brothertown members at the reunion than you have at the picnic we were at in Fond Du Lac. And this girl came from Napa Idaho with her child who was four years old and we enrolled the child at the reunion and we had two or three Peacemakers there plus some former Peacemakers plus some members of the petition committee and a bunch of Brothertown people there. And I sent the information …to have her enrolled and he would not do it [enroll her].

Additionally, participants pointed out that sometimes the BIN is excluding people through a lack of communication. Some noted that it was difficult for the Tribal Council and other volunteers to communicate with citizens due to their administrative structure, or lack thereof:

> I really get frustrated with the lack of response that a lot of Brothertown people, not just leaders, the Brothertown people, have to outsider questions. We're really gracious and warm and welcoming, you walk into the office and I'll give you a hug and I'll take you down and it's here, have this, have this, but it's a whole lack of consideration when responding to phone calls or emails is disturbing. I'm just blaming our structure, our inability to have, to be able to afford a fulltime office staff or a halftime office staff.

As noted earlier, the BIN depends largely on volunteers to complete tasks, and often they rely on the same small number of volunteers to get their work done. Interviewees shared that this made keeping in regular communication with the nation difficult, and it was difficult to communicate with the BIN itself.

Some others noted that these exclusionary communication practices were at times intentional. In other words, people within the BIN in leadership roles intentionally excluded other members (or potential members) for personal or political reasons. One interviewee stated:

> The biggest thing is that most people don't communicate with the tribe. I mean, it's difficult just to get the newsletter to people. There's so many gaps that are missing that it's just horrendous. Half the people don't want to be involved, half the people want to be involved but can't be, and then the ones that are involved and are involved or enrolled can't get the newsletter. It's difficult to get any information out. I think it'd be really difficult for anyone to depend, a lady called me in Milwaukee that's looking for work, I just happened to answer, they can't seem to figure out if she's enrolled or not. Or if she's got all her…nobody calls her back. I've heard dozens of stories you know, they call and they make phone calls and they talk to them and they say I'll get back to you but they never call them back. In years. But some people can call in and they get all the

> information they want. So it's a real…I don't know. I don't know what to call it. I know what's going on, I just don't want to call it that.

Several interviewees noted this intentional exclusion. They attributed it to personal and political differences within the nation that allowed those in power (i.e. in leadership positions) the authority and control to isolate others. One interviewee said:

> And the people who aren't enrolled who are newly discovered they're part-Brothertown will never get enrolled because nobody wants to pay any attention to them. There are people who are enrolled who have lived on reservations all their lives who can't get any information from the tribe because nobody calls them back because they got the wrong family name.

Geographic distance

Another challenge the nation faces is that many of its citizens are geographically spread out. This has significant implications for participation when most, if not all, of the main events in any given year are held at the community center in Fond du Lac. As one participant succinctly stated, "I think that our distribution is our biggest problem. We're not, you know, in one area in a community." This relates directly to the strong, yet small, volunteer base. Interviewees noted that it is very difficult to encourage people to volunteer when they literally cannot physically be there. When many projects depend on being in or near Fond du Lac, many people felt they were unable to participate, despite their willingness to do so. One interviewee noted, "The other thing that is really hard for our tribe is that our members are so spread out all over the country...it would be nice to have more members involved."

One interviewee thought that this distance could be reframed as a strength:

> Our distance should be a strength. The fact that we are spread out and that we have people who are all around the world who have information they can share and you know, jeeze, six years ago we were talking about we should be able to skype during meetings and we're not doing it but we should be able to skype during meetings and have Council members who are in Texas and California and Portland, you know, to be on Council and be active members, we should be able to do that, but I think that's a strength we haven't even begun to tap into.

However, they were in the minority, as more interviewees believed that the distance between citizens was a hindrance.

The issue of distance also relates to another challenge interviewees noted: getting other citizens more involved in the BIN. Some people might not be participating due to leading busy lives, as one interviewee noted:

> And, um, my problem is…it's trying to figure out how do we get people involved. You know, everybody is really busy, got lots of things going on, and it seems that we have the same people that show up at the same functions all the time, and how do we get the rest of the people involved?

This seemed to be a historical challenge. One interviewee said, "Even way back, like 15 people at their meetings. They don't get many people to their meetings…Yeah. No, they don't get people. No, there should be more, and it's the same people who end up doing the things all the time."

One interviewee described the challenges they had faced in encouraging people to volunteer: "I'm busy. I can't. My family comes first. Well, bring your family along. We're asking you to be involved with us. Be part of us. But they think, well they'll have to work at something, but why not? Why not be involved?" The challenge of involvement seemed especially critical for younger citizens. Several interviewees noted that it was difficult for them to engage with the nation: "Well, I wish that we could get younger people involved, because if we don't, as we pass on, there will be no one there."

Leadership

Lastly, several interviewees mentioned that there were challenges at the leadership level. Although almost every person I interviewed said that they hoped for federal recognition for the future of the BIN, some seemed to think that they were on track towards achieving that goal, or that the BIN has the appropriate leadership to pursue

it. For example, one interviewee thought the nation was being too ambitious and should refocus on the goal of recognition:

> I really can't see them succeeding in what it is, and if it does, if they do get federal recognition, that's great, but I can't see where they can maintain what they get because they don't have ways to raise funds, how are you going to maintain buildings and stuff when you don't have the ability to raise the money and all this stuff. I think, I think they're going too fast. I really do. That's just my opinion, but I mean, it's great to dream, but reality's gotta set in sooner or later.

Another citizen said, "My belief was that when we started out, all we did was want federal recognition. But it's now turned into we want a lot of things to go with that federal recognition. And that was never our goal. The goal was to get the federal recognition and fine, we are getting greedy and I don't go along with that." When considering this view, it is important to remember the length of time it takes to get federal recognition, which is often decades, even for successful tribes. When the BIN initially submitted their petition for recognition, they spent 32 years in the process, ultimately unsuccessfully.

Some seemed to think the leadership challenges were due to challenges or problems within the Tribal Council itself. One interviewee said, "I think right now, the council is in a weak position right now, they're probably in the weakest position they've ever been in." Another interviewee disagreed with what she saw as unfair practices within the Council itself:

> She [Council member] wouldn't let me record them [the minutes] right. She wouldn't let me, she would vote for other people, and I didn't go along with that stuff, it wasn't fair, honest, or anything, and I saw how, how people were, how the Council was picked and it was her preference, she picked her people, and I didn't like any of this.

One interviewee noted that Council meetings seemed to focus on surface-level issues, rather than diving into the important issues that needed to be discussed:

> I don't know if…you don't have anybody there on the Council now who has the knowledge that [redacted] has. I could name a bunch of people who you have now, you have people who have some surface knowledge but they don't have any in depth

> knowledge. It's very sad. That council meeting where I met you? They don't even talk about in-depth stuff. It's just kind of surface stuff. It's kind of sad.

As I spoke with citizens, I felt that many were immensely proud of the BIN, their heritage, and their fellow citizens. At the same time, many participants simply expressed frustration at the challenges they faced, such as lack of participation, the geographic distance between them, the leadership difficulties, or the exclusion they had experienced at one time or another. Some kind of concern was mentioned by every person I spoke to, without initial prompting from me. Often, a discussion of strengths would turn into the interviewee sharing their perceived challenges of the nation. There was a general feeling of limitation – that people were excited about who they were and what they were doing, but that they were still limited, that they wanted more. They felt there were physical or political limitations holding them back from realizing the full potential of their nation. They wanted more and they wanted things to be different, but there were barriers in their way. As one interviewee put it, "It seems like we're always running into roadblocks."

Health and health communication

Health issues

In my conversations with participants, we often discussed their health concerns for the participants themselves, their families, and their fellow BIN citizens. Several themes emerged more strongly than others, including health issues participants associated with American Indians, disease prevention and wellness (often related to health issues faced by American Indians at higher rates than their White counterparts), substance abuse issues, and mental health. Participants tended to focus more on physical health versus mental/emotional health and the treatment of disease/injury versus prevention. In the

following section, I will cover those and all other health issues mentioned, as they will have implications for understanding this data and moving forward in actionable steps.

The health issue mentioned most frequently was diabetes. Most participants had direct experience with diabetes (i.e. they had diabetes or someone in their immediate family was diabetic). As one participant shared, "We have a real diabetes problem in our family." Other participants noted the link between American Indians and diabetes: "We, as a Native people need to get back to more of the natural foods. Diabetes is real prominent amongst Indian people." Some participants linked the increase in diabetes in Native populations to the historical shift in dietary and exercise habits of Native peoples, which was largely in the control of non-Indians at the macro level. One participant said:

> Diabetes - huge, huge, huge...you know, I see how it progressed over the years through like the frybread as a commodity, the cheeses and so on we were given. I was going to say it doesn't necessarily promote good health, it just fed the belly, and that's another thing that's getting rid of Indians...I've seen us disappearing off anything that counts anymore.

In this conversation, the interviewee linked the poor diet of American Indians to the health problems many of them now suffer, and connected these modern problems to the governmental control the United States has had over Indigenous peoples, with policies of genocide, removal, and disconnection from traditional practices and ways of being.

One participant linked diabetes to the percentage of Native ancestry one had. "I can't really say if anybody who's currently Brothertown and not mixed with other tribes, so that their Native blood is, if their Native blood were higher, I'd say you're more at risk for these things." In other words, this interviewee thought that if a Brothertown citizen had more Native background, their chances of having diabetes and the associated complications would be higher, seemingly from genetic predispositions.

Connected to the issue of diabetes was obesity. Many interviewees shared that they had concerns about obesity or being overweight, often for both themselves and for fellow BIN citizens. Participants knew this was a concern and important disease precursor, and often shared that they were (or should be) trying to do something to lose weight. One participant said, “I’m overweight, have been for quite a few years, trying to be a bit more diligent about watching what I eat and how that affects [me].” Another shared, “You know I, I probably don’t, I know that I don’t eat probably the way I should and stuff like that.” Yet another participant said, “I'm smart enough to know how much of a risk I am, but I won't quit eating like I do.”

Additionally, many interviewees discussed inactivity and that staying active was an important health issue and prevention tool. Some participants noted that when they were more active, they felt better: “I felt better and stronger when I worked farming.” Others noted that even though they felt as though they were staying physically active in their lives, medical professionals encouraged them to be even more active. One participant said:

> And exercise, oh my goodness! It's been a struggle for me to walk everyday. But I know I have to walk. I keep thinking, but I walk around the house, I do my housework, work in the garden, do this, do that, no, you need to walk in addition.

Those who were active acknowledged that it was difficult to live an active lifestyle. One participant talked about how difficult it was to get people to live healthfully:

> Like my ma, I told her that one day, you know if could, try to walk down to the corner and back, get some more exercise. And she just looks at you like, yeah right! And other people, it, some care and some don’t, how’s that. Some you can talk to and yeah, I agree with you, but nothing ever gets done, and the next one that you talk to, yeah, great, I might start that and they might go for walks or buy a bike and start riding a bike. It’s up to each individual what they really want in their life. And it’s hard to pursue somebody. You might get one out of ten, how’s that. I mean, for go off track a little bit, but I was on

> the central safety team at work for ten or twelve years and that's kind of what we're talking about right here. Try to get people to change or do other things, 80% of them are going to turn their head and go the other way and the other 20 might go well yeah, that ain't a bad idea, we'll work on that and help you out, but you're going to have always negatives and you'll have a few positives, but you'll always have more negatives than you have positives. And you know as well as I do there's some stubborn people out there. You ain't going to tell me what to do. Well, I'm not telling you what to do, I'm just asking if you would like to change, don't worry about it.

Despite these difficulties, this individual was committed to staying active:

> Everybody tries to watch their health okay, but it's hard to get people involved in the plan and try to stick to it, I guess. But my theory is, if you want to live, you gotta change. Otherwise, you know, you're just cutting your life short. But that's like me, I go for my, I got my little tricycle and I try to go for three bike rides a day. Well, I've been hunting now quite a bit so I haven't been active on my bike, but when I can, I jump on it and I go all the way down to Mercury, then I turn around and come back. It's about a mile so I'm putting two miles, so that's six miles I day I try to get on the bike. You know, it's exercise and you know, I know it keeps me healthy, but it's something to do. You gotta stay active.

One participant shared that it was difficult to exercise because the nearest gym was 30 minutes away, expressing that in their eyes, exercise was typically something you did at a gym or other specialized facility. "I wish it [fitness center] were here, right in our community, but it's not, it's about half an hour away. Otherwise I think my husband and I would both go down."

Mentioned somewhat less frequently were hypertension and heart disease. One participant succinctly mapped their health concerns for themselves and the BIN onto the larger health issues facing Indian Country:

> I guess just the simple stuff that's common amongst Indian communities, diabetes, high blood pressure, heart disease. If you talk to some of the elders that come around to Homecoming, they all have the same thing, high blood pressure, heart disease, and diabetes. I mean, half my family's got it or died from it. So it just runs rampant. I've got it, I don't have diabetes, but I've got heart murmurs and chest pains all the time and my uncle who's just nine months older than me had a heart attack a few months ago. I mean every one of his siblings either has stents put in or heart attacks. And then high blood pressure runs rampant in the family.

Participants also mentioned several other health issues that were important for the American Indian population as a whole. One of these was mental health. Participants

shared that they or their family members had mental health challenges, and they often said they would like more, better, and/or more easily accessible mental health resources. Some participants shared their own specific mental health diagnoses, and discussed the difficulty they had had in accessing appropriate mental health care.

Participants also expressed concern about substance abuse for their fellow BIN citizen. One interviewee said:

> Well, just like I guess most people, I would love to have more substance abuse counseling, you know, psychological counseling. They're so limited. When my brothers were counseling with substance abuse, they say go seek counseling, but you're on a six month wait list. So to not use drugs for six months and then you think after that they need?

Some participants clearly linked mental health issues and substance abuse problems. As one participant said, "I spent most of my years self-medicating with alcohol and drugs." One participant linked substance abuse issues to a broader desire to engage in self-stimulating and often dangerous behavior:

> I think that addiction and addiction I want to use it in the broadest sense because I feel that it encompasses a lot of different things in my family you know beyond sort of alcohol and drugs but I also think that there are addictions to I don't even know how to put it in words because I don't think it's' a true addiction but an addiction a need to engage in dangerous activities. And whether it's compensating for something, I don't know what it is.

Participants also had concerns related to aging. Some described their own challenges with aging, such as one participant who said, "It's a mental feeling of slowing down...and I see my body aging, I see muscle tone, I see all these signs." Others talked about the aging population in the nation itself: "There is a lot of senior people out there and you know there are a couple with canes and the health problems like it is cancer or arthritis or something." Going along with issues of aging, several people noted the challenges of caregiving and shared that they would like more support as caregivers. One participant described how their parents were suffering from dementia, yet refused to

move off of their farm or stop living independently. Related to the stress of caregiving, one participant expressed desire for more accessible grief counseling.

Finally, there were some health issues that were mentioned by one or two participants, but did not stand out as strong themes throughout all interviews. These health issues include cancer, Alzheimer's disease, and dental health.

From these responses, it is clear that participants had some understanding of the health problems facing the larger American Indian population, and identified those same health issues within their own unrecognized tribe.

Health care coverage

I also discussed with participants how they accessed health care and how their family members accessed care. The majority of participants had private health insurance through their employer. Often, this coverage covered their family members, as well. The elders I spoke with were all covered by Medicare. Some participants I spoke with also had supplemental health insurance, although not all participants had additional or gap insurance.

Accessing health information

Participants described finding information about health in a variety of ways that at times correlated with their demographic groups. Younger people under the age of 50, or those who worked regularly with technology, expressed more comfort with finding quality information about their health on the Internet. As one participant shared with a laugh, "I go surfing!" Some participants also expressed confidence in their ability to evaluate the quality of information found online: "I'm pretty much a Google queen. I can

find anything I want, and I also know those aren't diagnoses, those are only suggestions, and I'll thake those suggestions and I'll bring them to my NP or my doctor."

However, several people expressed a reluctance to use the internet to find health information for fear of finding incorrect health information. They may have had personal experience with finding misinformation, as one participant stated: "That's a lot of misinformation is what I'm afraid of. I know people who go on the internet looking for symptoms and come up with this great disease. And they spend ten years of their life arguing about this disease that they don't have." Even if participants did not have experience with finding misinformation, they tended to be concerned about finding inaccurate information online. Some participants were directly advised by their healthcare providers not to use the internet to access health information: "I don't use the internet. I was taught a long time ago by my own doctor at the time who said stay off the internet."

Some participants felt that the best way to receive information was through a combination of both interpersonal communication and internet information. One participant described their search for health information this way: "Well, I would consult with my primary healthcare physician and I would probably look for things online." Another participant shared, "It probably would be best for me to start on a website. With information on a website, I'd like to talk to somebody. A combination. I use the website for a lot of information." Even individuals who were comfortable seeking information from the internet also liked to learn about health information from another person, as one participant discussed: "So I think it's nice to do research and I have sisters who are really good at that part, but then they still want to face to face, they want to talk about it. Yeah.

Especially when it comes to health, most of us feel more comfortable talking and then making a decision."

However, this preference for combining internet information and interpersonal information was not shared by all participants. Many older participants over the age of 50 said they strongly preferred to talk with someone face-to-face about their health concerns and to find health information, rather than read an article or go on the Internet. When participants sought out information, they had two main sources of information: their family members and their healthcare providers If they had a question about their health or a certain condition, they would typically call their doctor. If it was a condition that someone in their family had, they would talk with them about it. As one participant said, "Talking. Not researching, talking. Yup. My whole mother's generation, most of them, she won't do internet." Sometimes this was tied to being unfamiliar with technology, computers, and/or the internet, as well. One participant shared their method of learning about health information this way:

> I don't want to go in there and freak myself out worrying about symptoms of some awful disease and throw myself in a tizzy worrying about it, so I tend to just pay attention to what people have to say. Ask my mom, tell my mom what's going on and she'll tell me about her experiences or my dad will tell me or [redacted] will tell me or some other people will tell me, give me their experience they have with it, and I'll take that information, but I cannot look up. I tried WebMD one time, they had me with some awful shit. I was onto liver disease for awhile there and I just had the flu!

It was clear from conversations that participants had a great deal of trust in family members and healthcare professionals as sources of information: "I don't think anyone can go much further than asking their families…if you're going to find out any info, it's going to be from your family."

Lastly, some participants also described their preferences for receiving information outside of interpersonal conversations. By and large, participants were interested in visual forms of communication, be they charts, pictures, or graphics. Participants thought these visuals would be more memorable than written forms of information. One participant described their desire for more visual communication this way:

> I think if those Native publications had an article every now and again that was short, brief, to the point, entertaining that was about any type of health subject, that even written in the charts, interesting looking graphs, you know those things like flow charts, statistics, that reaches more people than you know. I think we want to see those interesting looking graphics and I think that's going to stick with everybody longer than just being told by your doctor to watch what you eat.

Improving the health of the Brothertown Indian Nation

Regardless of how participants and their families accessed health care or health information, they had distinct ideas about how their health could be improved. Almost all participants said they wished their health insurance coverage was less expensive. Some shared that they were unable to retire when they wanted to because of increased health care costs. They also wished that their insurance covered more health services, including dental, chiropractic, eye care, hearing care, mental health services, and preventive services.

Often, participants said that the health care system, regardless of how they were accessing care, was confusing. They weren't sure what programs they qualified for, how to access them, or how to find the best coverage for them. Once they had their insurance, they weren't sure how to find the best medical professionals for their situations. As one participant succinctly said, "It's overwhelming, really [Medicare]. They give you a big huge booklet, like who's going to read that?" When talking about searching for

information, one interviewee said, “Speaking for myself, I’m not good at all of that stuff. I get very confused on all of it. So then I don’t bother.”

Many participants had solutions for healthcare challenges. One participant offered a solution for this challenge: “I think if the Brothertowns want to help you with healthcare, they should bring in the people at the time older people, bring in people to help you get the right healthcare program for your needs that can be offered right now.” One participant had a similar thought:

> I was wondering if we could engaged in an MOU [memorandum of understanding] with a local hospital or have some sort of health representative on tribal council who can help either inform or learn more about whatever this reimbursement policy is and how it will go through and help our citizens understand Medicare and Medicaid a little better. I don’t know if that’s right or not, I don’t know if that’s something that’s already being done, and I don’t know how many of our citizens are eligible.

Another participant had the suggestion of having a small Tribal clinic for preventive care:

> [I’d like] somewhere where they [members] can come and get even preventive care or something, maybe not so much hospitalization or whatever, but like vaccinations and stuff. That would be kind of good. Every year they want the elderly and the young to get pneumonia and flu shots. I know a lot of places you can get them for free or for not very much, but it would be nice if we could have a place to go for that.

Another shared a successful interaction they had with a doctor who described herself as a concierge of the healthcare system to help the participant find a new physician, saying that this would be a useful service for all:

> So this woman, she works for Affinity Medical Group and all my physicians come from Affinity, I don’t care, so (laughing) I emailed her and the few things I told her about myself, we had a fifteen minute meeting a week later and she laid out like seven different physicians in the area and talked about the pros and cons based upon their location and personality and feedback, and oh my god, that was so beautiful. That’s exactly what we all need! (Laughing). Somebody who can filter through this!

One idea that bubbled up for several interviewees was collaborating with other nations to share information and services. For example, other nations publish newsletters

with health articles specifically for citizens, which could be shared with the Brothertown. Additionally, other members wondered if other nations could share the health resources they did have, be they actual medical services, preventive care, or information about navigating the health care system. One participant said:

> I think that there are lots of tribes that have done a really good job around public health education and it'd be hard to evaluate what they've done and see what applies for our nation rather than start something new or you know reinvent anything. There might be things that we can sort of use as a launching pad as already on solid research footing or solid financial footing, right, so it if it's a partnership that is also of interest to places like Oneida or I don't know how far Milwaukee is from Fond du Lac, but the Potawatomie may want to engage in it as well, but it's a conversation to have to say how can we make this jointly beneficial relationship, right? If they're able to process third party reimbursements through their clinics, you'd think they'd want to have patients there, too. It seems like that might be a, how do we explore partnership with some of the tribes that are a little further along in their health programs.

This participant expressed a desire to collaborate with many other Indian nations, yet wasn't quite sure how some of Brothertown's intertribal relationships were more developed than others. They said:

> And there's nothing that prevents us from doing that with nations all across the United States because our people live in so many different places. So what is it about our relationship with Oneida? But yet, we don't seem to have that same relationship with Stockbridge, and I don't believe we have that same relationship with Menomonee, but why? I think that this is sort of beyond health. This could go into education. Why isn't this a relationship that we could explore with some of the tribal colleges in the area?

One participant shared an idea they'd tried to implement before, but hadn't been able to: a blood drive at the community center.

Chapter 8: Discussion

In this research, we learned that citizens of the Brothertown Indian Nation (BIN) have many of the same health concerns and challenges as citizens of federally recognized tribes, as well as other citizens of the United States. In this way, their experience as being an American Indian is similar to the experience of being Indian in a recognized tribe. However, being a citizen of an unrecognized tribe has significant implications for one's identity and sense of self. This has consequences for self-identity, self-concept, group membership, and group identity. It also has important implications for several aspects of health communication, including what health promotion strategies will be most useful for the Brothertown in particular, based on information shared in interviews, as well as what strategies may best benefit citizens of unrecognized tribes and important information for healthcare professionals. These results connect back to the health of the BIN people and the health of their community, as identity and health are inextricably linked. Additionally, being part of a federally unrecognized tribe means that citizens of the BIN do not have access to the same health care and health resources as citizens of recognized tribes. Consequently, BIN citizens are adapting to this situation in new and resourceful ways.

Identity and being a Brothertown Indian Nation citizen

As I spoke with participants and went back over transcripts, one question kept coming through the conversations: what does it mean to identify as a citizen of the Brothertown Indian Nation? As with many social identities, the experience of being a citizen of the Brothertown Indian Nation is complicated, multi-layered, contradictory, and fluid. Some people feel the BIN identity is most closely related to the customs and practices of the founding tribes (Mohegan; Pequot at Groton, MA; Pequot at Stonington,

CT; Narragansett; Niantic; Tunxis; and the Pequot band of Montauk of Long Island). Others feel the BIN identity relates to the ways of being BIN citizens adopted after they interacted with European settlers and became Christians. Still others feel to be Brothertown is to be an amalgam of those contrasting identities. And still others are not sure; they may be new to the experience of being Brothertown and are still developing an understanding of what that means. And some feel that to be Brothertown is very similar to being a member of the dominant White society.

This brings up several questions. Is there any one "right" way to "be" a member of a group? What is the "right" way to be an American Indian (AI)? What is the right way to be a citizen of the Brothertown Indian Nation? It is not my place to provide answers. However, I will attempt to parse through these different identity conceptualizations and provide a theoretical framework for reconciling them.

Identity

First, I will suggest a path forward for the Brothertown related to identity, health, and wellbeing. The dominant, colonizing society – the White society – has always had a vested interest in determining the identity of racialized others. Largely, this is based on financial and economic interest and gain. During slavery and Jim Crow, the "one drop" rule applied to Black people, meaning that one drop of Black blood made someone Black (Dworkin & Lerum, 2009). This protected the economic interest that White people had in owning Black people. Although White men could force Black women to bear their children, they were still considered Black and, as such, profit-making commodities. This is a rare situation in which one's identity/lineage was determined matrilineally, rather

than patrilineally, due to the vested interest White slave-owning men had in producing more slaves for economic gain.

Similarly, the White and dominant society has been legislating what it means to be Native since colonization began. Dissimilar to White society's interactions with Black people, White society did *not* have a financial benefit from increasing the population of American Indians. To the contrary – the existence and proliferation of Native people meant fewer resources for Whites. As such, Native identity and Native people were initially (and continually, in some ways) supposed to be extinguished, through warfare, biological warfare, policy, and practice.

Today, American Indians are the only racial and ethnic group that the U.S. government legislates so directly, literally determining who is an American Indian and who is not (U.S. Department of the Interior, 2017). The U.S. government does not have a strong economic interest in increasing the population of American Indians. Although sovereign AI nations are not directly competing with the U.S. government and U.S. citizens for resources as they did during early colonization, they are still competing for some resources. Treaties guarantee AI nations certain rights and resources from the U.S. government. The fewer American Indians there are, the more resources the U.S. government has for other interests, such as federal funding, oil and gas resources, and land.

At this point, the BIN could only receive federal recognition as a sovereign nation through an act of Congress; the U.S. government does not get to determine the Brothertown's identity and what it means to be a citizen of the Brothertown Indian Nation. The White society does not get to decide who is Brothertown, what that means,

and what that looks like. The Brothertown people get to make those decisions – and this research shows there is no easy answer.

The Brothertown story is one of constant adaptation. Initially, they adopted some customs, rituals, and belief systems of European settlers in order to stake their claim in a changing world. In some respects, it was easier to be considered White rather than Native, and draw attention to the similarities with Whites rather than emphasize their differences. Their survival has depended on their ability to embrace different ways of being.

When viewing their history through this lens, it seems to make more sense that the Brothertown identity may be less straightforward than it initially appears. For some, embracing White customs and beliefs was in itself a valuable survival mechanism and part of their heritage, even though their Brothertown ancestors may have adapted these customs due to (at least in part) colonizing forces. Participants may also feel that it is easier to pass as White. Alternatively, they may be copying what they see going on around them in the predominantly White culture. For others, relating back to the initial White influence might feel more painful and dishonest, and it seems more sensible to relate back to the founding tribes. One way of thinking about this kind of identity might be as a spectrum, with White traditions and customs on one end and the traditions of the founding tribes on the other end. It might feel difficult for individuals who believe themselves to be on opposite ends of that spectrum to empathize with other viewpoints. However, this way of thinking about identity utilizes an either/or mindset and may not acknowledge the fluidity of identity. This history is complex, multilayered, and difficult to understand. Yet, that does not change the reality of this history, all of which is part of

Brothertown. The founding tribes had important histories, customs, and beliefs, some of which were carried forward into the founding of Brothertown, such as a horizontal government structure that focuses on consensus and deliberation. The adoption of Christianity, European dress, and European public life was an adaptation strategy that helped ensure the continued existence of the Brothertown post-contact. For some, relating to White society was thus an important piece of Brothertown history and survival, and also represented an adaptation strategy they carried with them (e.g. feeling like they related a great deal to White mainstream society).

During our conversations, individuals who stressed the similarities between the Brothertown and European settlers were not advocating for the disbanding of the tribe, or the assimilation of Brothertown people into the larger United States population, which might seem like an obvious next step if indeed the focus is on the BIN's similarities with White customs and behaviors. To be sure, these individuals were and are active participants in the BIN and had similar goals of federal recognition. To them, the best expression of being Brothertown was to showcase the similarities between the Brothertown and European settlers. That is what it meant to be a Brothertown Indian. That was the survival mechanism of their ancestors and what they wanted to bring forward with them today.

The Brothertown identity has always relied on the influence of White people, because that relates directly back to the formation of the nation itself. Again, it is not my role to determine what the Brothertown identity should be today, but rather, to elucidate and illustrate the thoughts of participants, and contribute to their suggestions for moving forward. This framework may be useful in understanding where "White" identity comes

into being for the broader Brothertown identity, as well as to find a place for this particular way of being in the discussion of Brothertown identity.

Furthermore, I argue there is no one right way to be a citizen of the Brothertown Indian Nation. As participants spoke with me, some described different ways of being or views of identity as conflicting. From their vantage point, it was not possible to have an identity that encompassed both the pre-contact customs and ways of being of their ancestors *and* the customs and habits their ancestors adopted from European influence. The "right" way to be a BIN citizen was seen as more rigid or fixed. It was either/or instead of both/and. For many participants, it seemed as though they did not see the value of different ways of conceptualizing Brothertown identity. Often, they described those with different mindsets as being ill-informed or simply wrong. I believe a more flexible attitude towards identity will not only more accurately reflect the BIN people, it will further promote the health and well-being of the BIN.

Instead of understanding Brothertown identity as fixed and permanent, I believe it would be more productive to be more inclusive of how others perceive themselves as Brothertown and how that is enacted. One of the strengths that was most celebrated by participants was the strength of community and the joy of being together. This can be made stronger if people feel as though they can bring their whole selves and relate to their BIN identity in a way that is comfortable and accessible for them.

This can also encourage citizens to embrace the fluidity of identity, and the realization that certain aspects of one's identity will be more salient in some situations. For example, many Brothertown citizens grew up with White relatives and may feel connected to parts of mainstream White culture. In some contexts and circumstances,

they may identify as White. This does not diminish their American Indian/Brothertown identity or make them "less Indian." Although some participants felt as though their upbringing in White communities and families somewhat negated their Indian identity, or as though there were a scale of "being Indian" that was visually evident, one could argue that this sense of identity is flawed, harmful, and ultimately comes from a colonized mindset. Instead, this may be seen as evidence of biculturalism or a way to move through spaces and allowing different parts of identity to become more salient in different situations (LaFromboise, Coleman, & Gerton, 1993).

Stereotypes and media portrayals

While considering how BIN citizens might conceptualize their identity, it is important to keep in mind the very active role stereotypes play in our views of American Indians, and how these stereotypes can be internalized by American Indians themselves. Just as stereotypes and prejudiced interactions can occur in an interpersonal context, they can also be internalized (Steele, 1997). In other words, American Indians may believe that AI stereotypes apply to them, which can actually cause them to act out the stereotypes in their life. For example, in the popular culture and media, AIs have been portrayed throughout history as savage, lawless, and conflict-seeking (Indians of the Midwest, 2011; Mihesuah, 1996). Other stereotypes focus on physical features of AIs (e.g. dark hair, dark eyes, copper-colored skin). Perhaps the most harmful stereotype of all is that AIs are no longer here at all, as is denoted by their infrequent appearances in the media (Fryberg & Stephens, 2010; Greenberg, Mastro, & Brand, 2002).

Other stereotypes may portray a romanticized version of American Indian life (Castarphen & Sanchez, 2010). This is sometimes thought of as the noble savage

stereotype. Rather than being bloodthirsty, the noble savage is in harmony with nature, proud, and virtuous (Danchevskaya, n.d.; Kopacz & Lawton, 2011). This may stem from the conflicting views of American Indians that Americans tend to hold. For example, although many actions of Americans have been to oppress or diminish American Indians, Americans also have had attitudes that honor American Indians (Deloria, 1995). This has also led to the development of stereotypes that American Indians possess vast environmental knowledge and are at one with the land (Miehusa, 1996). These romanticized views of American Indians may also lead to beliefs that they are incapable of living without White help (Deloria, 1998).

It is possible that participants were feeling the internalized pressure of living up to these stereotypes, and that stereotypes were informing their understanding of what it is to be an American Indian. Participants may have understood there was the "right" way to be Indian due to the prevalence of these stereotypes and the subsequent internalization of them. Some research has shown that the internalization of different American Indian stereotypes presented in the media can be harmful to one's sense of self-worth and sense of community, possibly because these stereotypes seem to limit the possibilities available to American Indians (Fryberg, Markus, Oyserman, & Stone, 2008).

New frameworks for Brothertown identity

The identity challenges faced by the Brothertown may be similar to those of people of other races and ethnicities. For example, biracial individuals with Black and White parents also have to navigate identity spaces that may be challenging. One way of understanding these identity difficulties can be encapsulated in the Ecological Model of Biraciality, which focuses more on context and assumes:

> (a) mixed-race people construct different racial identities based on various contextually specific logics, (b) there are no predictable stages of identity development because the process is not linear and there is no single optimal endpoint, and (c) privileging any one type of racial identity over another (i.e., multiracial over single-race identity) only replicates the essentialist flaws of previous models with a different outcome. (Rockquemore, Brunsma, & Delgado, 2009, p. 19)

This ecological model allows for people to engage in "border crossing." This means they can be simultaneously a part of several groups while holding multiple perspectives, move between social contexts, choose to stay on the "border" and embrace that hybridity, and feel more comfortable in one group yet still retain the ability to move within other groups (Rockquemore, Brunsma, & Delgado, 2009). Using this framework, the citizens of the BIN can hold several identities while still being part of those groups, even if they at times identify more with one way of being or another. In other words, there is no need to choose one group or privilege one way of viewing the world.

From this discussion, it is clear that the concept of what it means to identify as a citizen of the Brothertown Indian Nation is at a crossroads. There are many elements and viewpoints to consider, along with historical context. However, we know that a strong sense of self-identity and a strong sense of belonging within a group have positive health implications (Haslam et al, 2009; Putnam, 2000; Phinney, 1990; Smith & Silva, 2011; Blaine & Crocker, 1995; Branscombe, Schmitt, & Harvey, 1999). Those who feel secure in their identity and feel as though they belong securely to a group feel less stress, are better able to withstand adversity, and have better health outcomes than those with a less secure sense of identity. Developing a more inclusive, fluid, and flexible sense of identity may therefore have positive health implications for BIN citizens.

In addition to the ecological model of biraciality, there is another possible way of moving forward around the questions of identity in the Gone model. Developed by a

Professor of Psychology and Native American Studies at the University of Michigan, this framework allows for the construction of identities and allows for the fluidity and different understandings of identity expressed by the BIN participants:

> This approach [that] acknowledges that American Indian people actively construct cultural identities, drawing on the rich cultural resources in their own unique communities. Thus, Indian identities are intentional constructions by individual agents engaged in making sense of their experiences. At the same time, the possibilities for constructing such identities are channeled by the particular cultural histories, community traditions, and institutional relations that affect the tribal community in question, and such possibilities are not infinite, but limited. Thus, Indian identities are historical products of enduring social structures that are both powerful and pervasive. In short, the construction of cultural identity emerges at the confluence of intention and convention, agency and structure, individual and community, and mind and world…[This approach] recognizes that the construction of Indian identity is simultaneously facilitated and constrained by the forces of history, power, and tradition. Additionally, in view of the local character of history, power, and tradition, it may not make much sense to talk about Indian identity in generic terms. Finally, such identities vary in remarkable ways even within a single community, depending on the multiple ways that creative individuals might draw on existing cultural meanings and practices to make sense of their own personal experiences. (Gone, 2006, p. 65)

Using this model, it is possible to reconcile the ancient past with the more recent past with the present. Identity can be thought of as individual, changing, and personal. It is possible for individuals to have different senses of what it means to be Brothertown, yet exist together within the same community. Different senses of identity do not have to be at odds with each other – they can simply be the lived experience for the individual. There is no battle for Indianness, no reliance on blood quantum or lineage or the acting out of stereotypes, and no right or wrong way to be an Indian. Instead, the individual relates to her own knowledge of the community and shapes her identity accordingly. It may shift and change with new life experiences, and rely more or less heavily on certain cultural practices. There is also strong evidence that being comfortable with multiple identities (or biculturalism) has positive health implications, as well (LaFromboise, Coleman, & Gerton, 1993).

This message – that identities are culturally and individually constructed, and may shift as one moves through different spaces and makes meaning –is an important finding that should be communicated to BIN citizens for maximum health benefits. This process has begun with the sharing of these results, and the related suggestions that go along with them, with the BIN Tribal Council (Appendix E). This may also be relevant for other citizens of unrecognized tribes who are struggling with the concept of identity and inclusion.

Identity is culturally and individually constructed, and there is no one right way to be a citizen of the Brothertown Indian Nation. This inclusive understanding of individual identity can then be related back to the greater sense of group identity. It is clear from this research that Brothertown citizens do indeed have a strong sense of community, togetherness, and closeness with their fellow citizens. They are proud of who they are together and of their community. Being Brothertown is an important part of their family identity and they feel closer to both their family and their community due to their Brothertown heritage. The strong family ties many BIN citizens have can be very important for promoting health and wellbeing. As BIN citizens feel strongly connected to their families, they are more likely to stay healthier physically, emotionally, and socially (House, Landis, & Umberson, 1988; Umberson & Montez, 2010). Capitalizing on these family connections and the strength of familial relationships may be important for a future health promotion communication plan.

Additionally, this research shows that the BIN community often brings citizens meaning, happiness, and security. As individuals feel validated in their individual identity, they can more easily plug into the strength of the larger group, adding to their

identity security. Feeling a strong sense of connection to a group has positive health impacts for individuals (Haslam et al, 2009). The more inclusive the Brothertown are about what the Brothertown identity is, the stronger and healthier their people and community will be. Although the federal government is attempting to legislate what it is to be Brothertown through the federal recognition process, the *meaning* of the Brothertown identity is actually in the hands of Brothertown citizens and this is an exciting opportunity to develop a more inclusive identity and reap the positive health effects of doing so.

In some ways, this reshaping and conceptualizing of identity is a continuation of a process that began over 200 years ago. When Brothertown came into existence, it was a deliberate choice and determination by the people for the people. Today, when there are many forces acting upon the experience of the BIN citizen, the Brothertown people can also deliberately choose who is able to be Brothertown and what that experience can – or should – look like. That is not my role as an external researcher. Instead in this collaborative community-based research project, I was asked to listen to and reflect back the concerns of BIN citizens and collaborate on a health communication strategy.

Utilizing strengths to overcome challenges

In addition to conversations around identity and exclusion, participants discussed the BIN's strengths, as well as specific challenges they thought the BIN was facing, along with potential solutions to them. When discussing these challenges, participants tended to switch their pronoun usage from "We" to "They." This could possibly signal that participants felt less connected to the BIN when thinking about the tribe's challenges. Perhaps they feel as though they can't relate to the tribe in these circumstances. Or

perhaps they are simply frustrated with these challenges. This seems to point to the importance of working through these challenges.

Geographic distance

Citizens of the Brothertown Indian Nation live in all 50 states. Although about half of them live within a 50-mile radius of Fond du Lac, there are still around 2,000 citizens who live elsewhere (Burg, 2013). This would be a challenge for any kind of organization, but especially so for an Indian nation with limited resources. Participants shared that it was difficult to engage and include geographically disperse citizens. However, the participants and I have developed some ways of contextualizing these challenges within their identified strengths.

First, this distance can be seen as a strength, as some research participants pointed out. Living in different areas may mean that citizens have unique perspectives and ideas. Participants thought this diversity of perspectives should be welcomed at the table and contribute to keeping discussions and strategies fresh. Different people with different backgrounds may have unique ways of problem-solving and processing, which could be beneficial.

Second, there are new tools and techniques to overcome challenges created by distance. The internet allows for a range of distance communication through easily accessible programs. Citizens could teleconference into meetings and gatherings, share information quickly through internet resources, and collaborate on projects. Although not a replacement for in-person meetings, these new tools do provide a way to mitigate distance in some respects. The BIN is already doing some distance communication at

Tribal Council meetings, and this could be further encouraged at other events and for other communication purposes.

Using more internet-based communication tools can also help to build community while allowing for the utilization of a community health approach. Additionally, this focuses on the joy people find in being in community with one another. As participants and I develop messaging around identified health issues of concern[1], online media is one way to share these messages with geographically dispersed people. Although some older individuals tended not to prefer receiving health information online, others felt more comfortable searching for health information in this way. Younger people especially sought information online, so they may especially be interested in engaging with information online. This is crucial for the long-term survival of the nation as a whole, as well.

Additionally, internet-based platforms, such as social media like Facebook and Instagram, allow for the co-creation of knowledge, materials, and community. Moorhead, Hazlett, Harrison, Carroll, Irwin, and Hoving (2013) identified six main benefits of utilizing social media for health communication, including more interactions with others, more available, shared, and tailored information, better access to health information, peer support, public health surveillance, and the potential to influence health policy. In particular, focusing on actual engagement rather than a unidirectional flow of information

[1] My work with the BIN does not end with this dissertation. I have not had the time and capacity to develop the end products that I have discussed with Tribal Council and the Research Liaison, but these products will be developed, refined, and disseminated after the completion of this dissertation. Initial thoughts about what these products will be are described in the "Implications" section.

can be useful in communicating about health through social media (Ramanadhan, Mendez, Rao & Viswanath, 2013).

This can also be a way to discuss and perpetuate positive social norms around health and wellbeing. All participants believed that health and wellbeing were important issues for the BIN people. This indicates a community-held social norm. Future discussions, online and otherwise, around health and health promotion can utilize this positive social norm to elevate the importance of focusing on health and wellbeing issues.

Third, there are ways to distribute the volunteer workload even through geographic distance, which can also mitigate the intense workload volunteers currently carry. This builds on the strong BIN tradition of volunteer engagement, while protecting against volunteer burnout. For example, projects can be divided into more discrete tasks with clear steps. These tasks can then be delegated to a larger number of volunteers. Likely, some work can be done remotely, so more people in a wider geographic area can be included in the workload. Although it may take some time to initially set up, projects can be divided into discrete tasks that can be done remotely. Volunteers (particularly younger volunteers) could manage social media accounts, such as Facebook and Instagram. Other volunteers might work on specific projects, such as fundraising or development. Another area that may need robust volunteer help is maintaining records of outside requests. Participants described the administrative challenges of tracking requests, which sometimes unintentionally led to the exclusion of some individuals. This could be addressed by engaging youth volunteers to develop technology-based solutions for tracking requests, such as Google forms.

Fourth, it may be appropriate to better-utilize the skills and educational experience of BIN citizens. Many participants noted that they felt there a large number of BIN citizens are highly educated, and that this high educational attainment is very valued in the community. Historically, there may be reasons for the high number of highly educated citizens; the founding citizens of Brothertown cared deeply about education. Samson Occom spent a number of years raising funds to develop Dartmouth University, which was going to be an institution for American Indians before settlers reneged on their agreements. For instance, participants mentioned there are a large number of people who hold advanced degrees, such as law, medical, and doctoral degrees. Yet it is unclear whether the talents of these highly educated citizens are utilized for the promotion of the BIN. There may be ways of doing so that would require minimal time commitment from volunteers. For example, there is a fledgling health professions mentoring program within the tribe that aims to match youth interested in healthcare professions with medical professionals. Such programs in other areas (academia, law, social work, etc.) could increase youth involvement while capitalizing on the educational attainment of many citizens. Other volunteer projects can be developed to utilize citizens' strengths, such as working groups around different issues on which the BIN wants to progress, such as elder well being, wellness, and financial development. As projects are developed into discrete tasks, it is likely that they can be matched with a corresponding skill set in the membership.

Leadership

Participants did express concerns over the BIN leadership. Some felt that leadership was losing the focus on recognition by taking on other tasks or prioritizing

other needs, while others felt the leadership was too ambitious. Sometimes, this was coupled with the opinion that BIN leadership was focusing on surface-level issues, rather than diving into tougher and more important issues. Participants spoke about wanting to dig into deeper, more complicated issues that had bigger ramifications for the tribe, rather than spending time on more "trivial" day-to-day tasks, such as administrative decisions, facility management, and storage of items. These issues led participants to conclude that the leadership is simply in a weak position currently. Some even thought the leadership was participating in unfair or unethical practices, such as selectively recording minutes from meetings.

It may be worthwhile for leadership to continue to elicit feedback from their citizens, or perhaps to engage in strategic planning to help them determine their goals and action steps. This can help the leadership to remain focused on its larger goals and issues, while trying to ensure that goals are reasonable with concrete action steps. Citizens need to feel as though they can express their thoughts, feelings, and concerns freely, without fear of judgment or retribution.

This could also indicate that a new generation of leadership needs to step forth, or that there could be new opportunities for leadership. Particularly if the Brothertown chooses to move forward with more distance volunteer opportunities and electronic sharing of information, there may be room for new leadership growth and a chance to re-focus on larger issues while simultaneously energizing the youth population.

Involvement

These opportunities in leadership may speak to new avenues of participation for those citizens who are not as involved. Participants consistently talked about the

challenges of involving the younger generations, along with the worry that if the younger generations did not become engaged, tribal histories and traditions would not be properly passed down. Many participants became involved with the Brothertown at the behest of their families, and that tradition may need to be continued in different ways.

There may be new ways to engage younger generations, such as through specific leadership roles, awards, or scholarships. Because involving the younger generation is seen as such a large concern, it seems important to put resources towards determining the best way to involve youth and young people. This may also include a more robust focus on social media, including digital storytelling. Additionally, new ways of including youth may help citizens to feel more included, welcomed, and part of the tribe.

Feeling of limitation

There was also a general feeling of limitation among participants – that the tribe was limited and kept getting blocked at its attempts at progress. This could simply reflect the sometimes-overwhelming challenges they do face. Their denial of federal acknowledgement came after 32 years of bureaucratic red tape. Congress has not showed substantial interest in exploring changing their status. The feelings of limitation may simply be because the BIN *is* limited and has to work within external constraints, which necessitates resilience.

I want to note the flaws in the idea that marginalized groups must practice resilience. The concept of resilience generally ignores the conditions *necessitating* resilience. In other words, it is a downstream solution to a problem that has upstream origins. In order to be resilient, one must overcome and work through hardships. Often, marginalized peoples are urged to develop resiliency and mechanisms for promoting

resiliency, yet the upstream origins of problems are ignored (Davis, Cook, & Cohen, 2005). Even so, it seems as though resilience needs to be practiced within the BIN to work against feelings of limitation, frustration, and challenges.

Building on this sense of resilience, it may also be of use to formally and continually recognize the dedication and sacrifice of the leaders and volunteers in the BIN. Continually, participants noted that these individuals were some of the most important assets of the nation. However, we know that volunteers are susceptible to burnout and may not be able to maintain their workload (Bakker, Van Der Zee, Lewig, & Dollard, 2006). Although there are term limits on some leadership positions, there are no other formal ways of helping volunteers manage their duties. Additionally, there are no ways of formally recognizing the work of these individuals. Awards (or perhaps scholarship for younger leaders) might be valuable. Regardless, it is important that the community cherish and protect one of its greatest assets: its people. This also circles back to the importance of community and protecting this valuable asset.

Health promotion and communication strategies

In this health communication research, we see that citizens of a non-federally-recognized tribe are concerned about the same health issues that challenge federally recognized American Indians. Although this paper in no way is an epidemiological study and makes no attempt to quantify or describe the actual physiological health of the BIN, it does qualitatively describe the health experiences of a non-recognized tribe and sheds light on that experience. Participants shared that they have concerns about diabetes, obesity, hypertension, cardiovascular health, cancer, mental health, and substance abuse – all of which are significant challenges for American Indians (and indeed, the United

States) in other contexts (American Indian and Alaska Native Populations, 2014). Participants tended to be more concerned about physical health issues rather than mental/emotional health issues, although there was some concern about mental health, especially as it is linked to sensation-seeking behavior and substance abuse. Additionally, participants tended to focus on health outcomes, illnesses, and diseases, rather than the building blocks of health and how accessible—or inaccessible—they are to BIN citizens. This indicates that the BIN is not yet focusing on a health equity approach that acknowledges and addresses upstream determinants of health.

For example, participants tended to express concern about diabetes for themselves, their families, and their fellow BIN citizens. For many, diabetes was linked to being overweight, eating the wrong kind of food, and inactivity. These causes of diabetes, however, only extend one layer back in the health equity framework. One interview participant discussed the relationship between institutional power and diabetes (e.g. the government subsidization of unhealthy foods), although applying the health equity framework reveals multiple layers contributing to the increased diabetes risk in the BIN population (Figure 3). Because BIN citizens may not be considering upstream causes of health problems, action on these issues may be limited.

Figure 3 Health equity framework for diabetes in the BIN

To address this, future communication materials should communicate about health more broadly, using a health equity approach. Because many BIN citizens seem to be unfamiliar with the health equity framework, initial messaging could focus on the introduction of the model. This may lead to further discussions about how to influence upstream factors, building on those mentioned in Figure 3. It may be particularly useful to develop an appealing visual representation of the health equity approach for distribution (Geana, Greiner, Cully, Talawyma, & Daley, 2012). For example, it may be useful to discuss this approach at future Health and Wellness Fairs. Previous Fairs have focused on resources that relate more directly to health. In the future, guests who can speak to or provide information on changing upstream determinants may be helpful. This can capitalize on the preference for receiving health information interpersonally, as well. Potential attendees may include experts on traditional foods and exercise, housing resource organizations, and advocacy groups. This may be an opportunity to involve local healthcare providers, as well, so they can learn about the BIN experience and how their organizations may best provide care to BIN citizens. This is important because many

participants, particularly older participants, preferred to receive their health information from physicians or family members.

The data in this study provide useful information for developing targeted communications and messaging specifically for the Brothertown. Targeted communication strategies are developed specifically for a particular community, using information about that community to create relevant, meaningful content that has a higher likelihood of influencing community members (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2002). Targeted messages can be packaged in ways that are appealing to a group, provide evidence that the message is relevant for the group, use accessible language, draw from the experience of the community itself, and discuss health issues in the broader context of cultural values (Kreuter et al, 2002).

For the Brothertown, communication and intervention efforts will be targeted and tailored in several ways. First, written communication pieces will (at least initially) focus on the health issue most important to the Brothertown community: diabetes, along with its prevention and management. Messages will include strong and appealing visuals, rather than large blocks of text. Messaging will also incorporate the important Brothertown values of endurance, commitment, community, and family.

It is also crucial to encourage BIN citizens to share health information orally, especially among families. This reflects the strong preference for interpersonal communication and receiving information from deeply trusted sources. This also capitalizes on the strong family connections evident in the community.

Last, it is clear from this research that some BIN citizens are not sure how to evaluate sources of information. To take advantage of the internet and internet-based

communication, it will be helpful to discuss online source evaluation as part of this communication strategy. Even among those who prefer to talk about health directly with another person, there was often some interest in or familiarity with the internet, yet some mistrust of information sources. A visually-appealing guide to evaluating internet-based health information will be useful in this context.

Other communication literature can help provide a framework for structuring messaging and interventions for the Brothertown, too. It may be useful to consider the BIN's collectivist culture, as well. Participants continually discussed the importance of community, cohesion, and togetherness, indicating that there are at least some elements of a collectivist culture within the community. This has important implications for health communication, indicating may be more useful to frame health messaging in terms of loss prevention (Uskul, Sherman, & Fitzgibbon, 2009). For example, messaging around diabetes may stress that eating well and exercising can prevent diabetes and its specific outcomes, such as the loss of a limb. This way of framing messages also resonates with other Native constructs, such as the seventh generation concept (Moran, 1999). This concept has several pieces that are important to many Native cultures. First, it refers to a time for American Indian peoples to come together. Second, it refers to a unique temporal way of thinking that encourages Native people to consider both the perspectives of their ancestors seven generations ago, as well as their future descendents, seven generations in the future. Prevention and loss-focused messaging could refer to the seventh generation concept to encourage people to think about how their health behaviors resonate beyond them into the community and into the future.

Loss framing may be helpful based on people's perceptions of their specific disease risk, as well. Almost all participants described being concerned about diabetes and factors affecting diabetes (physical inactivity, obesity, and poor eating habits) for either themselves or their loved ones. This indicates they feel they are at a higher risk for diabetes. Some studies have shown that loss-framed messages are particularly important for individuals who feel they are at a high risk for a disease (Apanovitch, McCarthy, & Salovey, 2003; Maheswaran & Meyers-Levy, 1990; Gallagher, Updegraff, Rothman, & Sims, 2011). This provides additional evidence that loss-framed messages focusing on prevention might be more effective for BIN citizens than gain-framed messages.

The message source preference of family members or medical professionals can be incorporated in health communication plans, as well. Health communication literature tells us that message source can be very influential in trusting and absorbing a health communication message (Kreuter & McClure, 2004; Herek et al, 1998). Therefore, in thinking about successful communication strategies for the BIN, family should be incorporated as message sources for health communication pieces, be they oral, text-based, or multimedia. This may mean asking individuals to share culturally relevant, understandable health information within their families. It may also mean that there are educational opportunities around *where* credible health information can be found so that family members can provide accurate information. Considering almost all participants discussed the importance of family, especially in connection to their BIN ties, this strategy builds on that strength to promote better health and wellbeing.

This message source preference also provides some exciting opportunities for narrative communication strategies, as well. Considering the preference for learning

about health from family members and the oral tradition in American Indian cultures, narratives to and from family members about health issues may be especially persuasive. This may be particularly relevant due to the broad conceptualization of family for many BIN citizens, who consider not just their immediate family when thinking about the concept of family, but their extended family and community, as well. For instance, narrative communication pieces could focus on issues the community has identified as important (such as diabetes) and use storytelling to describe how people have made health changes to prevent diabetes or slow its progress. These could be written pieces or video stories, and may offer opportunities for youth involvement, as well.

Narrative communication pieces could also be used to share positive social norm information. For example, almost all participants discussed concern about obesity, physical inactivity, and conditions resulting from them, such as diabetes and hypertension. This shows there is a strong social norm that obesity and physical inactivity are important concerns for the BIN. Health concerns were not unimportant to anyone I spoke with, and although this may be due to selection bias, it likely speaks to the importance of health for other citizens of the BIN. Sharing this injunctive norm – that health and wellbeing are important as citizens of the BIN – could promote more healthful behaviors. By sharing normative experiences through narratives, community members may have opportunities to connect with one another, solidify injunctive social norms, and positively influence health behavior. Internet-based communication, as well as print or multimedia forms of communication, may also be appropriate venues to share newly acquired information about social norms regarding health.

However, there were some concerns about the self-efficacy of individuals to both influence their own health and the health of others. Although some participants felt empowered in taking charge of their health, others were less sure about what they could do to affect their health or how to access resources to improve health. Others felt as though they had limited influence on others' health and wellbeing. Looking at the Theory of Planned Behavior (Ajzen, 1985), this speaks to several perceived barriers preventing positive health behaviors and limited belief in self-efficacy. To address these, health communication strategies can work to address these barriers and self-efficacy beliefs. To develop communication pieces that are more fully grounded in the beliefs of the BIN, further exploration and discussion is needed to parse out specific behaviors to address. However, this research gives us an initial place from which to start.

For example, several people felt like they had limited opportunities to exercise. It may be useful to implement exercise activities at Tribal Council meetings and other community events. These could include activities that are easy to do on one's own with limited or no equipment. This could also further promote a community culture of wellness within the tribe itself, strengthening the belief that health and wellness are important to tribal leadership and citizens.

This can also build on collectivist ideals. Participants discussed at length the importance of community, deliberative decision-making, and that ultimately inclusion is a desired goal. This suggests that collectivism may be an important value for BIN citizens. As such, health messaging and health promotion efforts can frame taking steps to improve health as beneficial for the community at large. Using collectivist appeals can frame health promotion as a way to strengthen the community at large and ensure the

BIN's survival. It can take the focus off individuals and put it onto the broader community, so that individuals know their behavior is affecting those around them (Han & Shavitt, 1994; Lee et al, 2006). This may be done through the description of social norms and how an individual's behavior affects those around them. For those who feel that they have limited influence on others' health, this strategy may be useful.

Another communication consideration that developed in this research is that healthcare professionals may not be engaging in best practice communication strategies when working with BIN citizens. In healthcare practice, physicians likely have some awareness of the health problems that are more prevalent for people of color (Benz, Espinosa, Welsh, & Fontes, 2011). Depending on the situation, they may also collect racial and ethnic information from patients while providing care (Health Policy Snapshot, 2011). However, it is unclear whether healthcare providers are aware that there are federally unrecognized American Indians, such as BIN citizens. It is also unclear whether BIN citizens are identifying themselves as American Indian in healthcare contexts, and we do not know how much Brothertown citizens refer to their American Indian identity in everyday life. Do the physicians and health professionals they interact with understand that they're working with American Indians? If health professionals are unaware that they are interacting with American Indians, BIN citizens may not receive the care and understanding that would best improve their health. Alternatively, bringing up their American Indian identity may mean they could receive poorer care as a result of the physician's implicit biases. However, bringing up these identity issues with a healthcare provider may sensitize them to issues of discrimination and prompt them to provide more culturally sensitive care.

If a citizen's American Indian identity is unknown, medical professionals may not interact in a way that is culturally sensitive to the needs of Brothertown citizens, such as using visual aids when possible, focusing on interpersonal communication, taking time to build trust, and understanding the institutional structures that could affect consistent access to care. Healthcare professionals may not fully understand the dynamics that affect Brothertown citizens' health, such as their increased risk for certain health conditions like diabetes and hypertension, or the additional factors that may affect their health, such as intergenerational trauma. Healthcare professionals may also not truly understand what it means for a Brothertown citizen to identify as an American Indian – and so they should engage in a dialogue around that topic, asking questions such as "What does it mean to you to be Indian?" and "In what ways does your community see you as an Indian?" (Gone, 2006, p. 74). They may also not recognize the importance of other cultural health practices and recommend treatments that complement them (Gone, 2007). These considerations may apply to citizens of other federally unrecognized tribes, as well.

This research has also given us important information for healthcare professionals themselves as they communicate and interact with BIN patients. Healthcare professionals are increasingly aware that developing cultural competence can enhance patient-provider relationships and ultimately health outcomes for patients. For instance, the Process of Cultural Competence in the Delivery of Healthcare Services describes an integration of cultural knowledge, cultural skills, cultural awareness, cultural encounters, and cultural desire (Campinha-Bacote, 2002). In this model, healthcare providers are urged to see cultural competence as a continually-ongoing process, rather than a specific skill or set of skills that can be learned. When considering culture in healthcare settings, it is important

that healthcare providers remain reflective and open to new ways of thinking, rather than assuming their customary ways of practicing medicine and thinking about health are normative and correct (Kumas-Tan, Beagan, Loppie, MacLeod, & Frank, 2007). In this way, cultural awareness and sensitivity are not seen as burdensome, but rather are useful pieces of patient care that can help healthcare providers better understand and relate to their patients. One part of the model, cultural knowledge, states that healthcare providers must focus on understanding and integrating into their practice health-related beliefs and cultural values, along with disease incidence and prevalence and treatment efficacy. In understanding a culture's health-related beliefs, the provider can better understand the patient's worldview and thought patterns. This model also encourages healthcare providers to provide culturally-sensitive assessments when interacting with patients.

We can use this model within the contexts of the communication findings of this research to better understand how healthcare providers can provide culturally-sensitive care to BIN citizens. First, it may be useful for healthcare providers to understand the cultural values of BIN citizens, and their intersections with health. In this research, BIN citizens discussed several strongly-held cultural values. They deeply value their family connections and education, and they feel they have a strong sense of dedication and commitment to their community. To some, Christianity is also an important part of their lives. By understanding these values, healthcare providers may be able to develop more positive patient interactions. They may be able to appeal to a BIN patient's values of education and dedication to encourage patients to learn more about a condition and remain committed to preventing or treating it. By understanding the importance of family, a healthcare provider may ask BIN patients if they wish to include family

members in any way. For instance, a BIN citizen may want a family member to be present at appointments, or they may want to rely on family members to help them follow health advice or treatment plans. When working with patients with strong Christian beliefs, medical providers may recommend faith-based resources to support the patient's wellbeing. It is additionally important to note that the BIN have a unique and complex history, and today the tribe may be relatively unknown, even in their Wisconsin homelands. Acknowledging this history and the BIN's current challenges may help healthcare providers to contextualize part of a patient's experiences and provide space for acknowledging any stress this may cause.

Second, BIN citizens do have specific health-related beliefs. Understanding them could give healthcare providers a basis for discussing health information. For instance, some BIN citizens have a limited understanding of the health equity framework and may not fully understand the different factors affecting a disease or illness. A healthcare provider may wish to assess and discuss more upstream determinants of health with BIN patients. In addition to improving awareness of the upstream determinants of health, this may give BIN citizens ideas about how to change some upstream determinants that ultimately affect their health and wellness (e.g. increasing consumption of traditional foods or learning more about traditional exercise). This may also encourage BIN citizens to become engaged in health advocacy. Some BIN citizens also feel limited in their efficacy to positively influence their own health, and the health of loved ones. To address this, healthcare providers may wish to focus on strategies to enhance patients' feelings of self-efficacy, as well as strategies to positively influence the health of family members.

Third, medical professionals can take into account BIN citizen's interpersonal communication preferences to help ensure more positive and effective clinician-patient interactions and enhance their patient assessments. Many BIN citizens prefer to discuss health questions and issues directly with their healthcare providers. To accommodate this, healthcare providers should remain accessible to their patients to ensure a timely response to any questions, while making sure their patients know how to best access them. Healthcare professionals can also accommodate these communication preferences by being sensitive to whatever individual needs the patient may have. For example, a patient may feel overwhelmed when receiving a great deal of information from their provider, preferring for the physician or nurse to take the time to explain information in accessible and understandable terms. A patient may also appreciate a medical provider who respects and reflects their speech patterns, giving space for silence and taking the time needed so conversations and interactions don't feel rushed. Taking into consideration these communication preferences may help BIN citizens to feel heard while interacting with their healthcare providers. This may speak to their strong sense of community, as well; during these interactions, they may feel more connected to their healthcare provider and feel like they are a part of their healthcare community. Patients may wish to include family members in conversations with medical professionals, as well, since family members are another trusted source of health information for many BIN citizens. Including family members in these conversations may also ensure that correct, accurate information is shared within families.

Healthcare professionals also need to keep in mind BIN citizen's preference for receiving information. By and large, they prefer to *talk* about information rather than

read information. Sending a patient home with a stack of literature about a health condition may not be the most effective way to educate a BIN citizen about health issues. Instead, healthcare providers should understand BIN citizens' preference for discussing health information in person and take the time to do so during visits, or even through phone calls. It may then be appropriate to supplement these interpersonal conversations with written literature. When using written materials, healthcare providers should also consider the Brothertown preference for visual communication and provide materials that use interesting images, graphs, or charts. In this way, healthcare providers may be better able to communication about health – and BIN citizens may feel more satisfied with the experience, as well.

If healthcare providers want to encourage their patients to seek out other forms of information, they should bear in mind some BIN citizens' unfamiliarity and insecurity with internet-based information. Medical professionals may discuss trustworthy online sources of information with their BIN patients so they can feel more comfortable seeking information online. In this way, internet-based information sources can supplement interpersonal health conversations. This could be useful for individuals who are not confident in their abilities to find accurate online information.

It may seem ambitious for healthcare providers working with BIN citizens to follow these recommendations, but the medical community is continually working towards systems of care that are culturally competent (Flores, 2000; Horner, Salazar, Geiger, Bullock, Corbie-Smith, Cornog, & Flores, 2004; Jones, Cason, & Bond, 2004). Patient-provider communication and interaction are important pieces of any culturally competent system, and the features of each culture merit consideration. To improve the

health of BIN citizens individually, as well as the health of the tribe as a whole, these communication strategies should be taken into account.

One possibility for moving forward is to further solidify and strengthen the relationships between the Brothertown Indian Nation and their fellow tribes in Wisconsin. There be health areas in which the tribes can collaborate. For example, there may be existing resources the Oneida or Stockbridge can share, such as newsletters, written materials, or online materials. There may be health fairs or events they could work on together. There may also be best practices that could be relevant for Brothertown citizens, considering their previous relationships and geographic proximity. As one participant said, there is no need to reinvent the wheel if the BIN can collaborate with other Indian nations and capitalize on the work of other tribes.

Strengthening these collaborative partnerships may additionally further bolster the BIN's quest for recognition by legitimizing their claim to sovereign status, which could in turn bolster the self-identity of BIN citizens. Continuing to include the BIN in events, statewide recognitions, and intentional partnerships may bring positive effects at multiple levels. It may also be strategically useful to work towards official state recognition as other tribes have done, such as the Lumbee of North Carolina (Lumbee, 2016). This may open up further resources for the BIN and allow them to better collaborate with other tribes and the state of Wisconsin.

It is clear that BIN citizens have showed extraordinary resiliency in the face of major challenges. While acknowledging the important role resiliency has, focusing solely on that is akin to focusing solely on downstream symptoms rather than upstream causes. We must ask: what are the *circumstances* that are causing the need for resiliency?

Without acknowledging them, we are simply continually treating water from a polluted river rather than cutting off the source of pollution itself. In the case of the Brothertown, an important cause of the need for resiliency is quite simple.

The Brothertown Indian Nation formed directly because of European settlers and colonization. The seven founding tribes banded together for several reasons, primarily due to European contact. They came together because of their shared Christianity, which they learned about from settlers. They came together because they thought they would have a better chance of continued existence in a new world changed by the influence of European settlers. In this way, their existence was determined and governed by the White man. They formed as a way to survive the White man.

And today, they are still trying to survive the White man, who has determined that the Brothertown must meet some criteria in order to be considered American Indian, and in absence of that, must receive their status as American Indian from a governing body that is over 75% White and 0.5% Native American (Marcos, 2016). The Brothertown's sovereignty – their right to self-govern – is determined by Whites.

The Brothertown Indian Nation has responded to that challenge by continuing to exist and fight for what has always been theirs. However, a major reason for resiliency could be eliminated with the successful introduction of a restoration bill into Congress or the Senate to reinstate the BIN's federal recognition.

The Brothertown story is one of constant adaptation. Initially, they adopted some customs, rituals, and belief systems of the European settlers in order to stake their claim in a changing world. In some respects, it was easier to be considered White rather than Native, and draw attention to the similarities with Whites rather than emphasize their

differences. Their survival has depended on their ability to embrace different ways of being, and their ability to adapt and change as necessary has effects even today.

Limitations

This study does have challenges and limitations. First, it is subject to selection bias. Participants chose to participate in interviews, and I was not privy to as diverse an array of viewpoints as I would have been if I had interviewed a random sample of BIN citizens. However, it was crucial from an ethical standpoint that participants could explicitly participate in this community-based project as much or as little as they wished. I was able to speak with a range of ages and both men and women, although I did talk to slightly more women than men. These participants had varying levels of familiarity with the BIN, from having very little interaction to being heavily involved in multiple forms of leadership, and most of them had at least some moderate experience with the BIN. This diversity within the sample leads me to believe that despite this selection bias, I was able to speak to an appropriate breadth of participants.

I also recorded information qualitatively that would have been appropriate to obtain quantitatively (e.g. access to care, health information). However, it can be difficult to do accurate quantitative studies with Native populations, due to a vast history and body of experience of academic exploitation and mistrust (Caldwell et al, 2005; Manson, Garrouette, Goins, & Henderson, 2004). Although I did an exploratory survey to get perspectives about research topics when developing this study, I did not receive *any* responses, which leads me to believe a survey-based study or other use of quantitative methodology would not have succeeded. Finally, and most importantly, BIN collaborators preferred that I explore these questions qualitatively.

Additionally, this study was conducted with a single non-federally-recognized Indian nation, and the data here may not be generalizable to other non-recognized nations. However, there is little research about citizens of non-recognized Indian nations in general, and virtually none about their health-related experiences. This study can act as an important starting point and way to develop further strategies, theories, and research. It is exploratory in nature and should be treated as such.

Lastly, the community-based participatory approach did not receive as much participation throughout the research process. Although BIN citizens were invited in many ways (personally, through online and print advertising, and through Tribal Council discussions) to participate in the research process itself, no one was interested in doing so. Discussions with different individuals revealed that they felt like they did not have the capacity to work on another project, even though they were enthusiastic about the project itself. The Tribal Research Liaison contributed to data analysis and results dissemination, but also had limited capacity for participation. Thus, the overall project relied less on CBPR and Indigenous methodology and more on traditional research methods during the data collection and analysis. This may have been due to a lack of funding for this project. It was self-funded, so I did not have the capacity to fund co-researchers or offer large incentives for participation. Participation may also have been increased if I was able to extend the timeline of the project. However, as a graduate student, I had a limited amount of time to spend on this research. These limitations should be noted for those, especially self-funded graduate students working with an at-capacity community, pursuing this methodology in the future.

Chapter 9: Implications and recommendations

To close the circle of community-based participatory research, in this chapter, I will describe how results were presented to the BIN and what recommendations were co-created for moving forward. I will also briefly describe some planned products from this research, although (as noted earlier), these products are very much in the conceptualization phase and will be finished after the publication of this dissertation due to logistical constraints on my part.

The Tribal Council and other BIN citizens were uninterested in reading a lengthy dissertation. Instead, the Tribal Research Liaison and I collaborated on developing a printed handout of results to distribute to Tribal Council and other attendees of a Tribal Council meeting (Appendix E). During the creation of materials, the Research Liaison stressed that Tribal Council and others would like me to present concrete recommendations resulting from the research, rather than asking them for recommendations from the community data. In hindsight, it would have been helpful to put these recommendations on a separate document to pass out after the results were initially distributed, as including them with the results may have limited the conversation around these results.

Although I prepared a visual presentation, the Tribal Council did not at that time have the capability to present it. Instead, I talked through my results, stressing that anyone could stop me to ask questions at any time. The Research Liaison supported this process via Skype, clarifying points I made and stressing that she, too, was available to answer any questions.

There were very few questions asked or other feedback given at the time. Tribal Council seemed very interested in the results, with individuals expressing their gratitude and enthusiasm on moving forward with this new information. No results prompted further intense inquiry or other feedback. Generally, the feedback seemed positive, but it seemed like Tribal Council did not have the capacity to act on any of this information at that time.

To continue this cycle of feedback, I will continue to seek their input as we move forward together with implementing some of these recommendations and creating health communication products. In this way, the cycle continues to be iterative and community-driven. As I am able to devote more time to community products, I imagine the discoursive cycle of feedback will continue.

To move forward here, I will suggest several strategies for the development of a more inclusive and healthy Brothertown Indian Nation. These recommendations have been co-created with research participants to address the issues of health, identity, Brothertown strengths, and Brothertown challenges discussed in interviews. These build on the assets and strengths of the BIN and use citizens' insights to move the tribe towards a more inclusive sense of identity and belonging, stronger group identification, and a more diverse tribal volunteer structure, all of which support the community health of BIN citizens and will contribute to the health of BIN citizens at large. The following recommendations are laid out by placing the most feasible goals higher on the list and working towards more long-range goals lower down the list.

Recommendation 1: Develop new recordkeeping strategies for administrative requests.

Some of the struggles around exclusion may be addressed through administrative or technological challenges. For example, all requests (regardless of their nature) could be put into a recordkeeping system, such as Google Forms. This would then easily create an electronic record of each request the Brothertown office receives, which could be accessed anywhere. Although individuals would still have to go through and process/respond to each of the requests, there would be an easily shareable record of them, which could help keep communications from falling by the wayside. There may also be dedicated volunteer positions responsible for responding to different kinds of requests.

Other discussions of exclusion center on enrollment. As with other recognized tribes, enrollment can be a challenge, regardless of the situation. There may be internal struggles and disputes about how the enrollment process should work and what the requirements should be. In federally recognized tribes, these struggles often center revolve access to resources, such as gaming revenue (Jae, 2016). Enrollment criteria in some tribes have changed (sometimes in response to increased gaming revenues), resulting in the disenrollment of some citizens (Dao, 2011; Allen, 2017).

In some ways, these exclusionary discussions may be almost in anticipation of federal recognition. Perhaps citizens are anticipating the benefits of recognition and are leery of splitting the "per capita pie too" thinly. Although this was not discussed explicitly during interviews, this may be one reason for the struggles around enrollment and exclusion.

Alternatively, there may be an element of protectionism. Undoubtedly, there are and have been citizens who have been extraordinarily dedicated to the BIN. These are

individuals who give most, if not all, of their free time and energy back to the BIN. One possibility is that these individuals feel as though they are more established citizens of the nation, or they should more decision-making power in these circumstances. They may be leery of including others who may contribute far less to the tribe.

Recommendation 2: Develop new ways of communicating with tribal leadership

In order to work through this exclusion and promote a stronger sense of group identity, which will in turn positively influence health, it may be worthwhile to bring these issues into focus within the tribe. Participants expressed that this exclusion is painful and detrimental. To address this exclusion, there need to be a number of ways that citizens can communicate with leadership and participate in decision-making. This may come in the form of in-person surveys at events, anonymous ways of sharing opinions, or different leadership structures. For example, there could be new leadership roles to help ensure a wider variety of voices at the table. Future research could examine this exclusion and its roots, while working to build a more intentionally inclusive community.

Recommendation 3: Utilize internet-based communication technologies for meetings and projects, including social media use to increase youth engagement and promote positive social norms.

As mentioned in the discussion, there may be new ways of including people who are geographically distant while simultaneously increasing youth engagement through internet-based technologies, including social media such as Facebook, Twitter, and Instagram. Although some older BIN citizens may feel less comfortable using internet-based technologies, younger generations are far more comfortable. Focusing on these methods of communication can help citizens overcome geographic barriers while further

engaging youth. Using social media could also be a way to share positive social norms around health, as noted in the Discussion.

Recommendation 4: Develop more discrete volunteer tasks while matching skill sets to volunteer projects

To best capitalize on the immense knowledge participants believe is held within the tribe, volunteer tasks can be further developed into discrete projects that engage corresponding skill sets. Participants expressed several times that they wished to include more citizens in tribal activities, and this could be one way of doing so. Additionally, this can build on the educational strengths already held within the tribe.

Recommendation 5: Reassess strategic priorities and bring in new leadership opportunities as appropriate.

This may also be an appropriate time to engage in strategic planning. This process can help the community redefine priorities and goals while defining concrete action steps towards attaining them. This would also allow for the inclusion of a diverse set of voices, which is inherent in the strategic planning process. Additionally, there may be new roles identified for youth leadership, which could help engage the younger generations.

Recommendation 6: Develop leadership roles, awards, or scholarships specifically for younger generations to increase their involvement.

This strategic planning process may inherently lead to new youth opportunities. For example, specific youth awards or scholarships can serve multiple purposes. They can bring in the younger generation and increase their activity within the tribe. They can also serve as resume-building activities for the involved youth, which is helpful for educational and professional attainment.

Recommendation 7: Utilize social media to increase youth engagement and promote positive social norms.

As mentioned in the Discussion, there are many opportunities for youth to be involved through social media use. This opportunity has the benefit of building community, promoting health, and increasing youth involvement. Although the BIN currently has a Facebook presence, it could be enhanced in strategic ways. For example, youth could work on digital storytelling projects, photography, or building communities around shared interests. Social media also present other ways to dig into issues of identity.

Recommendation 8: Develop a comprehensive health promotion communication plan.

There are several products that will be developed as a result of this research. These include a print resource guide that identifies free and low-cost health and wellness resources in the geographic areas in which most BIN citizens live (near Fond du Lac). These also include online and print materials that encourage positive health behaviors using both an upstream and downstream health equity approach.

It may also be helpful to develop recommendations for medical professionals. While it is impossible to disseminate these widely, they may be disseminated at future Health and Wellness Fairs and given to local healthcare providers and local colleges that train medical professionals. These materials may educate healthcare providers around American Indian health. Medical professionals may also be misunderstanding the more typical Brothertown approach to accessing healthcare information. Many participants (especially older participants) in this health communication study preferred to get healthcare information directly from family members, placing importance on family

knowledge and incidence of disease. They used family connections to both learn about their own genetic predisposition for a disease or health condition, as well as learn about health issues. In addition to talking with family members, Brothertown citizens prefer to speak directly with physicians about their health concerns, rather than seeking information online or from other sources. This could be crucial information for healthcare professionals who work with older adults. Information could be shared incorrectly within families, or families simply may not have the most helpful information to share with each other. Physicians also may not realize the extent to which Brothertown citizens rely on them for the majority of their health information.

To address this, physicians should take steps to ensure their patients have access to quality health information and receive trustworthy information. They can take care to discuss the health information that could be shared in families with their patients, and provide reliable, trustworthy resources to supplement this information. Because physicians are not always easily accessible to their patients, they may want to ensure their patients have other methods of speaking quickly and easily with other healthcare providers so patients have resources for their questions. They may also give Brothertown patients American Indian-specific materials, or personally recommend special sources of information. If medical professionals do not have this broader contextual information, Brothertown citizens may not be getting the medical attention they need. These materials may also be disseminated to families within the BIN, as well, since families are an important source of health information for many BIN citizens.

This recommendation may have implications for other citizens of non-recognized tribes, as well, who may be in similar situations with their healthcare. We, as humans,

make assumptions about identity constantly, and this has implications for health professionals. Although a lack of knowledge about one's American Indian identity could prevent harmful implicit bias and stereotyping, it could also negatively influence a medical or social services professional's understanding of an American Indian patient holistically. This could negatively affect interpersonal interactions and limit treatment options. Medical professionals may also be missing information about alternative treatments patients participate in, such as traditional Native healing work.

Recommendation 9: Deliberate around BIN identity, recognizing that identity can be culturally and individually constructed.

As noted in the results, these different conceptualizations of identity ultimately seemed to lead to feelings of exclusion and ostracization. If a person did not fit within the bounds of what was considered to be Brothertown, they felt less welcome. This was noted both by individuals who felt excluded and those who witnessed such exclusion occurring. The questions of who gets to be a citizen of the Brothertown Indian Nation, and what that Brothertown identity can or should look like, are in the hands of the BIN people themselves. This may require thoughtful consideration, discussion, and deliberation, and could draw on the ecological model of biraciality and the Gone model, as mentioned in the Discussion. Developing this updated understanding of identity will have positive health effects for Brothertown citizens as they feel a stronger sense of self-identity and feel more secure in their group identity.

In addition to the concern about clashing identities and confusion over what it means to be Brothertown, there seems to be deliberate (and accidental) exclusion. Considering the challenges facing the tribe, including an uphill legislative battle, a small

and at-capacity volunteer force, and a citizenship that is geographically dispersed, this would seem the right moment to bring people together around a new, shared Brothertown identity and vision while developing new mechanisms for drawing in its citizenry.

This could begin with deliberate discussions around the Brothertown identity, with care taken to listen to all voices and especially include those who may not have had as much space at the table previously. These could happen at Tribal Council meetings, celebrations, or other Brothertown events. It may be easier to begin these conversations individually, or perhaps anonymously through mail or online information sharing platforms. Ultimately, these conversations could lead to more explicit conversations around the Brothertown mission, vision, and lived experience. A new definition of Brothertown identity may arise. New clarification could come for citizens, and hopefully, there will be a more inclusive understanding of Brothertown identity that does not rely solely on lineage or phenotypes–that it becomes clear that there is a place in the community for those with different experience levels with American Indian culture, different understandings of the Brothertown experience, and different goals and hopes for their citizenship. Alternatively, this visioning may aid the Brothertown leadership to more narrowly define citizenship and the community. However, these are choices for the Brothertown people and the systems of checks and balances they have in place to help them govern and move forward.

In addition to the exclusion that has developed from clashing identity conceptualizations, some exclusion is a mere symptom of the limited resources they have. If there is no funding to fully staff the administrative office, it is inevitable that requests will fall through the cracks. Those in leadership may be more likely to respond to

requests from people they know simply due to familiarity and the strengths of pre-existing relationships. When there is limited volunteer capacity, it seems to follow naturally that some things simply will not be able to be done.

It is important to keep in mind the important strengths the BIN have to build upon. Despite some feelings of exclusion and different viewpoints around identity, there is an incredibly strong sense of family and community reflected in the people, as well. Participants were involved with the BIN because of their family, and those strong family ties keep them connected to the tribe. The concept of togetherness, the value of family, and the feeling of interconnectedness resonated among participants. Often, participants felt as though the work they were doing with their BIN community was the most important work they'd done in their life. For participants, this sense of interconnection was emotional, tangible, and of great meaning. As the BIN develops new conversations around identity and inclusion, they have an extraordinarily strong platform from which to build. It may be useful to continue to highlight this sense of togetherness, community, and family throughout BIN events and communications.

Recommendation 10: Continue working toward federal recognition.

Clearly, becoming a federally recognized tribe will not solve the health and identity challenges the BIN faces, as many federally recognized Indian nations face their own health disparities and questions of identity. However, it could have important positive implications for the health and wellbeing of BIN citizens. This would affect several social determinants of health for BIN citizens that are upstream in the health equity framework, including (likely) improving access to resources that support health and wellbeing. These include more explicit access to healthcare, educational resources,

housing resources, and new financial opporutnities. This recognition would also mean that the BIN would be eligible for more grant opportunities. It may additionally solidify the identity of BIN citizens as American Indians.

Full list of recommendations

1. Develop new recordkeeping strategies for administrative requests.
2. Develop new ways of communicating with tribal leadership.
3. Utilize internet-based communication technologies for meetings and projects, including social media use to increase youth engagement and promote positive social norms.
4. Develop more discrete volunteer tasks while matching skill sets to volunteer projects
5. Reassess strategic priorities and bring in new leadership opportunities as appropriate.
6. Develop leadership roles, awards, or scholarships specifically for younger generations to increase their involvement.
7. Utilize social media to increase youth engagement and promote positive social norms.
8. Develop a comprehensive health promotion communication plan.
9. Deliberate around BIN identity, recognizing that identity can be culturally and individually constructed.
10. Continue working toward federal recognition.

Chapter 10: Conclusion

The Brothertown Indian Nation has a unique history and an exciting future. Despite their difficult history with the United States and the challenges that prevent them from currently being recognized as a sovereign Indian nation in the eyes of the federal government, they continue to operate as a sovereign nation.

This research develops a broader picture of the Brothertown experience, especially as it relates to health and health communication, and uses community insight to construct an asset-based path forward to better health for BIN citizens. This study describes some aspects of the contemporary experience of being a citizen of the Brothertown Indian Nation. Additionally, this research provides insight into how BIN citizens access healthcare and health information, because their experience is different from American Indians enrolled in federally recognized tribes who have explicit access to Indian Health Service clinics and health information. This study used a community-based participatory approach, and specifically relied on community knowledge to develop research questions and analyze data. Semi-structured, in-depth interviews were conducted with a broad cross-section of BIN citizens.

These data showed that the BIN has many strengths, including a dedicated volunteer base, strong family connections, a diversity of citizens, a commitment to consensus, highly-educated citizens, and pride in community. Interviews also showed the importance of family and connection for tribal citizens, as well as their anxiety about the participation of younger generations. Participants shared that they feel the BIN has several challenges to overcome, including significant geographic distance between its citizens, the sustainability of its at-capacity volunteer force, leadership challenges, and

feelings of unintentional and intentional exclusion. Additionally, there are several conceptualizations of what it means to be a BIN citizen. Some people feel that the authentic BIN identity is that of the founding tribes; others feel that the true BIN identity is closely related to White identity; and others still feel that to be a BIN citizen is to relate both to the founding tribes and to White identity.

This research showed that citizens of an unrecognized Indian nation have many of the same health concerns as their recognized counterparts, including diabetes, hypertension, heart disease, obesity and its complications, inactivity, mental health problems, and substance abuse issues. They prefer to access their health information interpersonally from family or trusted physicians, and some only have limited utility for online information. They feel a strong sense of community and collectivism.

This knowledge helps us to develop a more nuanced picture of the nation as a whole to build a targeted communication approach. Participants in this study showed high degrees of collectivism, which means that health messages may be more effective when they are framed to focus on prevention and potential losses. Citizens also feel as though they are at a high risk of some diseases, like diabetes, adding additional support for loss framing. What's more, the seventh generation indigenous framework may support loss and prevention-focused communications, as well.

BIN citizens prefer to learn about health messages from their family members or medical professionals, so narrative forms of communication will be especially useful for health messaging. This also capitalizes on the Native oral tradition. Narrative communication may provide some opportunities to share positive social norms around health and increase the self-efficacy of community members around specific health

activities they find difficult, such as incorporating exercise into daily life. This focus on interpersonal communication may also be helpful knowledge for medical professionals who interact with BIN citizens.

From this information, BIN citizens and I were able to co-create meaning and suggestions for moving forward, including a series of recommendations. These recommendations are guiding my next steps with the Brothertown Indian Nation, which include a health communication plan, developing a resource guide for health resources in the geographic region of many BIN citizens, and continuing the discussion around identity. As a community-based research project, this dissertation is by no means the final product for the tribe.

Future research

This research begins to explore an area of study in which little is known in the academic literature: the identity and health of citizens of unrecognized tribes. Although this research explores this landscape in a particular context, there are many more questions and research areas.

Similar research could be done with other unrecognized tribes to determine if the experiences of BIN citizens are similar to those of other tribes. This could lead to the development of a more robust framework of understanding of how best to support the health and wellbeing of those in unrecognized tribes. Such research could also further our general understanding of unrecognized tribes, potentially strengthening the case for their federal recognition.

Future research should further investigate these questions and challenges to determine how citizens of unrecognized tribes are racially identifying themselves in the

context of healthcare settings and determine the impact of this identification – or lack thereof. Additionally, identifying as American Indian (or not doing so) may have implications in everyday life – in interpersonal relationships, the workplace, educational settings, and so on. Do citizens of unrecognized tribes feel as though they can claim their American Indian identity? What feelings, challenges, and triumphs might this elicit? Might this interact with the identities of citizens of recognized tribes? Where does this fit in with the larger picture that includes an increasing number of people claiming American Indian heritage?

Future research could additionally expand on the communication findings of this research. First, it would be helpful to test the effectiveness of different ways of disseminating health information (e.g. from healthcare professionals and family members) to see if citizens' self-reported communication preferences are reflected. Second, further research may examine the efficacy of health promotion strategies using social norms and collectivist ideals in this unique community. Third, it would be useful to replicate a health promotion research study with an unrecognized tribe like the Brothertown that was successful with a recognized American Indian nation to further parse out the differences between recognized and unrecognized nations in the context of communication. Last, future communication research could use a community-based approach to continue to refine and develop this methodology in the communication field.

Future research may also look at the health of citizens of unrecognized tribes from an epidemiological perspective to determine how different populations are affected by disease and illness, which could point towards which interventions are most needed.

Lastly, more research needs to be done in general with federally unrecognized tribes to better understand the experiences of their citizens. This is a woefully neglected area of research, yet it is one that lends itself nicely to a participatory, community-based approach and a wide array of topics. One common misconception in the popular media about American Indians is that they no longer exist, due to infrequent or absent media portrayals (Fryberg & Stephens, 2010; Greenberg, Mastro, & Brand, 2002). One can only imagine how this perception is intensified for those belonging to unrecognized tribes.

In the field of health promotion, most – if not all – of academic attention is focused on federally recognized Indian nations. Yet there are hundreds of tribes that are not federally recognized and thousands of individuals who identify as American Indian. They may be facing the same health and wellbeing challenges as other American Indians, yet they often do not have the same resources. They may also have challenges with their individual and group identities, further compounding their health issues. As we work to eliminate health disparities and promote the health and wellbeing of all people, citizens of federally unrecognized tribes need to remain in the picture, and we must continue to consider and work against the root causes of these disparities, rather than simply treating the downstream effects. For the Brothertown Indian Nation, and likely for many other federally unrecognized nations, one important upstream cause of health disparities could be eliminated with federal recognition.

Appendix A

Current plan for Brothertown health research

Haley Madden, PhD student, UW-Madison
Interested in participating, providing feedback, or helping me conduct the research?
Contact me at **hcpmadden@gmail.com** or 608.770.1811

About the project

My own background is in health communication, and for my dissertation research project, the members of the Brothertown Indian Nation have been gracious enough to agree to work with me on topics in which we were all interested.

While the topics are described below in the research questions, they primarily relate to how BIN members access healthcare. This is information we don't yet know, may be useful to the BIN, and may be useful to other Nations that aren't federally recognized.

We can also use this research time to learn more about the health concerns of BIN members, as well as the strengths of the BIN community. Hopefully, this information will further show that the BIN operates as a Nation and can be used to help support federally recognition process.

Additionally, this information may be able to help BIN members access healthcare and health information, as well as provide a starting point for creating more health resources. This research may lead to the formation of support services for the BIN or more health resources for BIN members, allow the BIN to be eligible for and receive more grant funding, or create other positive outcomes for the Nation. Part of my job is to make sure that the research outcomes are useful for you!

Research questions – information we collect about these questions will be kept anonymous and confidential!

- How do BIN members access healthcare?
- What are the strengths of these different access methods?
- What are the challenges of these different access methods?
- How do BIN members access health information?
- What are the strengths of these different access methods?
- What are the challenges of these different access methods?
- How does the current healthcare system (both how people access care individually and the system as a bigger unit) meet the needs of BIN members?
- What can it improve?
- What are the biggest personal health concerns of BIN members?
- What are the biggest health concerns for the BIN community?
- What all is included in health? What do we mean?

- What do BIN members believe the Nation can do to promote health and wellness for members?
- What do BIN members believe are the biggest community assets of the BIN, both in terms of health and in terms of the community as a whole?

Methods

To learn more about these research questions, I would like to focus on qualitative methodology. I believe these questions can be examined in several ways.

Talking Circles
Talking Circles will allow for equal and free conversation among participants, with everyone feeling able to speak. Participants will be asked to share their experiences and thoughts, with each person able to talk and respond to others. There will be some questions that are used to guide discussion, but ultimately the participants can have a lot of input into what they would like to speak about and how they would like to approach the questions. These are typically done with five to 20 participants.

Interviews
Some participants may prefer to speak one-on-one, or may be unable to attend an Talking Circle event. For these people, interviews may be more appropriate. I will create questions in advance that can be brought forth for approval. Interviews typically function like conversations. Although the predetermined questions can act as a guide and reference point, it is more important for the participant to feel at ease and comfortable, in addition to feeling like he or she can speak freely. Interviews can happen in person, on the phone, or through a video conferencing system, depending on the geographic location of participants.

Confidentiality
All information collected is and will be kept confidential and anonymous. Participants will not be identified in any way in any publications or materials resulting from data collection. If participants would like to talk about issues privately, they can do so, and participate in larger group discussions for other issues if they would like. That is completely up to the participants.

Participants

The BIN has many members, some of whom are spread over large geographic areas. I would like to schedule Talking Circles on days when BIN members may already be convening, such as on Council Meeting days. That way, a wide range of participants may be able to join. For those who are unable to attend on those days, I could schedule other events at the Community Center or at other central locations. Hopefully, these strategies will allow for the inclusion of many people in the area. For those who are unable to attend these meetings and are located in the Wisconsin area, we could work to schedule individual interviews. For those members who are outside the Wisconsin area, phone or Skype interviews may be a better choice.

I would like to include many different perspectives in this project if possible. Depending on the interest level, we may have to limit the number of participants so that the data analysis is still manageable. Talking Circles should have at least five and no more than 20 participants, and I would like to do several of them if we have the interest level. I can do individual interviews with up to about 30 people.

I would like to advertise these opportunities through the BIN newsletter, email lists (if possible), the BIN website, Facebook, or call people individually who may be interested in participating.

Participant incentives

I am open to suggestions about how to increase participation. Because my funding is coming out of my own pocket at this point, I was thinking about offering snacks and drinks at gatherings. However, if anyone has ideas about how to incentivize further, please let me know! Some potential ways to increase participation:

- $5 off a BIN store item
- A monetary incentive ($10 for participation, for example)
- Pass out resources for participants, such as information about healthy eating, ways of accessing health information, or information about preventative care
- A healthy cooking demonstration using Brothertown recipes
- A free screening for blood pressure or blood glucose

Moving forward

As I move forward with my research, I would like to make sure my processes are suitable for the BIN and that the project will be as useful as possible. As much as possible, I would like to show my plans to the Council or other interested individuals before moving forward them. We could also put together a small committee of people who would like to give me feedback, approve plans, or work with me in any other way on this research – if you're interested, please let me know!

If this plan sounds feasible, I will develop more specific methods (including questions to ask in Talking Circles and Interviews). I will have to submit these methods to the Institutional Review Board of the University of Wisconsin-Madison, as well, which is a review process to ensure that this research is done fairly and ethically.

Tentative timeline

March 1: Create a working group who is interested in giving feedback and/or participating
April 1: Have the final methods, informed consent forms, and research questions submitted for approval, begin advertising opportunities for participation
May 1 through August: Collect data

September 1: Begin data analysis

Appendix B

BROTHERTOWN INDIAN NATION

Institutional Review Board
Education and Social/Behavioral Science
University of Wisconsin
Madison, Wisconsin 53706

Dear IRB Members,

The Brothertown Indian Nation Tribal Council is pleased to confirm our support of the research project entitled "Brothertown Community-based Health Research" with Principal Investigator Patricia Loew, PhD, Professor of Life Sciences Communication at UW-Madison and Haley Madden, doctoral student in Life Sciences Communication.

As mentioned in the project flyer, this is a community-based study about health care and health information in the Brothertown Indian Nation. The study has been discussed and jointly developed over the past several months and is being overseen by the Brothertown Tribal Council.

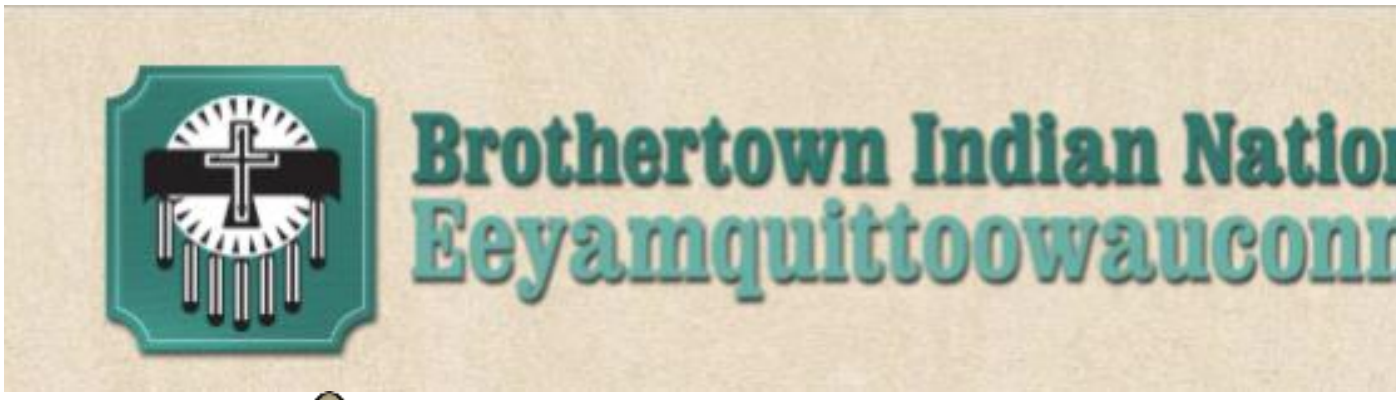
Please let us know if there is anything else you need or that we can do to help with the successful initiation and completion of this important study.

Jeremy Marx 3/21/15

Jeremy Marx
Chairman
Brothertown Indian Nation

Phone: 920-929-9964 Fax 920-929-9965 BrothertownOffice@BrothertownIndians.org
P.O. Box 2206 Fond du Lac, Wisconsin 54936-2206 www.BrothertownIndians.org

Appendix C



WISCONSIN
UNIVERSITY OF WISCONSIN–MADISON

Calling all Brothertown Indian I members!

If you are over 18 years of age, you are eligible to participate in a com health care and health information in the Brothertown Indian Nation!

is being overseen by the Brothertown Tribal Council.

What: Participants can participate in individual interviews or group around 30 to 60 minutes

Who: Patty Loew, Bad River Ojibwe and UW-Madison Professor, an

student, are working on this project

Where: You choose! Haley can talk with you at Brothertown meet
Council meeting, Brothertown Picnic, or Homecoming) or on an indivi
for you. You can also complete your interview on the phone!

When: This study will be going on through October **Contact**: H
hmadden@wisc.edu, 608.262.0654

Thank you for your help!


Appendix D

Interview questions

Background information

- Can you tell me about your Brothertown background?
    - What you did growing up?
    -

Health care information

- How do you access health care? Can you walk me through that process?
- What do you like about your health care program?
- What don't you like about your health care program?
- Do you feel like your health needs are being met? Why or why not?
- How could this system of care improve?
- Do you know anyone who has accessed IHS services?

Health information

- When you're looking for health information, where do you find it?
- What is easy about finding health information?
- What is hard for you about finding health information?

Health concerns

- What does health mean for you?
- What health concerns do you have for the Brothertown Indian Nation?
- What are your own health concerns?

Brothertown assets

- What do you think the BIN can do to promote your own health? The health of the Nation?
- What do you think are the strengths of the Brothertown people?
- How do you think these strengths can improve the health of the Brothertown people?

Other information

- Is there anything else you'd like to share?
- Is there anything I haven't asked you, but I should have?

Appendix E

Brothertown Indian Nation Health Project Findings

These findings are from 20 interviews completed with Brothertown Indian Nation citizens over the past year. Courtney Cottrell has been invaluable in collaborating around analyzing the data and determining next steps. Here, I have the major themes, sub-themes, and important information about each of them. I also have some questions that can be used for further discussion, as well as some questions and thoughts around moving forward. This project was developed to listen to citizens' voices and use them to determine where to go next. I am happy to offer my thoughts and work on future projects and resources while also ensuring that the steps taken reflect the voice of the Brothertown Indian Nation people

One important theme that emerged in these conversations was what it meant to be a citizen of the Brothertown Indian Nation - and who the Brothertown Indian Nation is. The other main theme was health, including how people access health care and health information, as well as what their concerns around health were.

I am happy to talk about any of the findings in greater detail, and can be contacted at hmadden@wisc.edu or 608-770-1811. It has been a privilege to talk with people and get to know you all, and I am deeply grateful for this opportunity.

- Haley Madden

Being a citizen of the Brothertown Indian Nation (BIN)

Identity

For many participants, their BIN citizenship was a really important part of their identity. They had known about their BIN heritage all their lives and it is a defining characteristic of how they see themselves and move through the world.

Some people had different conceptualizations or ideas of what it means to be a BIN citizen. Some of these different conceptualizations included:

- Focusing on Christian traditions
- Focusing on the similarities between the BIN founders and other Europeans around them at the time
- Focusing on the cultural traditions of the BIN's founding tribes
- Incorporating some of the traditions of the BIN's tribal neighbors, such as the Oneida

- Blending different cultural traditions (e.g. Christianity and the customs of the founding tribes)

As I was talking with people and analyzing results, one thing stood out to me: people were saying that there is no one way to be an American Indian and no singular way to be a BIN citizen. This may be an opportunity to explicitly remind citizens that they are indeed a part of the nation and their expression of identity is welcome, even if it is different from someone else's interpretation of what it means to be a citizen. This could help foster greater inclusivity and sense of welcoming. Feeling secure and welcomed in your identity has important positive health implications. For example, feeling like you are a secure part of a group decreases stress, which is very important for health.

Questions

- What are the "right" ways (if any) to be a BIN citizen?
- How can the BIN help all its citizens feel included and welcome?

Moving forward

- How can we improve community health through a celebration of the BIN identity?
- The topic of identity might warrant further discussion with the citizens and leadership. Some suggestions I have included:
    - State explicitly what it means to be a citizen and what ways there are to be a citizen (e.g. stating clearly and reiterating at events/meetings/communications that there are many different ways to identify as a citizen of the BIN, if that is how people feel)
    - Continue discussions around identity, and especially encouraging those who have different ideas to work together on bridging the divide – these discussions could be built into meetings and events
    - Continue to ask citizens what would help them feel included through discussions and surveys
    - Continue to focus on citizen participation, stressing that any kind of participation is helpful, be it financial, volunteer, experience, etc.

Family

Family was a very important part of many participants' lives, especially when it came to involvement with the BIN. Many participants were involved through the urging of their families. Often participants had a familial closeness with their fellow citizens, regardless of actual family connections.

Participants did express that it was difficult to involve younger family members in BIN activities. This could be due to people living far away or having busy lifestyles. Sometimes, this issue was seen as worrisome, as some people noted that it's important to involve the younger generation for the success of the nation.

Questions

- How can the involvement of young people be encouraged?
- Are there new ways to involve those who are far away?

Moving Forward

- It might be helpful to be explicit about what the benefits of citizenship are and why it is important to stay involved
    - I could help to develop a social marketing campaign to help draw in more volunteers and participants
- If possible, it could be helpful to offer incentivized ways to involve young people, such as scholarships and awards
- There could be specific leadership or committee positions for young people
- There could also be specific service projects for young people, as these activities can be very beneficial for personal growth, as well as resume-building
- There may be a way to utilize online resources more effectively (e.g. listservs, Facebook groups, Google Hangouts) to help people feel more connected despite geographic distance

Values

Many participants spoke with incredible pride and love for the BIN and the work they do for the nation. People consistently noted the immense dedication of fellow citizens and it was very clear how important BIN involvement is for many. Christianity was mentioned less frequently as an important value within the BIN.

Questions and Moving Forward

- What is the role of Christianity in the BIN today? Should there be any new discussions of its role?
- How are health and Christianity linked in the BIN?
- Are there any new or different ways to celebrate the dedication of BIN volunteers?
- Are there other cultural values to focus on?

Strengths

The BIN has many distinctive strengths that participants mentioned. In addition to the amazing dedication of its citizens, participants often mentioned the high number of

highly-educated people in the nation, as well as the strong sense of community. Sometimes, the geographic distance among citizens was considered a strength, as it was seen as a way to include more diverse perspectives. Disagreement was also considered to be a strength, as it allows for different perspectives to be considered and for decisions to be made with great care.

Questions

- How can the BIN continue to build on these strengths?
- Are there other ways to capitalize on the geographic distance between citizens?
- Are there ways to better-utilize the talents of BIN citizens?
- How can we prevent burnout among the people who are very involved?

Moving Forward

- Prevent volunteer burnout by asking people to work in teams on projects, rather than individually
- Develop strategic ways to reduce friction in situations with conflict
- There could be specific projects developed for people to best utilize their talents

Opportunities

Some participants wanted to discuss what they saw as challenges or opportunities for growth in the BIN. There were three main areas discussed. First, participants want to increase the participation of other citizens in BIN activities, especially young people.

Second, some participants felt as though there were some feelings of exclusion from the BIN and its citizens, and that BIN could do more work to make every citizen feel included. For example, some people felt that if they were not a member of a specific family or lineage, they were not full citizens and did not have as much room at the table. This can have health consequences, as *feeling* excluded (regardless of what is happening) can cause distress and stress.

Third, some people felt that there were different cultural traditions that were at odds with one another, which relates back to participants' thoughts about identity (that there are different understandings of what it means to be a BIN citizen). For example, some participants relate back to strong Christian traditions, while others relate back to the cultural traditions of the founding nations, and still others worried about using cultural practices that did not explicitly come from the BIN.

Questions

- How can the BIN work to involve more people in activities?
- What are some ways you see people being excluded?

- How can the BIN become a more inclusive nation?
- What cultural traditions do or should belong to the BIN? Are there some that should not?

Moving forward

It may be worthwhile to discuss these issues further at general membership meetings, or ask that the Tribal Council (or another group) develop strategies to capitalize on these opportunities. Some ideas that I have include:

- Develop a new way for citizens to get in touch with Tribal Council, Peacemakers, or other leaders, perhaps anonymously
    - This could be online (such as a "submit feedback" form), or through regular surveys, which could be online
- Develop new pathways for people to be involved remotely
    - I know there is some teleconferencing going on already. Could there be other ways to help citizens connect with Tribal Council – or other citizens who live near them?
    - One idea is a meeting "starter pack" to help those far away feel more connected (e.g. some materials that could be provided for those far away to help them develop their own BIN gatherings, such as a suggested format, cultural traditions, discussion topics, etc.)
- Create discrete and explicit tasks for people to do remotely
    - Often, it's really helpful for people to have a really clear idea of what they're supposed to be doing, so the more explicit the task, the better. There could also be working groups that focus on specific issues. It may take some time to set up, but might ultimately involve more people.
- Develop more rewards or accolades for one's activities in the BIN, such as leadership awards
    - These could include a wide variety of topics and might be especially helpful for young people
- Have general meeting discussions around BIN culture and what it means
    - I know there are many things to discuss at meetings, and there is often time included for some special activities, such as crafts. These discussions could be incorporated into that space.

Health

Accessing care and health insurance wants and needs

Participants I spoke with are accessing care through private insurance and federal programs, such as Medicaid and Medicare. While the BIN cannot necessarily assist with these wants and needs at this time, they may be helpful to consider for future

programming, grant seeking, etc, and are helping me develop new resources to offer citizens. Although many participants were satisfied with their care, participants noted several things they wanted, including:`

- Less expensive insurance
- A better understanding of the insurance options available
- A better understanding of federal programs
- Better coverage, especially for things like dental, vision, prescription medications, and alternative care (like chiropractic care)

Questions

- Are there any other resources citizens would like to see?

Moving forward

After some investigating online, I did find some interesting language on the Indian Health Services (IHS) page, which states that federally recognized nations can provide IHS care to eligible people, which includes people who are: "regarded by the community in which he lives as an Indian OR Alaska Native." This may mean that BIN citizens may be eligible for IHS care if they have: 1. some lineage of a specific recognized tribe, 2. are recognized by members of that tribe as American Indian through their BIN enrollment, and/or 3. the tribe has sufficient funding to offer services. For those in need of care or special services (such as prescription coverage), it may be worthwhile to look into using IHS clinics.

I will also be developing resources about different health programs and resources that are available (e.g. free clinics or services, program descriptions, etc.).

Health issues

There were several health issues that participants were concerned about for themselves, their families, and fellow BIN citizens, including:

- Diabetes
- Heart disease
- High blood pressure
- Obesity
- Inactivity
- Cancer
- Alzheimer's
- Mental health
- Substance abuse
- Dental health
- Grief/trauma counseling

Questions

- Are there other major health concerns that are missing?

Moving forward
I would like to develop some resources relating to these health issues that can be widely available for all. If there are specific ways you'd like me to develop these, please get in touch!

Finding information
For most participants, it was important to learn about new health information from physicians or family members, rather than researching information on the internet.

Questions and Moving forward
- Are there any topics you think your fellow citizens may feel uncomfortable with or have difficulty talking about?
- What information would be most helpful to have available online?
- How can we promote positive and productive conversations around health within families and the BIN?

Health questions
Lastly, there were a few health-related questions that participants had. Namely, participants were unsure about the availability of health programs and benefits. Participants also wondered if there were benefits available to citizens of federally unrecognized nations.

Questions
- Are there other health-related questions that come to mind for you?

Moving forward
Again, I would like to develop some resources to help address questions around the availability of health programs and benefits!

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