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# In/visible: an ethnographic case study of the pursuit of a good life in Boston's Little Saigon

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BOSTON UNIVERSITY  
SCHOOL OF MEDICINE

Thesis

**IN/VISIBLE: AN ETHNOGRAPHIC CASE STUDY OF THE PURSUIT OF A  
GOOD LIFE IN BOSTON'S LITTLE SAIGON**

by

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B.S., University of Florida, 2017

Submitted in partial fulfillment of the  
requirements for the degree of  
Master of Science

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## **DEDICATION**

For my grandmother, Donna.

## **ACKNOWLEDGMENTS**

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**HANNAH MARY BAILEY**

**ABSTRACT**

Little existing research examines how Vietnamese American individuals conceptualize wellness in relation to the community in which they live. Fewer studies examine the ways in which communities of Vietnamese expatriates form networks of support, based around community resources. Even fewer, if any, focus on these qualities within the context of Boston's own Little Saigon – Fields Corner.

This ethnography analyzes discussions with and observations of individuals living in a predominantly Vietnamese neighborhood in Boston who are a part of a support group for families of children with special needs. Through this analysis, two key themes emerge. First, through the learning of information and sharing of knowledge, this Network's connections have impacts far beyond the four walls of their bi-weekly meeting space. Second, wellness for the parents in this group is directly tied to existing as a part of a community support network which allows them to successfully navigate three distinct institutions of care for their children – the medical and special education systems, as well as the expression of Vietnamese culture that exists in this neighborhood.

I argue that in discussions with members of this support group, it is necessary to focus on channels alternative to biomedical mental health services when confronting the pursuit of a life worth living. This network acts as a site of social change through parental advocacy for their children's flourishing within various institutions. Parents then act as

vectors of consciousness to raise awareness for specific action. Within this context, parents are enabled to fight for their definition of a life worth living and their personal wellbeing.



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## LIST OF ABBREVIATIONS

ADA.....	Americans with Disabilities Act of 1990
AMI.....	Any Mental Illness
BU.....	Boston University
CDC.....	Centers for Disease Control and Prevention
CHW.....	Community Health Worker
CMA.....	Critical Medical Anthropology
DMZ.....	Demilitarized Zone
DRV.....	Democratic Republic of Vietnam
EEOC.....	Equal Employment Opportunity Commission
ICESCR.....	International Covenant on Economic, Social and Cultural Rights
IDEA.....	Individuals with Disabilities Education Act
IEP.....	Individualized Education Program
IRB.....	Institutional Review Board
JFK/UMass.....	John Fitzgerald Kennedy/University of Massachusetts MBTA stop
LGBTQ+.....	Lesbian, Gay, Bi-Sexual, Transgender, Queer, Plus
MACCP.....	Medical Anthropology and Cross-Cultural Practice
MBTA.....	Massachusetts Bay Transit Authority
MIT.....	Massachusetts Institute of Technology
PV.....	PhotoVoice
SMI.....	Serious Mental Illness

UNHCR..... United Nations High Commissioner for Refugees  
US/USA ..... United States/United States of America  
USSR..... Union of Soviet Socialist Republics (The Soviet Union)  
VACA ..... Vietnamese American Civic Association  
VCP..... Communist Party of Vietnam  
VietAID..... Vietnamese American Initiative for Development  
WHO..... World Health Organization

## Chapter 1: Introduction



Figure 1: JFK/UMass MBTA Station, Dorchester, MA (Bailey 2018)



As I near the corner of Dorchester Avenue and Cottage Street in Dorchester, I join the small group of people standing on the sidewalk waiting for the crosswalk signal to change. The Dorchester Market on the corner is open for business, their daily deals scrawled on the outside chalkboards. Two dollars and ninety-nine cents for a pound of chicken tenders. Two dollars and forty-nine cents for a pound of pork chops. As I continue down the street, I walk past trash -- Dunkin Donuts cups and straws as well as more mini-alcohol bottles, in Boston known as nips. Rain drips off of a rooftop and landing on a metal bin to my left, ringing metallically with each drop. I round the corner and see the JFK/UMass MBTA station. A train pulls up to the platform and I quicken my pace, the sound of cars on the I-93 rushing past on the flyover above. I take the stairs two at a time, scan my Charlie Card, and hop on the Ashmont-bound train to Fields Corner.

It's 10:47 in the morning and I think to myself that I'm probably going to be late. Twenty minutes later, I exit onto the platform at Fields Corner and take the stairs down into the station. The inside of the station looks modern and shiny with large windows letting in natural light throughout the building. There are no missing tiles on the floor like there are at the JFK/UMass stop. The space is large, with tiles extending up the high walls, reaching up at least two or three stories in height.

As I take a second set up stairs up to street level and to the Charles Street exit, piles of dainty, white flowers swirl in the wind on the floor of the station. A uniformed MTBA attendant bends over with a broom and dustpan to sweep them up. As I exit, more flowers fall from the trees. A gust of wind sends a new swirl into the station lobby. I pause on Charles Street. I know that VietAID and VACA are to my left, but I turn right towards the church and the bakery (Field Notes, Bailey 2018).

### **Setting the Scene**

In 1975, the Vietnam War came to an end and a large-scale diaspora began. Refugees fled to camps in Malaysia and Australia, among others. A substantial portion of these people made their way to the United States and were resettled by the government throughout the country. After a time, as people shifted and moved throughout the nation, large communities formed in Southern California, Louisiana, and Texas – places where at least the climate felt like home. Several thousand, who were placed in Boston, Massachusetts, stayed put. This is where our story begins, with the settlement that formed near South Boston, in a neighborhood called Dorchester, and a borough called Fields Corner.

This vibrant neighborhood is home to many Bostonians. In the year I lived there, I saw flags from Ireland, Poland, Cuba, Argentina, and Vietnam draped over porches and strung up on poles. The people of Dorchester are proud to be from there – Dorchester Day is one of the largest events of the year, next to the celebrations for St. Patrick’s Day and Super Bowl Sunday. One of the most frequent brags I heard was that the Mayor of

Boston, Marty Walsh, was born and raised there. There are several distinct ethnic enclaves that exist within the neighborhood. On the walk north up Dorchester Avenue, the main drag affectionately called Dot Ave by locals, one passes through what is considered the Vietnamese section, then into the traditionally Irish section, then through a Polish enclave, and ends at Broadway Street in Southie (South Boston).

The pride that residents have in Dorchester is nuanced by their pride in their own ethnic communities and the history of that community's presence in the area. This stems, in part, from Boston's past segregation practices, but also from the sense of nationalism and connection people feel toward their ancestral homes. However, at the same time, the pride in Dorchester can conflict with this ethnic pride. In the fall of 2018, there was discussion of creating a "cultural district" in one section of the neighborhood and calling it "Little Saigon," a nod to the home of many who live in this area. This suggestion was met with stern arguments from non-Vietnamese residents, who argued that the name "fails to reflect the identities of other village residents" (Smith 2018).

Fields Corner is a section of Dorchester "bounded by Bowdoin Street, Washington Street, Ashmont Street, and the train tracks on Clayton Street" (American Planning Association 2018). This is the epicenter of Vietnamese culture in Boston and the New England area. People travel from miles around to visit the *pho* and *bánh mì* shops that line the streets here and many store signs are written in both English and Vietnamese. Traditional Boston triple-decker houses and locally owned shops with Southeast Asian cultural influences are seen within the same block. New housing

developments made up of partly government-subsidized housing, partly gentrified and overpriced apartments, line the thoroughfares side by side.

If one ventures far enough down Adams Street, they will pass a Catholic church, several shops selling Boba tea, small grocery markets, fishmongers, and a Buddhist temple. The awnings over the doorways of the shops are colorful, albeit faded and sometimes torn. The brick walls with their stained grout enclose salons and bodegas, sometimes unlabeled, only to be found by those who know their locations. The names of Vietnamese physicians decorate the white awnings at the intersection of Adams and Dorchester Avenue. These small doctor's offices are nestled amongst locally-owned businesses, a post office, bank, and Domino's pizza. This corner is where I spent the majority of my free time over the year I lived in Dorchester and the summer when I conducted my field work.

Throughout the majority of my research, I worked with a Vietnamese parent support group. This group, which I will call The Network, was created by my key informant Trang<sup>1</sup> after she came to the United States from Vietnam and found herself in need of support and assistance in caring for her daughter. Her daughter, along with many of the other children whose parents participate in The Network, is on the autism spectrum. In the years that The Network has been in operation, they have helped over 120 families gain support and resources for their children. During the time that I spent with them, I saw no fewer than fifteen families represented by mothers, fathers, grandparents,

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<sup>1</sup> All names of people and locations, except for neighborhoods in Boston, have been altered to protect the identities of my informants and the institutions they are associated with.

and children. These individuals would be the ones to agree to talk to me about “wellness” in Fields Corner and the ones who would allow me into their monthly meetings and celebrations.

The following pages represent an ethnography of this family group. I will highlight the ways in which the parents support one another in the face of a stressful and stigmatizing diagnosis while maintaining a sense of wellbeing that is tied to health, family, and culture. Through the sharing of information and knowledge, this network acts as a site of social change through parental advocacy for their children’s flourishing within various institutions – the biomedical, the educational, and the cultural. Parents then act as vectors of consciousness to raise awareness for specific action. Within this context, parents are enabled to fight for their definition of a life worth living and their personal wellbeing.

In the following pages, I will refer to “the community” as a shorthand for the family circle as the members of this group function as a sort of community of care (Mattingly 2010). This label will only ever be applied to the family circle as the data I collected only reflect the lived experience of members of that group and people who work closely with its members. Additionally, I refer to the individuals I worked with as Vietnamese and Vietnamese-American to reflect the diverse set of personal identifications reflected in daily conversations.

## **The Evolution of a Question**

The central questions that formed the basis of the research for this thesis include: “What if someone does not want to access mental health care?” and “What if they frame their illness outside the biomedical model or pursue other forms of support?” There is a built-in problem with framing mental health care as a black and white issue and demonizing or pitying those who do not seek care for whatever reason. This stems from the very definitions of illness and the medical sphere within which it was created. This then means that wellness does not have to be defined by how often someone sees their doctor or the medication they do or do not take, but rather may be defined by the ways people come together as a community. With this in mind, I began my research in Fields Corner.

Compared to other cities across the nation – Houston, Texas and San Jose, California, for example – Boston has a low proportion of Vietnamese residents. The 2010 census recorded a population of 11,670 living in Boston, while the number in the Greater Boston Area and surrounding towns reached to over 30,000 (University of Massachusetts, Boston 2018). Among these Vietnamese New Englanders, seven out of ten live in Dorchester (Lo and Tran 2012) and seven out of ten are immigrants to the United States (Smith 2019). This is the largest concentration of Vietnamese residents in one place in the Greater Boston Area and in the state of Massachusetts. In Dorchester, Fields Corner is the epicenter of social and business activities for Vietnamese folks - there are many locally-owned restaurants and cafes; two distinct places of worship for Buddhist and Catholic Vietnamese alike; and community organizations offering

everything from legal advice to summer camps for children. However, where there is a concentration of people, there is also a need for adequate medical care, something which Dorchester lacks.

In Fields Corner, a handful of the “mom and pop” doctors’ offices lining the streets belong to Vietnamese and Vietnamese-American physicians. In the main square where I did the bulk of my fieldwork, a space of approximately two city blocks, I counted no fewer than three such offices. However, all of these appeared to be a combination of dental practices and the offices of general practitioners. Signs on the outsides of buildings proclaimed "primary medical care," "walk-ins welcome," and “family dental” (Field Notes, Bailey 2018). Although primary care providers are considered to be a part of the mental health care team, it is difficult for someone who is not specially trained in assisting those with any mental illness (AMI) or serious mental illness (SMI) diagnoses to provide adequate care. Adequate care, as defined by the International Covenant on Economic, Social and Cultural Rights (ICESCR), is “...the highest attainable standard of physical and mental health” (ICESCR 1966). This vague definition raises more questions than it answers because there is no set definition of the highest attainable standard. Moreover, the highest standard attainable by some nations may be completely different than those attainable by another, or they may use different scales altogether (University of Minnesota 2003). However, one may be able to assume that this standard applies to the number of physicians per capita in a certain area.

There is a lack of biomedical mental health resources in Dorchester for the Vietnamese Bostonians, which should be a priority for health care providers, public

health officials, and those involved in health policy. This idea will be revisited in the conclusion of this thesis. As I became involved in The Network and the Fields Corner neighborhood, I thought I would find a recognition of the need for more mental health services in the area and I prepared to discuss the pursuit of that care with informants. Instead, I learned of community resources that residents utilize and that “mental health” is not the most meaningful term, accessing mental health care is not the main priority. People did not want to discuss illness, and I came to understand why. This thesis will explore the question: How do Vietnamese and Vietnamese-American members of an established multi-generational community in Boston perceive and experience mental and emotional wellbeing, challenges to this wellbeing, and the pursuit of related care?

## **Summary**

In this thesis, I argue that social support networks, as materialized in this circle, can act as sites of social change through advocacy. Parents advocate for their children’s ability to flourish within major social institutions and in society. This particular network is a site where the “personal” and “institutional” intersect and, if only for the length of a meeting, exist on the same plane. This allows parents to act as vectors of consciousness to raise awareness for specific action. Within this context of advocacy and social awareness, parents are enabled to fight for their definition of a life worth living, the wellbeing of their children, as well as their personal wellbeing.

In the Background chapter, I will provide foundational information necessary to understand the context of this thesis. I will discuss of critical phenomenology, which



allowed me to explore the meaning-centered experiences of my participants. I will also cover: 1) briefly, the history of the Vietnam-American war; 2) the waves of immigration out of Vietnam, post-Vietnam-American war; 3) the history of the neighborhood where I conducted my field work; 4) the sociopolitical context of the United States during the 1960s and '70s which set the stage for the attitudes of Bostonians toward immigrants; and 5) conclude with a description of the various systems within which the parents of this support network act. This is followed by the Methods chapter, in which I describe the process of conducting my research, including the circumstances that lead to my ability to work with the Vietnamese community in Dorchester, the steps I took to apply to the Boston University Institutional Review Board, and the analytical process of reviewing my data.

Chapter 4, titled “I Cannot Only Be a Mother: Parents as a Part of the Health Care Team” will provide an introduction to The Network itself and how its members navigate the complex systems relating to health and wellness for children with special needs in the United States. In this chapter, I will use analysis of literature and data to support my assertion that parents are an essential part of the health care team. This argument is situated within a discussion of the medical hierarchy which interacts with this group of families in visible and invisible ways. I will provide descriptions of various healthcare professionals – specifically community health workers – who work within this system and interact with parents of children with disabilities, often on a daily basis. I believe that Trang herself acts as a community health worker for the parents of the group she has created. I will explain this connection using quotes from two interviews, conducted with

Trang and Chi An, another member of this support network. Finally, I will describe and support my reasons for asserting that parents are a part of the healthcare team.

In Chapter 5, titled “‘To Survive...You Have to Speak Their Language’: Wellbeing in the Context of a Support Network,” I will discuss how The Network supports and promotes wellbeing between members and throughout the larger Vietnamese community and the city of Boston. In this chapter, I argue that a local sense of wellbeing and a related worry that permeates the experience of raising children is important to understanding the act of empowerment to advocacy that occurs within this organization. This chapter draws on observations as Network meetings and discussions with community members about how they utilize community resources to overcome struggles to support their personal wellness. This chapter will include a discussion of the theoretical definitions of wellness and resources and how telling one’s story may be the starting point of advocacy.

In Chapter 6, titled “A Tale of Two Têts: From Surviving to Flourishing Within a Doubly Invisible Community,” follows the story of two separate celebrations of the Vietnamese Lunar New Year, Têt, over two years. The first section describes a gathering with vast numbers in attendance – a version of this festival put on for the Vietnamese population in New England. As the largest event of its kind in the area, it draws crowds of thousands. At the same time, a smaller celebration of a similar kind takes place just down the street. This chapter provides an explanation and analysis of the importance of this time of year to the Vietnamese community in the Boston area and internationally. Moreover, it explores the significance of what a second, in/visible Têt means to members

of The Network and how the concepts of ritual, symbolism, placemaking, and cultural identity play into definitions of surviving, thriving, and flourishing. I argue that The Network and the events and meetings it puts on promotes parents' wellbeing in their ability to explore and enjoy their own culture and heritage. The support that parents and families receive at these events fosters a feeling of support and a sense of belonging.

The concluding chapter of this thesis, titled "In/Visibility and Medical Silence," will discuss the concept of silences, specifically medical silence and the anonymity that comes with existing as an immigrant community in the United States. Moreover, I argue that the families who are a part of The Network are doubly invisible, as suggested by the title of the previous chapter. Because of diagnoses that are stigmatized throughout the predominantly Western culture of the United States as well as more traditional values potentially held by smaller Vietnamese-American enclaves, parents of this group receive little visibility. This is the importance of The Network. Through information and knowledge sharing, parents are emboldened to advocate for themselves and for their children. They are emboldened to fight for their right to a life worth living – to thrive and flourish.

## Chapter 2: Background



Figure 2: A peeling mural located outside of the Fields Corner MBTA station. The labels on the buildings depicted read “Bank,” “Post Office,” and “Pho.” The person in the window of the pink building, calling to the group on the grassy lawn, asks, “Are you talking about healthy relationships?” The statement at the bottom of the mural declares, “We are,” followed by an out-of-date web address (Bailey 2018).

History is embodied in Fields Corner and, in some cases, in the people I met. Walking into Fields Corner, at times, feels like walking into a bygone era – homes that have been there for decades line the streets behind brick sidewalks and well-established stores. Then, in the same instant of that feeling, one may walk past a café that cannot be called anything but modern with exposed-wood walls and shiny espresso machines sitting behind counters at which lines of young people wait impatiently to place their orders. The elderly men sitting outside some of these cafés at decorative metal tables, talking over their morning coffee or tea, seem like installations as much as the church around the corner or the hundred-year-old triple decker houses.

At the outset of my research, I hoped to address the following question: How do Vietnamese and Vietnamese-American members of an established multi-generational community in Boston perceive and experience mental and emotional wellbeing, challenges to this wellbeing, and the pursuit of related care? While this question was the impetus for the research I conducted in the Summer of 2018, taking a grounded theory approach to the data I collected took me away from this question. Instead of focusing on all of these aspects as they relate to individuals within the Vietnamese community, I focus here on one specific group of individuals – a support network of Vietnamese families whose children have special needs. The wellbeing of each parent in this group is tied to their ability to get information and share knowledge relating to three institutions they come into contact with every day: the biomedical institution that they must navigate to access care for children who have complex medical diagnoses; the special education system that strives to help children but is so convoluted and bureaucratic that, in reality, it

makes life more difficult for parents and children; and the institution of Vietnamese culture in the Greater Boston Area which provides a insulative barrier from the larger city population.

To address my research question and the related arguments that arose through my field work and subsequent data analysis, I begin with a discussion of critical phenomenology. I will examine this form of inquiry, which allowed me to explore the meaning-centered experiences of my participants, as both an anthropological theory and method. Second, I will explain topics which are important to understanding my data and the context of the community where I worked: 1) briefly, the history of the Vietnam-American war; 2) the waves of immigration out of Vietnam, post-Vietnam-American war; 3) the history of the neighborhood where I conducted my field work; 4) the sociopolitical context of the United States during the 1960s and '70s which set the stage for the attitudes of Bostonians toward immigrants; and 5) conclude with a description of the various systems within which the parents of this support network act.

## **A Phenomenological Framework**

“I am a collector of stories,” I replied, responding to the often-asked question “what is medical anthropology?” This time, the inquirer was a woman who presented at a family support group meeting in July of 2018. I use this phrase to explain my way of “doing” medical anthropology because it embodies the overarching theoretical lens through which I approach my research, namely phenomenology. Anthropologists and sociologists alike employ this method to get at the root of how experiences form from the

process of living or, as Desjarlais and Throop write, “the study of things as they appear in our lived experiences” (2011). This paradigm can help a researcher understand the Other (Foucault 1982) through their own social relations and modes of perception (Desjarlais and Throop 2011). Phenomenology is a way of explaining the world through the stories of others, focusing on the concepts of temporality, intersubjectivity, and embodiment (Katz and Csordas 2003). If these three aspects are essential to the practice of phenomenological anthropology, then one must collect the stories of others to understand them.

It is important to consider the structural and social violence imposed upon Vietnamese refugees and more recent Vietnamese immigrants to the United States when analyzing access to care and movement within federal institutions and complex social relationships. Critical Medical Anthropology (CMA) defines health in terms of the resources available to a person and how the institutions that be impact access to these resources, which are needed in order to live life to a high degree of satisfaction (Baer et al. 1986). Viewing my data through a critical lens allows further insight into the health seeking practices and daily lives of my participants.

It then follows that critical phenomenology incorporates aspects of both CMA and phenomenology. Sarah Willen defines critical phenomenology in a three-part model that includes “judicial status...sociopolitical condition...and a mode of being-in-the-world” (2007). For the purposes of this thesis, I will focus on the sociopolitical condition that shapes the lives of im/migrant parents of children with special needs, navigating within a federal system that in recent years has made it more than clear that they are not welcome.

Additionally, it is important to understand the way the parents of this support network are in the world to understand the ways they interact within the systems and the choices they make for themselves and in the care of their children.

Within a larger frame of Critical Phenomenology, I utilized a grounded theory approach to collecting and analyzing data. First defined in the 1960s by the anthropologist team of Glaser and Strauss in their book *The Discovery of Grounded Theory* (1967), grounded theory emphasizes going from data to theory through “simultaneous data collection and analysis” (Charmaz and Belgrave 2015). This method was necessary throughout my research due to the difficulties I had at the start with breaking into the community, which I will discuss further in Methods. Maintaining a more open theoretical and methodological framework allowed my research to occur more organically.





Figure 3: “Map of Vietnam and surrounding territories in the era of French colonialism” (Lawrence 2008). Note the names of the different regions and surrounding nations.

### **Mounting Tensions**

Remnants of the impact of Vietnam’s colonial past, the violent wars in recent memory, and the now-infamous escape of refugees from Saigon are aspects of Vietnamese history that are still present today in many ways throughout Dorchester.

Detail of the Vietnam-American War is important for the following reasons: 1) this war was violent, bloody, and traumatizing in a way that previous wars in Vietnam had not

been, thus impacting those who lived through it in lasting ways, and 2) it had a large influence on American sentiment towards Vietnamese refugees entering the country after the end of the war, including those who settled in the Boston area.

Anti-French sentiment increased in Vietnam after the two World Wars and rebellions sprang up across the nation; many Vietnamese men were conscripted as soldiers and laborers for the French. The nation also saw feminist movements in which women began to embrace a Western lifestyle, incorporating new fashions into their wardrobes as well as joining the labor force. The Labor Movement that swept across the United Kingdom and established communist parties throughout the European continent also made its way to the region. With these movements came the rise of published Vietnamese newspapers, which were often used to disseminate new political ideas. The Labor Movement sparked the interest of one man who would go on to establish the Vietnamese Communist Party (VCP) under the alias Ho Chi Minh<sup>2</sup> (Lien and Sharrock 2014), one of the loudest voices in the cry for Vietnamese independence. At the end of World War II, Ho Chi Minh and the VCP seized governmental power from the defeated Japanese, who gained control from the French. They declared Vietnam's official independence in 1945. In response, France seized control of South Vietnam. The nation was on the precipice of two more large-scale conflicts.

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<sup>2</sup> Ho Chi Minh, the Communist leader of North Vietnam, went by several names throughout his life. At birth, his parents gave him the name Nguyen Sinh Cung or Nguyen Tat Thanh – there is discrepancy over which was his true name. Later in life, he adopted the name Nguyen Ai Quoc, meaning “Nguyen who loves his country” (Quinn-Judge 2002). Finally and most famously, he assumed the name Ho Chi Minh, meaning “Ho the Most Enlightened” (Quinn-Judge 2002).

## **Kháng chiến chống Mỹ (Resistance War Against America)**

At the 1954 Geneva Convention, representatives from nations involved in the recent wars in Asia met to discuss the current situation in Vietnam and come to an agreement for future peace. The convention convened in Geneva, Switzerland to discuss and find concluding solutions to the First Indochina War<sup>3</sup> and the Korean War. The attendees included North and South Korea, the United States, France, Great Britain, the Peoples' Republic of China, the Union of Soviet Socialist Republics (USSR), North Vietnam (then known as the Democratic Republic of Vietnam), South Vietnam (the State of Vietnam), Cambodia, and Laos (Geneva Agreements 1954). These attendees would soon become players in the war to follow. Some nations had their own agenda for the conference, however: the United States wanted to stop the spread of communism into other Southeast Asian nations; France wanted assistance in the southern Vietnamese city of Điện Biên Phủ, where the Việt Minh, under control of revolutionary Ho Chi Minh had French forces surrounded, with all supply lines cut off; the Democratic Republic of Vietnam (DRV) wanted to unify the nation under a communist government; the State of Vietnam wanted independence from the DRV (Lien and Sharrock 2014).

At the conference's end, the nations convened to discuss solutions to the First Indochina War reached an agreement that designated several stipulations. Among these were: 1) a ceasefire between the French and the DRV, 2) a temporary border between North and South Vietnam at the 17th parallel (Lawrence 2008), 3) and a demilitarization

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<sup>3</sup> Also known as the French War

zone (DMZ) at this border. The agreement also stipulated that after two years, Vietnam would hold fair and open elections to select a new president. However, this did not happen. The agreement required that “movement of all the forces of either party into its regrouping zone on either side” (Geneva Agreement 1954) of the DMZ would be allowed for the next 300 days. During this time, Vietnamese citizens could take the opportunity to travel to whichever zone they wished.

This led to the mass migration of people from both sides of the DMZ. About seventy to eighty percent of the population moving from the North to the South was Catholic Vietnamese. Many of those fleeing from the South were Việt Minh soldiers and civilians (Lien and Sharrock 2014). Cities on both sides of the demarcation line were not prepared for the masses entering their borders, leading to a strain on public utilities and hygiene, as well as food shortages. Moreover, under the French regime, the North and South had each developed their own cultures and linguistic styles, which led to prejudice against and suspicion towards newcomers during this period of internal migration. Even in Vietnamese communities today, individuals with “northern” accents are less trusted than those with “southern” accents (personal communication 2019). The consequences of the Geneva Agreement created tensions within the nation which, exacerbated by involvement by the United States, set the stage for war.

In early 1955, the United States, continuing its anti-communist agenda, began to send troops and supplies to South Vietnam at the same time as China and the Soviet Union began to send assistance to the North. Because the mounting tension built up to the Vietnam-American War, there are discrepancies over the actual start date, although most

sources agree it began around 1945, with direct United States military involvement beginning in the mid-1950s. The US's involvement in the politics of and support of South Vietnam, coupled with a regime change, tipped the scales toward war.

### **Seeking Refuge**

The Vietnamese government estimates that throughout the entirety of the conflict, there were around “1.1 million military and almost 2 million civilian deaths” (Lien and Sharrock 2014) while the number of injured Vietnamese soldiers and civilians numbered close to 3 million on both sides. These numbers do not include those who attempted to escape Vietnam after the war ended – around 12 million sought refuge around the world. The waves of immigration out of Vietnam and subsequent resettlement around the world and in the United States was three-fold (Desbarats 1985). The first phase occurred in the final days of the war. American troops attempted to evacuate all remaining Americans and as many South Vietnamese individuals as possible in an operation named Operation Frequent Wind. This mission evacuated around seven thousand United States citizens and two thousand Vietnamese citizens, many of whom were government workers, families of American soldiers, or those with ties to the US government (Patterson 2015). The second wave occurred in the months following the fall of Saigon, as millions of Vietnamese escaped on makeshift boats, sailing for nearby countries. History will never know exactly how many people attempted to escape after the fall of Saigon in April of 1975 because indeterminable numbers perished in the voyage, due to storms and harsh conditions, and at the hands of pirates. The third wave came in 1982, as a result of the

Laotian and Cambodian conflicts at that time. A portion of the people who escaped Vietnam after the war eventually settled in Boston, primarily in South Boston, Roxbury, and Dorchester.

Vietnamese were not the only Southeast Asian immigrants to the United States at this time. Laos and Cambodia, Vietnam's neighbors to the west, experienced their own conflicts throughout the second half of the Vietnam-American War and continuing for years after. The infamous Cambodian Genocide resulted in the murder of between 1.5 and 3 million people, justified by the reigning government's misguided notion that "class was the manifestation of an essentialist 'organic purity'" (Owens 2014). The lesser-known Laotian conflict (referred to as The Secret War) occurred during the Vietnam-American War, in the 1960s and '70s. This civil war pitted communist forces, including forces from North Vietnam, against the ruling monastic government (Kurlantzick 2017). The number of refugees coming from this part of the world tapered off into the 1990s due to relative governmental stabilization in these nations. The United States stopped accepting Vietnamese refugees in the mid-1980s (personal communication 2018) and in 1995, the United States and Vietnam reestablished diplomatic ties.

### **Culture Changes in the United States during the Vietnam War and Through the Cold War Era**

The 1960s, a time when the United States was embroiled in the Vietnam-American War and witnessed a complex amalgam of emotionally charged events. While the Vietnam-American War was well underway abroad, tensions were rising back home.

In this decade, the US experienced a clash between intense anti-Communist and anti-War sentiment. The former kept governmental fervor for the war alive. The latter boiled over from peaceful protests into outright and violent resistance against the war.

Simultaneously, the height of the Civil Rights movement, a movement which supported the freedom of black individuals living in the United States, saw the rise of the Black Panther Party and the assassinations of many influential like Reverend Martin Luther King, Jr, and Malcom X, as well as President John F. Kennedy and Robert F. Kennedy. This period was important to the rise of feminism and the Disability Rights Movement, as well. These and many more sociopolitical facets of daily life in the United States had long-term impacts on the nation. These events also influenced the way people viewed and reacted to Vietnamese refugees arriving in later decades.

The Vietnam-American War was the first war broadcast to televisions and movie theatres across the nation. This made the American civilian public a sort of second-hand witness to the atrocities of war. Because of this, protests broke out across the nation, although mostly in colleges and universities. These sit ins and marches are cited as being one of the main reasons anti-war ideas were transmitted to the public (Kindig 2008) during this time. Groups advocating for peace made sure that information was disseminated to the public and press alike. Teach-ins became a common and successful way to train new activists for the cause (Zimmerman 2017).

Many people came to stand against the war, “it wasn’t just leftist students and hippies.... Many people were against it because there was no sense that the United States could win” (Levy 2018). Protest anthems like John Lennon’s *Imagine* and Creedence

Clearwater Revival's *Fortunate Son* became the mainstream. Reasons for protest ranged from the moral to the economic – some worried that the US should have no say in another country's attempt to rid itself of foreign rule, others that the US's involvement was not only costing taxpayer dollars but hundreds of thousands of lives, as well. The nation became polarized over the war, the protests against it, as well as racialized politics occurring during this time. Rev. Dr. Martin Luther King, Jr. said that this was “a white man's war, a black man's fight.” At the time, African Americans represented less than twelve percent of the United States population, but more than twenty five percent of those who fought.

As opposed to the war as so much of the country was by the time it ended, the view toward Vietnamese refugees was less than positive. According to a 1975 Gallup Poll asking “whether recently evacuated South Vietnamese should be permitted to live in the United States” (Stern 1981), 52 percent of those polled responded in the negative. Those who responded in the positive represented a far smaller percentage at only 36. This 1981 study cites concerns about the already over-crowded labor market of the mid-1970s. Over half of those who responded to this poll (51 percent) agreed that they would not be opposed if those admitted were screened based on occupational skills. While the United States opened its borders to “Hungarian refugees in the 1950s and Cuban refugees in the 1960s” (ibid.), which might establish a precedent, polls show that more than half of Americans were opposed to these as well, suggesting that the American public has a history of being more recalcitrant toward taking in refugees.



## A History of Little Saigon<sup>4</sup>

This sentiment extended to the ways in which Vietnamese individuals settling in the United States were treated. Communities who had welcomed refugees and migrants in the past, were not open to providing support for this group. Thus, the government relied on institutional and individual sponsors<sup>5</sup> and decided where refugees would resettle, often in poor, urban areas (Zhou and Bankston 1998). Those who received sponsorships<sup>6</sup> and were settled in the Massachusetts area ended up in the poorest sections of the city, areas which were already known for their overt racism.

While, surely, some refugees were accepted with open arms, in Boston they were often met with hostility. Violence was directed toward new Vietnamese residents of East and South Boston, where they were first settled, by other residents without the recognition that these were allies in the recent war. In this post-war era, tensions were high. Lingering anti-Communist sentiment was directed at anyone who appeared to be from Vietnam and newcomers became the target of gang violence. It was common for Southeast Asian refugees, not just Vietnamese, to experience harassment in the form of “banging on doors, rock throwing, and verbal abuse... vandalism to immigrant’s homes,

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<sup>4</sup> There is a grassroots push to rename Fields Corner to reflect the long-standing, influential Vietnamese presence in the neighborhood. Proponents of this suggest names like Little Saigon or Viet Town. Opponents of the change suggest that, due to the corner’s multicultural representations, they would prefer a more culture-neutral option (Smith 2018).

<sup>5</sup> The current process for admitting refugees to the United States is as follows: 1) The Office of the United Nations High Commissioner for Refugees refers a refugee to be considered for refugee status; 2) the United States government screens the individual using an extensive series of background checks and interviews; 3) if the person is approved, they are assigned to one of nine non-governmental organizations which helps that person to integrate into the United States (UNHCR 2019).

<sup>6</sup> The United States defines refugee as “a person with well-founded fear of persecution for reasons of race, religion, nationality, political opinion or membership in a particular social group, who has been forced to flee his or her country because of persecution, war or violence” (Cepla 2019).

cars, and other properties... physical attacks and arson” (Bratberg 2017). In fact, even today the Vietnamese Americans in Boston still struggle with identity and aggravation. In one 2015 article about the 40th Anniversary of the fall of Saigon, a woman, referencing red and gold striped flags hanging from storefronts, stated: "The flags are a reminder that we are South Vietnamese, not North Vietnamese" (Enwemeka 2015).

Articles published in The Boston Globe in the mid-1980s cite poor living conditions and violence at that time. A particularly poignant example of this comes from one 1984 article:

“When the door to the second floor apartment opened, a rush of stale, hot air leaped out into the hallway, filling the corridor with a smell like wet socks. ... a baby was asleep on a mattress in the corner. The couch had sheets because it serves as a bed in the three room apartment..., home to six and sometimes 10 people. ... Open doors and broken windows lead into cellars where rats burrow into old garbage. Any city inspector...could get writer’s cramp from filling out violation forms” (Barnicle 1984).

Many historical records of Dorchester and Fields Corner focus on the distant past. The records kept by the neighborhood’s own historical society are limited to mostly images from the area’s early history. Of the few articles kept on the society’s website, none refer to Fields Corner. Online newspaper archives from The Boston Globe and Dorchester Reporter proved invaluable resources of information about the history of Vietnamese settlement in the area. However, reporters, like in the article quoted above,

tended to focus on maltreatment and important events, rather than the daily lives of the people. Additionally, one must keep in mind the potential for biased or even sensationalized news articles intended to grab readers' attentions. Because of this, oral accounts, relayed by informants and in personal communications, became one of my most reliable sources of information on the history of the area.

According to these sources, a best estimate for Vietnamese settlement in Boston is around 1975, at the end of the Vietnam War. By the mid-1980s there was a thriving community in Fields Corner. Articles about Vietnamese Bostonians begin to appear in *The Boston Globe* and similar news sources in the late 1970s. Several informants referenced "the community" in the 1980s and 1990s, suggesting that Vietnamese individuals were already living in the area prior. Informants would speak of the area in terms of restaurants and businesses – Ba Le, "the place to get a banh mi" (Field Notes, Bailey 2018), had been in the area since the '90s...Kimmy's pharmacy, shelves stocked with tiger balm next to Tylenol, had been in business since the late 1980s.

## **System Navigation**

The Network is made up of families whose children have complex medical diagnoses. For some of them, this is limited to Autism Spectrum Disorder, a complex diagnosis in its own right, which can cause "significant social, communication and behavioral challenges" (CDC 2019). For others, comorbid diagnoses such as Downs Syndrome, make access to healthcare, education, and cultural identity even more difficult. During my time with this group, I identified these three factors (access to

healthcare, education, and cultural identity) as key systems parents navigate on a daily basis when caring for children and themselves.

### *The Health Care System and Medical Hierarchy*

The medical system in the United States is western, biomedical, and complex. Fabrega (1976) writes that this is a form of a cognized system, a “model which they [people] have of the world and in terms of which they manage their affairs.” It relies on the interaction of the sick with medical professionals to address the *effects* of disease, if not the disease itself. When discussing the medical system, it is important to consider the concept of the “sick role.” This concept relates to “illness as such and the role of patient in interaction with therapeutic agents” (Parsons 1975). This concept explains the *ways of being sick* that are accepted within any given society – accepted deviance. For example, in the United States, it is generally understood that if a person is ill, they will stay home from school, work, et cetera, until they are well again. The accepted pattern of illness is thrown out of balance, however, when a chronic illness emerges. The patient will never recover and therefore cannot fulfill their side of the sick role. Illnesses that are not readily visible, such as diabetes, fit this category. Individuals with severe developmental or intellectual disabilities, whose symptoms are more apparent, have a difficult time fulfilling the sick role or even appearing like they are attempting to fulfill the sick role. There is no quick or easy fix, which adds to the stigma placed on these individuals and the unease felt by able-bodied individuals toward them.

The care needed is extensive and the path is not always clear. “Hierarchy of resort” (Schwartz 1969) is a term often used to describe the process by which a person or family rank “alternative choices for treatment of illness” (ibid.). While Schwartz originally defined this term in reference to people of the Manus culture in the Admiralty Islands throughout the mid-20<sup>th</sup> century, it holds true today. Parents of The Network must make similar decisions when seeking healthcare. Often this involves the coordination of various physicians throughout the course of their child’s life. For example, Trang says:

“I try to coordinate as much as I can so that all the members of my daughter’s interdisciplinary medical team can talk to one another. I do this to ensure quality care for her. You just have to keep up with the changes of your child and keep up with learning as much as you can to be well equipped and well informed. The process can be tiring and emotionally draining as once you come up with one strategy, your daughter changes her behavior and you have to find different strategy. It is an ongoing learning process” (Pham 2019).

The complexity of this process is due, in part, to the medical system itself and the way it is structured in the United States. Although a goal of the medical system is to provide care to all, because of the insurance system that is tied up with the healing system, it can be hard for some to access adequate care. “Medical hierarchy” is a term used to describe the interactions between professionals and patients at all levels within the medical system and how they are ranked by others within the system. Hughes and Salas (2013) provide the following definition: a system which “comprises a set of

integrated levels within which members are ranked both by their disciplines and levels of authority.” In other words, this is a system steeped in the biopolitics of medicine, the policing of bodies, and the values that are placed on high levels of education within the United States. Certain individuals, typically those with the highest levels of education, income, and status, have the power to exist easily within this sphere. Those who speak the language (English and/or the medicolegal jargon often used within hospitals and clinics) possess the information needed to get what they want.

There are many moving parts within this system that parents must learn to navigate. In the United States, a parent’s first interaction with the medical system for childcare is typically with an obstetric physician or gynecologist. After a child is born, parents interact with pediatricians. For children, the first signs of intellectual and developmental difference present when children are young (CDC 2018). Because much of a child’s formative years are spent in a school environment, teachers can often be the first to identify if a child is not meeting developmental milestones. If a child is under three years of age when signs are detected, families have the option for what are called early intervention programs. If a child is three or above, the public school system provides services for children and families. From here, the health care touchstones for parents caring for a child with special needs vary greatly because each specific case is so specific. Through the help seeking process, families can encounter anyone from physical and speech therapists to cardiologists and surgeons, depending on the child’s needs.

### *Special Education*

The Special Education system in the United States is designed to “provide equal access to education for children ages birth through 21 by providing specialized services that will lead to school success in the general curriculum” (Special Education Guide 2019). Parents in The Network come into contact with this system when their children reach school age. As mentioned above, teachers and school administrators can be the first people to identify a child as having developmental and intellectual delays. Schools can be the first place children receive care within the complex and overlapping healthcare system, so they are essential to the wellbeing of both children and parents. This system has been affected and shaped by key legislation and Supreme Court decision. As I will cover in Chapter 5, people with disabilities have often been discriminated against and mistreated throughout the country’s history. However, in the last hundred years, the Civil Rights and Disability Rights movements have created structures within which these individuals can thrive.

The first of these is *Brown v Board of Education of Topeka (1954)*. This case explored whether segregation within public schools “solely on the basis of race” violated the Equal Protection clause of the Fourteenth Amendment of the Constitution of the United States. In an opinion which famously states that “separate educational facilities are inherently unequal” (*Brown v Board 1954*), the Court held that, yes, segregation based on race was unconstitutional. Although this case is traditionally considered a key case in the history of civil rights, it had great implications for the rights of people with

disabilities, as well. If segregation based on race was unconstitutional, it was not too far a stretch to deem segregation of other groups unconstitutional.

The Rehabilitation Act of 1973, a key piece of legislation in the history of disability rights in the United States, dictates that discrimination “on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors” (US Department of Justice 2009) is prohibited. The Act includes Section 504, where specific protections are enumerated against the discrimination of individuals with disabilities. This is the first piece of legislation to specifically advance the protection of the rights of the disabled on a federal level. Additionally, because of the broad language used in the Sections of this Act, these protections extend to public schools, where the needs of disabled students must be met as adequately as their able-bodied counterparts.

The Individuals with Disabilities Education Act (IDEA) expanded upon Section 504 of the Rehabilitation Act of 1973 by dictating that students with disabilities be provided free public education tailored to their individual needs (US Department of Justice 2009). This act requires public schools to work with parents to develop an Individualized Education Program (IEP) specific to that student’s needs. This plan outlines the specific education goals and related services that each student is entitled to. According to the Act, each year a team of people, typically including the parents, teachers, school officials, and a representative from a special education agency, are



required to meet to discuss the past year's IEP and make updates for the coming year.

Schools are required to implement these agreements to the best of their ability.

Even with the implementation of so many statutes and regulations, students can fall through the cracks of the system and not receive a quality education. This is determined in part by the school the student attends, the neighborhood in which they live, and their parent's ability to advocate on their behalf. Within the context of *The Network*, some parents feel that their children's educational needs are not being fully met. I will discuss this further in a later chapter. However, it is important to note now that much of the struggle *Network* parents experience is due to language barriers in jargon-heavy conversations and not knowing fully what they are entitled to ask for in these meetings (personal communication 2019).

### *Cultural Systems*

Because of the history that brought the community to Boston, their circumstances since, and the cultural ties that still hold strong, being Vietnamese is an essential identity for those who live in Fields Corner. The social connections people make throughout the community form a larger network of support outside *The Network* itself. These connections create an insular group that is difficult for outsiders to break into and what makes this community so important for those who live in it. So then, what does it mean to be Vietnamese in Fields Corner? How is "Vietnamese culture" expressed in this neighborhood?

It is possible to spend a day in Fields Corner and not hear any English spoken (Field Notes, Bailey 2018). Because “Vietnamese immigrants are less likely to be proficient in English than the overall foreign-born population” including only “66 percent of Vietnamese ages 5 and over” (Alperin and Batalova 2018) reporting a limited English proficiency, this is essential to some residents’ abilities to live and perform day-to-day tasks. Signs, such as those in the Community Health Center, informational material, such as the bulletins handed out in St. Michael’s Catholic Church every week, are translated into English and Vietnamese. This language specificity assists individuals who are not English proficient, but also makes it easier for young Vietnamese Americans to maintain ties to the language of their parents and grandparents.



Figure 4: A statue of Our Lady of La Vang in St. Michael's church in Dorchester

(Bailey 2018)

The religious centers in the village represent the diversity of religious practice within Vietnamese populations throughout the world. Two of these places of worship in Fields Corner are the Catholic church, St. Michael's, and the Buddhist temple. Both incorporate meaningful symbols, colors, and phrases into the decoration of the structures, such as the words surrounding the statue in Figure?? and the script on the gate in Figure?? below. Important statutes also exist in both locations. When one enters the front doors of the worship center in St. Michael's, one is greeted by a statue of Our Lady of La Vang (Figure?? above), a vision of Mary which is said to have appeared to Catholics under persecution in Vietnam centuries ago. The words behind the statue declare "Lạy Đức mẹ La Vang xin cầu cho chúng con",<sup>7</sup> those at her feet in neon say "quê hương"<sup>8</sup> (Field Notes, Hannah Bailey 2018). Just a few blocks down the street, is the Buddhist Temple. Similar to the Catholic church, the temple is a place for people to gather to practice their beliefs. The bright yellow front gates open onto a courtyard filled with trees, fountains, and a prominent statue of the Buddha himself.

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<sup>7</sup> "Our Lady of La Vang, pray for our children"

<sup>8</sup> "Homeland"



Figure 5: The front gates of the Buddhist Temple in Fields Corner (Bailey 2018)

### *Culture and Medicine*

Culture extends to the ways in which Vietnamese individuals living in this community access healthcare, as well. *Familiar Medicine: Everyday Health Knowledge in Today's Vietnam*, by David Craig, is an ethnography of the medical system in Vietnam, which pays special attention to the ways in which political, social, and familial factors influence health-seeking practices in Vietnam. Craig asserts that “drugs travel better than the professional and systemic knowledge that should define and prescribe their use” (Craig, 2002), emphasizing the globalization of medicine. Because of the highly plural nature of medicine in Vietnam, as drugs move from hospitals or distributors to pharmacies to individual hands, they move into “areas constructed from other ways of

thinking” (Craig, 2002). Consumers then apply their knowledge of various medical practices from the East, South, and North to the medicines they receive.

The health seeking patterns of Vietnamese Americans living in Fields Corner are not as different as one might imagine. These patterns are still impacted by politics, social interactions, and family, as in Vietnam. In fact, it is possible that healthcare choices are impacted by these factors for most people, at least in Boston. However, what makes the practices of this community, and more specifically for the families of The Network, unique is the circumstances under which they seek care. The politics that impact these is not limited to the insurance they have or the availability of doctor’s offices in their neighborhood. The negative light shone on many immigrant communities and the stress of having to potentially prove citizenship make people more careful about when and how they seek care. Social interactions for members of The Network may be strained with individuals who are not accepting of their child’s special needs. Health seeking patterns can be impacted by family relationships when choosing a hierarchy of resort. Often younger generations will turn to their elders when making these decisions (personal communication 2019).

### **Concluding Thoughts**

Fields Corner is a vibrant neighborhood. This much is clear and is visible simply by walking down any street. The Vietnamese enclave which has formed in this area represents a community of individuals who have experienced or known others who have experienced great trauma in their life. Although the historical milieu discussed in this

chapter might hint at a community that has not been able to overcome, I argue the opposite. Through evidence gathered during my field work in this neighborhood and with members of The Circle, I argue that ties built and strengthened over the past forty years of Vietnamese settlement in Fields Corner contribute to the collective and individual wellness of those who identify as its members.

### Chapter 3: Methods



Figure 6: A view of the refurbished chocolate factory which houses the Coalition, along with many other businesses (Bailey 2018)

The following chapter describes the phenomenological research I conducted between the Fall of 2017 and the Summer of 2019. This ethnography examines and analyzes the shared perceptions of wellness held by members of a Vietnamese family support network in Fields Corner in Boston, Massachusetts and the ways they strive to flourish daily. In order to describe the methods used, I will start with my introduction to the Vietnamese community in Boston and how I came to work with The Network through a Graduate Internship at an organization I call The Coalition. This chapter also covers the process of applying to the Institutional Review Board (IRB) at Boston University and some of the challenges I experienced along the way.

## **The Beginning**

I began my application to the Medical Anthropology and Cross-Cultural Practice (MACCP) program at the Boston University School of Medicine (BUSM) in the Fall of 2016. The application asked me to list three potential topics I would be interested in researching, one of which I listed as “mental health in immigrant communities,” or something along those lines. In my undergraduate medical anthropology classes, I realized that there existed a dearth in instruction on this topic – something that surprised and even shocked me. It was jarring to realize that there was little to no discussion of trauma or acculturative stress, two topics which are important to consider when studying expatriate communities. I approached my research with these subjects in mind.

As a Florida native, I was unfamiliar with Boston and the various ethnic enclaves nestled in its boroughs. A preliminary search to identify groups I could potentially work



with revealed many diverse communities. One such of these exists in Fields Corner, in Dorchester, one of Boston's largest neighborhoods. This is the Vietnamese community, which has existed in the area for several decades. Currently numbering around thirty-thousand strong, this is the largest Vietnamese settlement in the Northeast and one of the largest on the eastern seaboard of the United States (Alperin and Batalova 2018).

The results of this search led me to a discussion with a professor, who connected me with a Vietnamese woman who I will call Trang. When I received the message from my professor telling me about her contact, it came with the news of a potential community-based, service-learning internship site – a requirement of the Medical Anthropology Master of Science at Boston University. I was thrilled – I had just been introduced to that fabled gatekeeper of anthropological fieldwork, the person with “control over key sources and avenues of opportunity” (Hammersley and Atkinson 1995). A researcher's work can be decided by a gatekeeper and whether or not one gains the trust of this person.

As it turned out, I could not have conducted this study without Trang's help. She is a leader within the Boston Vietnamese and Disability Rights communities. This leadership has set her apart as a highly respected member of her community, something she has received multiple recognitions and commendations for from advocacy organizations and local government alike. Not only is she a highly-educated, intelligent woman, she has earned the respect of her peers through her position as a source of information for other parents of children with disabilities – she is connected within a system that is nearly impossible to navigate. In sharing her knowledge and connecting families with sources of

information, Trang assists the parents of The Network access care in the medical and educational systems their children's' lives are entwined with.

### **The Coalition**

I first met Trang and another contact who I will call John through a series of emails over the summer of 2017. With this came another introduction to the organization I mentioned above – The Coalition – of which John was a high-level executive and Trang was an employee. This organization is dedicated to the important task of providing resources and support to families of and children with special needs throughout New England, similar to the parent circle I would come to know. After a long thread and a subsequent phone call between my graduate advisor, Trang, John, and me, we agreed that I would conduct my 200+ hour internship at the Coalition through the end of 2017 and 2018. Along with assisting my internship supervisor (Trang), the goal of this internship was to allow me to make connections within the Vietnamese community and to gain experience working with individuals with disabilities.

At this preliminary stage, my research question centered around mental illness and intellectual disability in the Vietnamese community, focusing on the relationship between parent, child, and Medical System. I wanted to understand how access to health care was affected by factors like self/stigma and institutional discrimination. The knowledge that I would be working with the Coalition directly shaped this idea. I operated under the assumption that this joint study of mental illness and disability would be a natural combination, especially when studying access to care. Some suggested that this was too broad of a topic, others stated that mental illness was not the same as disability. I

wondered why, prompting a semester's study into Disability Studies and the Disability Rights movement, resulting in a paper on the topic.

### *Challenges and Changes*

On my first day at The Coalition in mid-October, I arrived at a building in Charlestown, north of Boston. The old chocolate factory loomed above me, its windows now filled with paraphernalia of the various businesses it housed. I made my way to the second floor, where I met Trang and John in a conference room in the back corner of the office. The room was almost entirely windows, with one set facing outside and the other opening onto the Coalition office. The back windows looked upon a roller hockey rink that I never saw in use during the almost nine months I spent at the Coalition; the windows that faced inside allowed everyone in the office see into the room, like a fishbowl. The following is an excerpt from my field notes about this meeting:

*October 20, 2017*

Overall, the meeting went well except it raised some concerns in my mind. Trang, who I originally thought had said she could translate for me during support groups and interviews, told me that she would not be able to and that there is no one else at the Coalition who could. They suggested I hire someone from the hospital, which I cannot afford. Trang also seemed very hesitant to agree to bring me to the support group meetings as she believes it would disturb the meeting. Of course, the last thing I want to do is make the people who go to the focus groups feel like they can't say what they want to, but part of me feels like I should insist on going so that the people who attend the support groups

can get to know my face. A third thing that worried me was that they told me the Coalition's focus is not on mental health. I don't want to change my research question away from a mental health focus, so I'm not entirely sure what to do. Maybe I need to change my internship site to somewhere that deals more directly with mental illness? I would like to stay with the Coalition if possible, but this meeting was a little disheartening (Field Notes, Bailey 2017)

Going into this meeting at the Coalition, I had my mind made up that I wanted to study mental health and health care access. However, as I note in the above excerpt, I worried that my involvement with the Coalition would lead my research in a direction I was not comfortable with – toward disability, a subject which I knew far less about. I had to take into account the ideas of my internship supervisors while staying true to the work I set out to do. Ultimately, while I worked closely with The Network which is immersed in the worlds of disability advocacy, healthcare, and special education, I decided not to focus on either mental health or disability. Instead, my focus turned to wellness and wellbeing. I became interested in the ways that parents work towards their personal definitions of a good life.

From late October 2017 through June 2018, I spent four or five hours each week at the Coalition office. During my first few weeks there, I met with John and Trang each day. It was during one of these meetings that Trang told me about the stigma surrounding mental illness in the Vietnamese community. I had read about this stigma previously in my background research, but my findings were confirmed by Trang. To paraphrase what she said, parents would be very insulted if I, as a researcher and outsider to the

community, asked them about their child with mental illness. This conversation encouraged me to be courteous and cautious when speaking with Network members. Moreover, it made me realize the importance of terminology – up to this point, I did not think to separate mental illness and disability in my study because I thought them to be largely one and the same.

### *A New Focus*

After several months at The Coalition, I felt that I had had very little contact with the Vietnamese community. As I needed these connections to be able to conduct my impending field research, I decided to look for another internship site. I let Trang and John know of my decision in February, however I stayed on at the Coalition as a volunteer until July. I made this decision because I felt that I had not fulfilled my agreement with Trang and John. I began attending church services at the local Catholic church and spending my days in local coffee shops and restaurants, hoping to talk to community members.

While this community based approach led to new connections and contacts, specifically at St. Michael's, an email in late July 2018 proved to be the most important development in my research. Trang emailed me one Tuesday morning, telling me about a meeting of her family support group. She let me know that their guest speaker that night would be a professor from Harvard University who planned to present on the topic of storytelling. Because I am an anthropologist, Trang thought that I would find the information interesting and invited me to sit in on the meeting. From this point on, I began attending as many Network meetings as I could. It was at this juncture that Trang

began to introduce me to some of her friends and colleagues for interviews and data collection. During my internship at The Coalition, I felt that I was wasting time that could otherwise have been spent in the community, making connections. What I did not realize until Trang reached out to me, was that this internship and my persistence as a volunteer built trust between the two of us. It was through this process that Trang trusted me enough to invite me to one of these meetings.

### **The Institutional Review Board**

The decision to shift my focus from mental health, disability, and family health care access to community wellbeing came from several meetings with various individuals over the next several months. My topic remained relatively fluid up until I underwent the process of submitting my project proposal to the Boston University Institutional Review Board for review.

I began my application to the Boston University Medical School IRB in mid-March of 2018. At the same time, I was attending masses at St. Michael's regularly, as well as continuing to volunteer at the Coalition. With its lengthy forms and highly-detailed language, the IRB application was confusing. The thought that the decision of the IRB Board could potentially end my research was daunting (I was not aware at the time that the IRB would merely suggest edits to my proposal and not reject the whole thing outright). I was able to submit my research plan, classified as "exempt human subjects research," with the aid of my advisers and classmates. I believed that I had finally settled on a research question and methods for my project. The question I set out to answer was

“How do Vietnamese/Vietnamese-Americans in an established multi-generational community in Boston perceive and experience mental and emotional wellness, challenges to this wellness, and the pursuit of related care?” I developed this carefully-worded question over the course of several months in the hopes of understanding and describing the nuances of mental health in this Vietnamese community. The wording I used in the question is purposeful. I use both “Vietnamese” and “Vietnamese-American” when describing Fields Corner residents to encompass all individuals of self-identified Vietnamese heritage living in the neighborhood. I use the term “multigenerational” because, while most of the people I spoke with were members of the first- or 1.5-generation, the neighborhood is home to individuals who have had connections to the area for decades. This is also why I say that it is well-established. Finally, I choose to focus on wellness instead of health – an important distinction which allowed me to have conversations with people that I wouldn’t have been able to have otherwise. I planned to use two methods with two groups of people to collect data: discussion-based, semi-formal interviews with individuals I identified as “community leaders” and a method called Photo Voice with “community members.”

Photo Voice (PV) seemed an ideal method for the research I hoped to conduct when I first learned about it. Through connections at BU and the Coalition, I met a researcher who uses this method in her studies with great success. Hearing about her research, I became interested in this method and the different applications of its products. Essentially, PV entails discussing a topic with research participants and sending those participants off into the world armed with cameras and the instructions to take pictures on

that theme. For the purposes of my research, I planned to ask my participants to take pictures of things in their community that represented some form or cause of mental wellness or unwellness. I anticipated pictures of the Buddhist temple or the Boys and Girls Club down the street or an empty storefront or a broken window. I hoped that pictures could act as a conduit around the language barrier I expected to encounter. My goal was to use these pictures to create an art gallery in St. Michael's or lay out a picture map of the community – some art piece that I could give back to the people I worked with to say “See? This is what we've been working towards!” However, none of this happened.

I had heard stories of the difficulties of recruitment, but I naively thought that once people heard about my project, they would be fascinated and all but volunteer to participate. I worried about having such a large number of participants that I set aside three weeks on my calendar for initial PV interviews. I could not have been more mistaken. I met with Trang at the beginning of the summer, after the approval of my IRB application, to explain PV and to get advice about my interview guides. However, she was curious as to why this method was important or even relevant to my research. She was right in suggesting that although it may be interesting, it would not do anything to help answer my questions that simply talking with someone would not do. In fact, it would make my whole study more difficult for me and for my participants. On top of the difficult-to-understand instructions, PV would require participants to stay in contact with me for up to four weeks total for an initial interview, time for them to take their pictures, followed by a final interview to analyze and discuss their photos together. For these



reasons, I decided to forgo PV and instead conducted regular unstructured and semi-structured interviews along the same guidelines as the questions I planned to ask during the follow-up PV interview.

I also discovered that people were much more likely to talk to me if I framed my research in terms of “wellbeing” instead of illness and mental illness. Telling potential participants that my research focused on the “perceptions of community wellbeing” was a conversation-starter. Some people would ask about the meaning of “community,” which I will elaborate on in a later analytical chapter. This segued into questions about how they define the community they live in. Others would ask me to explain “wellbeing,” to which I would respond with an example of a community resource that supports the neighborhood. Wording my topic vaguely allowed me to get to the heart of the questions I wanted to discuss more easily.

The application I submitted to the IRB stipulated that my sample size would not exceed 60 ( $N = 60$ ) and that the sample would be made up of “community leaders, physicians, social workers, and academics in the community (n not exceeding 15), parents of children in the community with mental/emotional unwellness experience (n not exceeding 15), people in the community with mental/emotional unwellness experience (n not exceeding 15), and people in the community without identified mental/emotional unwellness experience (n not exceeding 15).” This number was astronomically high for a three-month research period, but I chose this sample size to ensure reliability. The reasoning for this was twofold: first, the more participants I included in my study, the more likely I would be to reach data saturation to a level that the data would corroborate

itself; second, choosing a number much higher than expected would protect against having to submit revisions to the BU IRB which could cause delays during a short research window. My inclusion criteria were also extremely varied for the same reason. I did not want to limit myself in the number of possible participants, because I expected I would have a hard time recruiting otherwise.

My initial plan for recruitment was a mixture of word-of-mouth, flyering, and meeting people through participant observation. In actuality, almost all of my recruitment happened through Trang, who introduced me to members of her family support circle who would be willing to speak with me. She also introduced me to other individuals who are considered leaders amongst the Vietnamese families I worked with. One of these people is an affiliate of Boston City Hall and another acts as a translator for many Network events. Any other conversations I had with community members arose naturally through participant observation after Mass at St. Michael's and at different storefronts around the neighborhood.

I should make it clear that I only recorded one interview, with a person I knew before my research began. However, I made the decision not to use this interview, as the person had only lived in the area for one year and was not Vietnamese/Vietnamese-American. I could have made the argument that they fit the inclusion criteria, but felt that this would invalidate the data I had collected through interactions with individuals who more closely fit the study criteria. It is for these reasons that the majority of the data presented in this thesis comes from the informal conversations I had with people. These

were all people who knew about my research and fit my research criteria, but who were not comfortable being recorded or quoted.

Nevertheless, all of my notes and observations provided me with invaluable data for analysis. Of the people I spoke with, five are women and three are men, several of whom have children with special needs and are a part of the aforementioned parent support group. Everyone I spoke with is involved with The Network in some way, usually through connection with Trang. Most lived in or around Fields Corner and frequented the locations where I conducted my participant observation. Several people told me that they are from Vietnam and moved here within the last twenty years. Those who are members of the support group frequently cited “access to health care for their children” as a primary motive for moving to the United States.

### **Data Analysis Software**

Throughout the entire research process, spanning from Fall 2018 through the Spring of 2019, I have maintained a notebook of field jottings, which I type into field notes and keep in an encrypted file on a laptop computer which is in my possession most of the time. I have also voraciously read scholarly works, newspaper articles, theoretical books, ethnographies, and more in order to build up my background knowledge of mental illness, health seeking, anthropological theories and methods, and Vietnamese communities in the United States and abroad. The notes from this reading are also contained within the notebook with my field jottings.

In order to analyze my data, I type all of my notes from reading, my field notebook, my interviews, and discussions from the duration of my research. I then enter these documents into the NVivo coding system, along with articles and newspaper clippings relevant to my background research. The NVivo system allows me to select words, phrases, passages in the documents I upload and enter them into a code. The program then organizes the data into a web using the codes and subcodes I provide, showing the relationships between. Using this system, I identify codes and themes within my notes on my own thoughts, my observations, my interviews, etc. For example, using the codes and subsequent relationship web developed by NVivo from my data, I know that members of the parent circle I worked with are more likely to speak about the worries of other members of the parent circle or their own children, rather than their own worries.

### **Emergent Themes and Arguments**

My data and subsequent analysis show several themes developing from my research. These suggest that certain community institutions act as sources of support for members of the community and, therefore, wellbeing. Another common thread among my data is worrying, specifically worrying about children, as a proxy for worry about oneself. A third aspect of the data I gathered is that all the parents of this circle are fighting daily for their right and their child's right to live well. These themes led me to the development of an overall argument for this thesis, which is supported by the data I have gathered. In this thesis, I argue that social support networks, as materialized in this

circle, can act as sites of social change through advocacy. Parents advocate for their children's ability to flourish within major social institutions and in society. This particular network is a site where the "personal" and "institutional" intersect and, if only for the length of a meeting, exist on the same plane. This allows parents to act as vectors of consciousness to raise awareness for specific action. Within this context of advocacy and social awareness, parents are enabled to fight for their definition of a life worth living, the wellbeing of their children, as well as their personal wellbeing.

### **Concluding Thoughts**

As I became more involved with the Vietnamese community in Boston, as I became more familiar with the area, and as I came to understand the realities of conducting research within both of these contexts, my research question changed and shifted. The question I will answer throughout the rest of this thesis is: How do Vietnamese/Vietnamese-Americans in an established multi-generational community in Boston perceive and experience mental and emotional wellbeing, challenges to this wellbeing, and the pursuit of related care? I am confident in this question and its ability to accurately frame the findings of my research. Each of the three sections listed in this question – perception and experience of mental and emotional wellbeing, challenges to that wellbeing, and the related care – is important to understand a more holistic picture of wellbeing amongst the members of Trang's family support circle.



characters line the back wall above a counter topped with aluminum trays of steaming rice cakes. A chalkboard with remnants of scribbles from a class earlier in the day hangs on the wall by the entrance.

It is about 7:30 PM – the meeting has already lasted half an hour longer than it was supposed to and does not show signs of stopping soon. Outside, the sun has long since set and the glow of a nearby streetlight illuminates a corner of the window. Pens are poised above paper as the parent members of this Vietnamese family support group listen intently. A presenter from an autism advocacy organization in the Boston area, clad in a bright purple pantsuit, stands at the front of the room. As she clicks through each slide of her presentation, projected directly onto the wall from a small device sitting on the table, she explains the benefits and perils of MassHealth insurance, the Massachusetts State public health insurance plan. One half of each slide is written in English and the other in Vietnamese. A woman named Trang<sup>9</sup> translates the presenter’s words into Vietnamese for the benefit of the parents who are not English-proficient. When parents have questions or contributions, Trang translates back into English for the benefit of those who are not Vietnamese-proficient. This is the typical meeting format of the family support group I worked with for over a year in 2018 and 2019.

Trang Pham, the key informant and gatekeeper to my research, founded this group. After arriving in the United States and having her daughter, who is on the autism spectrum, Ms. Pham found herself in need of resources and support. According to Chi An

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<sup>9</sup> All names of people and locations, except for neighborhoods in Boston, have been altered to protect the identities of my informants and the institutions with which they are associated.

Nguyen, Trang's friend and frequent translator at the parent group meetings, after she gave birth to her daughter, many of the women Trang was friends with no longer wanted to associate with her "because her child did not act like theirs...because she was different" (Nguyen 2019). Through connections she made with other mothers of children with special needs, she was able to create this network. All of the families who participate in this group have children with physical, emotional, mental, and developmental disabilities, ranging from high to low levels of functioning.

During the time that I spent with this group at bi-monthly meetings and at community celebrations and gatherings, I saw no fewer than fifteen families represented by mothers, fathers, grandparents, and children. Since its inception, the group has touched the lives of over 200 families worldwide – many of the meetings and events are transmitted via Facebook to people around the country and in Vietnam. The network is best defined as a support group, created with the aim of providing parents with resources and information to develop their existing knowledge. This then gives parents the power to advocate for their child's right to a life worth living within various institutions – the medical institution, the educational system, and Vietnamese-American culture.

Each of the parents in this group has a full-time job in providing care to their children, much of which revolves around health needs. In this chapter, I will use analysis of literature and data to support my assertion that parents are an essential part of the healthcare team. I will begin with an analysis of the medical hierarchy and describe, briefly, several of the actors within that system. Next, I will provide a discussion of community health workers (CHWs) and their roles in patient care. I believe that Trang



herself acts as a community health worker for the parents of the group she has created. I will explain this connection using quotes from two interviews, conducted with Trang and Chi An. Finally, I will describe and support my reasons for asserting that parents are a part of the healthcare team and conclude with suggestions for further research and recommendations for those in power within the hierarchy.

Parents are the ones best prepared to care for their children because of the first-hand, intimate knowledge they have of their children, their personalities, their health history...everything. Raising a child with special needs is highly involved and, at times, exhausting. In cases where parents are not native English-speakers or are new to the United States, these stressors can be further exacerbated when parents come into contact with various institutions they have no previous experience with or knowledge of. From the special education system and Individualized Education Programs (IEPs) to the healthcare system and insurance, parents – all parents, not just those in the special circumstances described here – need all the support and information they can get. Support networks, like the one I worked with,<sup>10</sup> act to equip parents with the information they need to knowledgeably act as advocates for their children’s wellbeing and ability to flourish in daily life.

## **Networks of Support**

Each month, twice a month, this group of families meets. The topics may be different each meeting and families pick and choose which are most relevant to them.

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<sup>10</sup>I will use “The Network” as a formal pseudonym for this group.

Because of this attendance fluctuation, some families may not see each other for months, if topics are not relevant to them. Sometimes parents bring children; sometimes caregivers come with them. Typically, there is a guest presenter. When the group meets for events other than meetings, such as for a Têt celebration or for days in the park, faces that are new to me come out. One thing, however, remains constant – support.

The meeting described in the introduction to this chapter provides a vignette into the inner workings of the meeting, for parents. This aspect is strictly informational. The lectures are didactic and presenters often utilize PowerPoint presentations. If one does not arrive early or stay behind after the meetings, one may believe that these parents are only here for informational purposes. However, spending extra time allows one to realize the level of support and friendship the parent members of this group and their children experience through participation.

One unseasonably warm day in early spring, I arrived half an hour early to a Network meeting – far too early for anyone to have gathered yet. However, as I passed through the last set of double doors heading towards the meeting room, I noticed a small group of parents and children sat in the lobby area. Two of the children, one wearing thick glasses, the other a pair of large noise-cancelling headphones, huddled around a tablet. They intermittently poked the screen, responding to the prompts of whatever game they were playing. Sitting next to them, watching the kids out of the corner of her eye while talking to another member of the small group, was a young woman I recognized as an employee of the Community Health Center who often acted as caretaker for children while meetings were happening. I waved from across the room and gestured to the

meeting room, asking if it was open yet. She smiled, nodded, and stood up from her spot on the ground. I thought she was going to show me where the room was, but she turned away and headed outside. Several women were headed up the walkway, carrying trays of food and plastic-wrapped containers of water bottles. They greeted each other warmly and continued to transfer food and drink into the room.

As more and more people arrived, the atmosphere of the space began to seem almost jovial. Food and water were passed from person to person until everyone happily ate. As guest speakers arrived, piles of handouts and flyers gathered on the tables. Some people slid their stack of papers under plates to be used as temporary placemats, others scanned the documents, highlighting and writing in the margins, turning to others and pointing out interesting details. Parents, many of whom came straight from work, appeared weary as yawns circled the room. However, jokes and laughs followed closely behind. Newcomers exchanged hugs and handshakes with their friends as they made their way first to the food on the back counter and then to their seats. The sound of friendly conversations grew louder – with my limited Vietnamese understanding I picked up that most people were updating each other on their days at work. Eventually, the group began to form clusters of the people who were better acquainted than others. The seats around the table, some of which were saved for friends not yet arrived, filled quickly and the chatter died down as the presentation began (Bailey 2018, Field Notes).

This group is made of a collection of individuals in need of resources. Funk and Drew (2017) describe a support group as a “valuable service and resource that brings together people affected by a similar concern so they can explore solutions to overcome

shared challenges and feel supported by others who have had similar experiences and who may better understand each other's situation." The Network fits each aspect of this definition, even in the unique circumstance that each parent experiences. However, the unique experiences of these parents create a sort of shadow definition of a support group. For each surface-level facet of this traditional definition, one can find an even deeper, often more important detail pertaining to The Network and its members.

In the context of the Network, the "similar concern" that Funk and Drew define is the experience of raising a child with special needs. Even more specifically, raising a child while attempting to maintain cultural and social ties to the Vietnamese community in Boston and abroad. Blasi (1993) writes that "two aspects that make up a concrete identity, namely the specific contents around which one's sense of self is constructed ... and the modes in which identity is subjectively experienced." Therefore, the shared identity ("similar concern" of these parents) is defined by similar aspects of their lives. The challenges parents face are reflected in whatever the topic of that week's meeting may be. Some parents may face particular challenges with insurance or employment and so attend those meetings more frequently than meetings about special education. However, more than this, parents face systemic challenges that are reflected in the struggle to access resources. One example of this is the lack of language-specificity that exists within many institutional processes. In Boston, a city with a very visible Vietnamese population, one can find signs and flyers within governmental buildings written in that language. But this is not enough because often the specificity stops there as there are few Vietnamese-speaking employees to assist parents.

The two key phrases from Funk and Drew's original definition illuminates the ways in which The Network is more than just a place for information gathering and knowledge sharing. By focusing on the aspects of the group that *bring people together* in a way that allows for a greater *understanding* of each person's lived experience, one can see that this group is a source of support for all those involved. Chi An told me "They inspire and encourage each other. They get support from among themselves that they don't get from anywhere outside the group."

### **Information and Knowledge**

Throughout this thesis, I will develop discussions around the ideas of information and knowledge. The difference between information and knowledge is slight, but in the context of The Network it is fairly important because it differentiates between the tools the parent members of the group already possess and what tools they might be given by a presenter. It is important to make a clear distinction between these. Acknowledging that the parents have their own lived experiences relating to, for example, the care of their children or specific terms to use with physicians, also acknowledges that they have power. After all, the saying goes that knowledge *is* power.

Information is *factive*, based in fact, meaning that "if the report is true, the informational content is true too" (Israel and Perry 1990). This cut-and-dry definition suggests that there is little interaction between the "report" and the person receiving the report. For whatever reason, this information is taken to be true. Knowledge, similarly, deals with the interface between people and "informational content." However, the

distinct difference here is that knowledge is *relational*. Knowledge is based on sets of rules “rules by which one decides where to live, how kin are to be classified, how deference is to be expressed, etc.” (D’Andrade 1982). Similarly, Zagzebski (2017) writes that knowledge is dependent on a conscious understanding and relation to information. She writes: “On one side of the relation is a conscious subject, and on the other side is a portion of reality to which the knower is directly or indirectly related” (ibid.). This is why I argue that information can transform into knowledge when one begins to identify with it. In the case of parents in The Network, the information gained at meetings is transformed into knowledge through the social aspects of the group. As parents share information and personal knowledge with one another, the amount of knowledge shared by the group as a whole grows through the daily shared experience of raising a child with special needs.

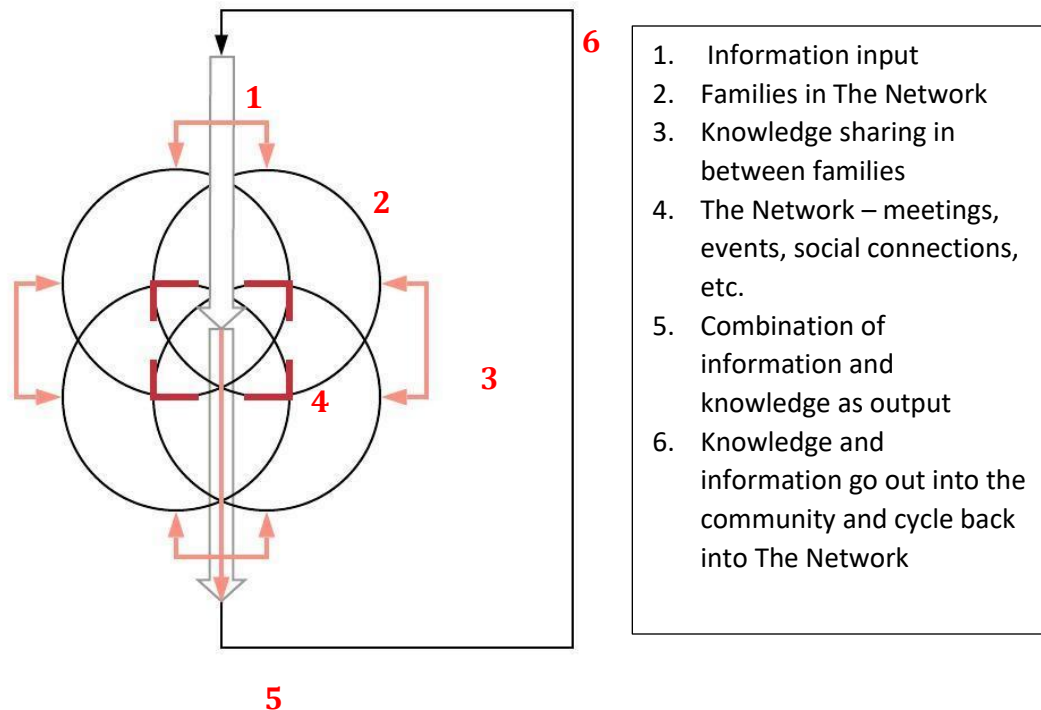


Figure 8: The cycle of information and knowledge into and out of The Network

(Bailey 2019)

As shown in Figure 8 above, information and knowledge cycle into and out of The Network in a nearly constant stream. Information comes into The Network through speakers and various presentations given at monthly meetings. These meetings are a space where families can come together, represented by the intersection of the overlapping circles, highlighted with the red dashes. Knowledge, represented by the light red arrows, resonates throughout the families of The Network as they come into contact with one another and share stories and lived experience. This information then, as discussed above, becomes knowledge. Information and knowledge, in the form of both storytelling and networking, then funnel out of the meetings through the parents' interactions with others outside this group. In some cases, this information continues on

into the world, only impacting the family members who attend meetings and their loved ones. In other cases, parents go out into the Greater Boston community, sharing the information they received at these meetings – not only sharing with other Vietnamese parents, but negotiating with representatives of various institutions. They become the recognized experts of their own story and are empowered to keep the cycle of information flowing.

### **Community Health Workers**

Community health workers (CHWs) represent a category of semi-professionals within the medical system who are able to provide assistance to patients on a unique level. CHWs are community members “trained to bridge the gap between health care providers and patients” (Kangovi, et al. 2015) so they are able to reach patients on a much deeper level than other medical professionals. These individuals serve as liaisons to the community, providing links to medical, school, and Vietnamese cultures (in the case of the CHWs who work in conjunction with The Network). Findley, et al. (2012) state that Community Health Workers are the people best equipped within the medical system to “break down barriers so that people can receive the healthcare services they need,” and, importantly, “assist them in benefitting fully from those services.” Members of this workforce in the United States have helped patients “navigate health and social service systems, helped address socioeconomic barriers such as homelessness, and promoted healthy behaviors, among other functions” (Kangovi, et al. 2015). Because of the role CHWs play as community members and vectors of institutional knowledge/information,



there is an opportunity to help people truly change their lives. Additionally, CHWs are technically not a “professionalized” group, and therefore are not constrained by the guidelines and standards medical professionals working in a hospital setting may be. This means that they are able to meet patients where they are – in their home, in a restaurant, or even on the street. Traditionally, this meant that CHWs acted in a grassroots capacity, rising from the need of the moment rather than through formal training. However, in recent decades, hospitals and clinics have selected and trained personnel from the community to act in this capacity, somewhat diminishing the original intent of the vocation. In cases where these individuals are chosen, trained, and returned to their community with newfound medical knowledge, the habitus and medical paradigm of the person may have been shifted. A person who once believed that an herbal tea or tiger balm would cure a cold or muscle ache might now suggest biomedical remedies as a replacement. To some, this may seem like a positive shift; to others it could represent the loss of an important, although unconscious, tie to heritage.

This shift in habitus, however, is not the case with members of The Network, which maintains vestiges of its grassroots beginnings. While some of the parents, including Trang herself, have received education and hold degrees in health-related fields, these individuals were not chosen by medical institutions to be cultural or community representatives. Rather, they chose to do this work because of their involvement in their children’s lives and their experience navigating a complex system with a unique situation. As Trang once told me, “You have to keep up with the changes of your [child] and keep up with learning as much as you can to be well equipped and

well informed. The process can be tiring and emotionally draining.... It is an ongoing learning process” (Pham 2019).

In the Spring of 2019, a collection of CHWs from Boston Medical Center and community health centers in the neighborhoods surrounding the hospital presented to the students of a medical anthropology course titled “Culture and Politics of Health Care Work”. They formed an informal panel, lining the front of the room, and told stories of the lives they impacted through their work and the challenges they have faced in their line of work. One of the most impactful stories was told by a young man who works with Latinx populations in the South End of Boston. He told us of a man who was suffering from alcoholism and was living on the streets. A physician would have looked at this man’s case, and potentially written it off as a lost cause because of the socioeconomic and structural factors driving this man to homelessness and to drink. The man was adamant against trying to “cure” his alcoholism, even though it was causing a whole host of other medical problems and was linked to the reasons why he had not been able to maintain a steady living situation in the past. The CHW explained that he was able to work with the man to get him into a more stable housing situation and work on getting care for his symptoms not related to alcohol use. After a while, the man came around to the idea of “getting sober” and eventually did so. Because he had the assistance of a Community Health Worker who was able to work with him long-term on a variety of issues, he was able to begin a larger recovery process in his life.

Many of the stories this class heard that day ran in a similar vein. A woman on the panel spoke about her experience interacting with a young child who came to the United

States without his parents and only spoke Arabic. As a native Arabic speaker herself, although from a different part of the world, she was able to communicate with the child, relate to him, and ease his nerves. This is one of the more important facets of what makes CHWs unique in the way they practice. Because they share some community tie – be it through language, culture, or neighborhood – with the people they serve, they are able to relate on a level that physicians or nurses or social workers in a hospital setting may not be able to.

### **Parents as a Part of the Medical Team**

Parents act as caretakers for their children with special needs in a variety of ways every day. Trang, my key informant, told me in an interview, “I cannot only be a mother, I have to be every kind of therapist, too” (Pham 2019). Trang is a mother, a lay therapist, and a CHW all rolled into one. Parents are intimately involved in every aspect of the day-to-day routine, even outside of regular jobs and caring for other children and family members. This routine many times involves the medical care of children where parents must interact with many medical professionals. Working with doctors and medical staff can be very difficult for parents in The Network, “sometimes due to the cultural difference and due to the lack of fully understanding all medical terms” (ibid.). This is a common experience among parents I have spoken with over the past year. While these parents may act as different kinds of therapists, as Trang says, they must also work with an interdisciplinary team and know the language and jargon used in various settings, like

clinics, schools, and social services as well. Such navigation is not easy, and there is a very steep learning curve.

While Trang has been working within these systems for years, this process can prove to be very intense, frustrating, and confusing for parents, especially if their child has been recently diagnosed or if they are unfamiliar with the systems within the US. In families with recent diagnoses of autism, one study found that many share feelings of “sadness, anger, depression, and disagreement” while others felt “relief and affirmation.” In some cases, there is a sense of “increased closeness and parental understanding following a diagnosis of a developmental disability” (Banach, et al. 2010). Because of these varied feelings, it is important for parents to have a support network.

Within Vietnamese communities, support is important because of the stigma that comes with a disability diagnosis and stereotyping by the larger United States population. Chi An identified two important factors for parents who join the group, that are related to this. First, “they [the parents] have each other. They inspire and encourage each other. They think ‘I see you at the meeting; I feel less alone’” (Nguyen 2019). For the parents in this support group, a large part of the support they receive from this group comes from the camaraderie they experience and the commiseration they share in with other parents. This bi-monthly safe space also allows parents the space to worry about and care for themselves and their own personal wellbeing. One study even asserts that because parents come together in this way, they are not only the most qualified to take care of their children, but they are the most qualified to care for one another (Kerr and McIntosh 2000). This in turn leads to better care for their loved ones. According to an article

published in the *Journal of Child and Family Studies*, parent wellbeing is directly related to child wellbeing (Cohen 2009). The wellbeing – mental, physical, social – of a parent correlates to the wellbeing of a child. Social connectedness or a “cognitive structure representing regularities in patterns of interpersonal relatedness” (Baldwin 1992), such as the kind found in support groups, can be a determining factor in increasing wellness.

The second factor Chi An identified is that the parents have increased visibility as a group that combats stereotypes. Chi An discussed the idea that people of Asian heritages are likely to go to impressive universities and work in academia – the perception of the “ideal immigrant.” Chi An states that “Because the group is now larger, they can work with institutions and big groups. It shows people that ‘This is our reality, too. Vietnamese people don’t just get into Harvard and MIT. We have children who are left behind, who are stuck, sick, and left behind” (Nguyen 2019). This visibility not only allows parents to combat the stereotypes placed on themselves and their children, but it also allows parents to network and connect with individuals with institutional power throughout Boston. In sharing ideas and networking, the parents are able to become advocates for their children and their right to a full and meaningful life.

### **Parents as Community Health Workers**

The Network itself functions as a community health organization that has a stake in its participants’ lives at multiple levels. However, it is also important to take note of the ways specific actors participate in this group. When asked to describe The Network, Trang said “This group supports one another emotionally and to share resources so that

we all can navigate the complex educational, social, medical, and recreational systems to access appropriate services for our loved ones” (Pham 2019). Moreover, “the group continues to raise awareness of disability within our own community so that our loved ones are accepted and fully included in the community” (ibid.). When asked to describe her role within the group, she stated:

I am the founder of the group, so it means a lot to me when I see more and more parents start to open up about having a child with disability and reach out for help. As the founder, you always listen to family stories and identify speakers who can come to share knowledge and information. I do this so that the rest of the parents can be more informed and advocate for their loved ones. At the same time, I need to build the capacity of parent leaders who can help me in supporting the other parents. The senior ones help the newer members and spread the word so that parents know that they are not alone (Pham 2019).

Within The Network, Trang acts as a community health worker. Findley and colleagues provide a definition of CHAs that mirror, almost directly, the quotes above. They write that CHAs work within a network of community “outreach, community education, informal counseling, social support, and advocacy” (2012). Additionally, “CHWs also build individual and community capacity by increasing health knowledge and self-sufficiency” (ibid.). Because of the work she does, in the way she does it, I argue that Trang, and the parent leaders she identified in her interview, are community health workers themselves. Even outside of the Vietnamese community, this small group

reaches out and works with many individuals and organizations throughout the Boston area. They work to disseminate much needed information to any parent in the community who may need it, with an end goal of advocacy and equity for children with special needs. Community Health Workers bring information into conversation with lived experience. This combination has power within systems where knowledge is a common currency.

The challenge here, however, is to not let this information overpower lived experience and the knowledge gained from first-hand experience. Some things cannot be taught in a training session. This is one of many reasons why The Network is so important for Vietnamese parents in the Boston area. Although information passed from institutional representatives (meeting presenters) can prove invaluable to parents, the knowledge shared between one another holds greater importance. These are the tips and solutions parents offer to one another when faced with the unique difficulties these families face. Frequently, at meetings and events, parents would exchange the name of a physician who was willing to work with them on a specific health concern; an aspect of the MassHealth website that could help expedite the arduous insurance application process; or the name of an advocate who had worked with them and helped in an IEP meeting.

### **Concluding Thoughts**

Parents are an essential part of the health care team and should be considered as such when discussing access to care for children with special needs. Because of the interactions parents have with their children, they know them best. Trang told me, “I

spend 24/7 with my daughter. I understand her better than a physician ever will because of that. She communicates with a communication device (smart pad) so it is hard for professionals to truly understand her in a fifteen-minute session” (Pham 2019). Parents have the most hands-on training from day-to-day care for their loved ones, which ought to be considered when assessing the degree to which parents are considered a part of the medical team. Additionally, support and resource groups, like The Network, arm parents with the knowledge they need to appropriately navigate various systems within the United States. In the following chapter, I will explore the ways in which this knowledge and system navigation can help parents advocate for their children’s right to flourishing in the medical system, in schools, and in their own community. Key elements of exchange of knowledge in this support group are sharing “worry” and developing skills to “access resources”.



**Chapter 5: “To Survive...You Have to Speak Their Language”: Wellbeing in the  
Context of a Support Network**



Figure 9: Red paper lanterns, a symbol of good luck for the New Year, hang on a streetlamp on the corner of Adams Street and Dorchester Avenue (Bailey 2019)

What is wellbeing? What does it mean in the context of a support network like the one Trang created? Is this any different from more general definitions of wellbeing? The “wellbeing” experienced by the members of this community is unique to the network in which it exists. At one time, I believed that this experience could be defined by the physical space of Fields Corner itself, but in fact it is a far more ephemeral entity, existing through those who participate in the Network. The wellbeing that grows in this context may be universal – one would be hard pressed to find a group for whom the wellbeing that comes from fellowship with others or caring for children holds no stock. However, I argue that a local sense of wellbeing and a related worry that permeates the experience of raising children with special needs is important to understanding the act of empowerment to advocacy that occurs within this organization.

In the United States, formal support groups have existed for over two centuries (White 2009) and information networks for as long as there has been information to share. For support networks like The Network, labels that were once used to stigmatize and alienate, can be strategic. Reclaiming words and labels, as the LGBTQ+ and anti-psychiatry movements have done, allows differently-abled people to in turn reclaim “disparaged identities and [restore] dignity and pride to difference” (Menzies, et al. 2013). Furthermore, they provide a method of organization which, in turn, gives individuals a reason to come together for a specific purpose. For example, this parent group utilizes several labels: parent, autism, Vietnamese. Without these three dimensions factors the group would not have formed. The language specificity of this group is something that its members have not seen before and is, many times, their reason for

joining this particular group. Two allies of the group told me during informal conversations that there are groups that provide culture-specific and language-specific resources for Vietnamese families throughout the country. However, they know of no other groups that provide language-specific information in a group created by and for Vietnamese parents that places as much of an emphasis on cultural inclusion as this one. Such groups do exist in places like San Jose, California, and Houston, Texas, where large populations of Vietnamese people have also settled. However, at some level, it does not matter within the context of The Network whether these do exist. For families in Boston, this group is *their* source of support and information.

Wellbeing within the context of the Vietnamese family network maintains a local definition as well. The parents who are part of this group share the lived experience of navigating the United States' special education system and the medical hierarchy, including medical insurance providers, in their own language, idioms, and cultural frame. Many of these parents do not have a strong English proficiency, something that is often seen across the Vietnamese-American population in the United States (Alperin and Batalova 2018), making it even more difficult to navigate these systems which operate within a medicolegal realm and utilize the associated jargon. It is difficult to separate local and universal meanings of wellbeing from one another when writing about a Network that is simultaneously insular and extensive. However, this distinction is important to further an understanding of the people who live there.

## Local Wellbeing and Story Telling

One warm Tuesday evening in August, I found myself walking through sliding glass double doors into the Community Health Center that stands on a main thoroughfare in Fields Corner. Trang had extended an invitation to me to attend a Network meeting that morning, letting me know that she had recruited a guest speaker to come talk to her parents.<sup>11</sup> In her email, she said “not sure if you are interested in learning about the history of disability and story telling. If yes...” (personal communication 2018) she continued by describing the location to me. It was a place that I knew from previous Network events and from daily life in the neighborhood. This place is central to many things that happen in Dorchester, from children’s karate classes in the old gymnasium to farmer’s markets in the warm months. I responded that I would see her there. Although Trang had extended this invitation for the first time many months earlier while I was an intern at The Coalition<sup>12</sup> where she worked, this was the first I was able to attend.

As the cool air washed over me, I took the stairs up to the reception desk sitting in the middle of the tiled lobby. The young woman sitting behind the desk provided directions to the room where the group would meet in a string of “left, right, left, left, through the doors, on the left” that felt rehearsed, as if it were the third time she had given them. At a certain point, probably around the second “left,” the directions became irrelevant – I was able to follow the sounds of children laughing and adults talking.

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<sup>11</sup> Trang often referred to the members of the Network as “my parents.”

<sup>12</sup> The Coalition is the de-identified name of an organization in New England that assists parents of children with special needs through the provision of resources and guidance.

The small room was filled with people, a few of whom I recognized from previous Network and community events, but many of whom were new to me. Several children played a small game of tag, darting around chairs and parents to tap one another on the shoulder, squealing with delight when they were no longer “it.” A short queue formed at the back counter where trays of steaming food were laid. I stepped inside and tried to find Trang. She was gathering papers into small stacks and handing them to the parents around her. Glancing up briefly, we made eye contact and she waved me into the room with a smile and an invitation to sit at the table, more literally than metaphorically. Another woman, seeing my exchange with Trang, waved to get my attention then pointed at the back counter – “Go get food!” she yelled over the din. I put my things down in a plastic chair in the back of the room, again hearing “go get food!” although I was not sure if it was directed at me this time. Either way, I made my way over to the trays. A child stood in line ahead of me, piling his plate with all kinds of food from the steaming trays. I said hello and asked him which of the dishes he recommended – I recognized spring rolls but had never seen the rest. He wordlessly pointed to a tray that held slices of something opaque white (steamed rice cakes, I learned).

After everyone was fed, the guest speaker arrived – a woman from Harvard University, Trang told me. While children left the room accompanied by older siblings and care assistants, the Network meeting began. Trang welcomed everyone and introduced the speaker. A woman sitting at the front of the table began to translate into English. She continued to translate for the rest of the night, from English into Vietnamese and back again to the benefit of all those present. While the purpose of the talk was to

illustrate how storytelling is a form of advocacy and can be a useful tool for parents, a large portion of it focused on the history of disability in the United States and continued up through the Disability Rights Movement and present day advocacy movements.

### *Disability in the United States*

The history of disability in the United States has often been fraught with misunderstanding and mistreatment, to put it lightly. Starting in the 1800s, individuals with various disabilities were marginalized and separated from the rest of the population in institutions “that simply warehoused disabled people” (Nielsen 2012) where they were largely forgotten and received little actual care or treatment. At the same time, the nation saw important milestones in the promotion of equity such as the development of schools for those with hearing and vision impairments. In *A Disability History of the United States*, Kim E. Nielsen writes “Throughout all of this [discussions over who is a “person” going on in the country at that time], people with disabilities sought to exercise their own educational, civil, and institutional leadership. Conversely, in contestations over who was fit to be present in the civic world, and who was not, people with disabilities found themselves increasingly regulated. Those considered not fit for public life were variably shut away, gawked at, and exoticized” (ibid.).

Throughout the early 1900s, researchers made advances in science and technology that aided people suffering from a variety of ailments, including physical and mental disabilities. Standards of sanitation increased as physicians and researchers developed and discovered new medicines, like penicillin. However, these advances were

often also made at the expense of those who were, at the time, still considered “subhuman,” as physical differences were assumed to be linked to mental ones (Nielsen 2012). Experimentation on and sterilization of young people with disabilities became common practice throughout the first half of the century, as a part of the eugenics movement.

With the rise of the Civil Rights and Feminist movements of the 1960s and ‘70s came a wave now known as the “Disability Rights Movement,” in which the voices of disabled individuals who had been advocating for their right to a life worth living finally seized the attention of political authorities. The next decades saw increased recognition of the role people with disabilities can play in American society, along with increased accommodations for those who use wheelchairs and have visual and auditory impairments. The first large legal shift in policy related to disability rights occurred with the 1973 Rehabilitation Act’s Section 504 “which banned discrimination on the basis of disability by recipients of federal funds” (Sims 2017). Several landmark Supreme Court cases followed this, fighting against discrimination toward people with disabilities in public, the workplace, and in many other facets of daily. These and many more were followed by several key pieces of legislation - the Education for Handicapped Children’s Act of 1975, now known as the Individuals with Disabilities Education Act (IDEA), and the Americans with Disabilities Act (ADA) of 1990. The ADA is the nation’s “first comprehensive civil rights law addressing the needs of people with disabilities, prohibiting discrimination in employment, public services, public accommodations, and telecommunications” (EEOC 2019).

Even within the context of the immense changes that have occurred within the United States' legislation and legal realms and the supports that are in place to care for children and adults with disabilities, the parents of the Vietnamese family support network still struggle. Key to this is the omnipresent shade of ethnocentrism which accompanies much policy in the United States. The policies and statutes created by Congress to ensure persons with disabilities the right to achieve their own life worth living only make a difference when people understand *how* to claim their rights and access services. The daily job of caring for and advocating for children is not easy given the high level of misinformation, half-truths, and opaque bureaucratic processes that are part and parcel of acting within the special education and medical systems. However, information the parent members of The Network gain, the fellowship they experience, and the knowledge they share during the bi-monthly meetings acts to moderate some of the stress they experience.

### *Storytelling as Advocacy*

After going through the history of disability in the United States, the presenter began to speak about the power of storytelling within the context of her life. To open this section, she intoned the words of Rudyard Kipling who once said, "if history were taught in the form of stories, it would never be forgotten." Within this frame, she explained the story of her own child, whose disability changed her life. She explained that her daughter was born with a hole in her heart as well as Downs Syndrome. From that moment, her life turned into one of advocacy for her child. This resonated with several of the parents



in attendance, one of whom said her child was born with the same conditions. People began to exchange pieces of their stories, through the aid of translation, and discuss the commonalities between their roles as parents and caregivers. Through this conversation, it became clear that the stories exchanged in these meetings came from a place of advocacy, but more importantly that all involved believed that in order to affect change these stories needed to be heard by political authorities. As Rosaldo writes, “the meanings carried by our words must thus depend not just on what we say, but who we are and what we hope our interlocutors to know” (1982). By sharing common stories, the parents articulate a vision of flourishing (Willen 2003), a necessary starting point for advocacy.

Within this discussion, several parents shared their stories of experience with MassHealth insurance -- the Massachusetts State public health insurance plan. One father was especially frustrated. Raising his hand, he said “This is all great, but what do we *do*? Because, as a group, schools do not implement our IEPs”<sup>13</sup> (Field Notes 2019). The speaker looked taken aback, and the father continued, “More than that, what about our insurance? Because when I call in to my company, they tell me I don’t qualify for any of the things you are telling me that I qualify for. They tell me my son can’t be on my insurance and that adding MassHealth as secondary<sup>14</sup> isn’t an option. Are they lying to

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<sup>13</sup> An IEP is an Individualized Education Program Plan (often referred to as just IEP) which acts as a directive for schools on how to best serve and teach each child with special needs that attends that school. Ask any parent of a child with special needs – IEPs are frustrating and very often are not carried out correctly unless parents can afford costly legal assistance or other legal advocates.

<sup>14</sup> Some parents are eligible to obtain a MassHealth insurance plan to supplement their private insurance that they get through work, as is the case for this father.

me?” After thinking for a minute, the presenter told the father to meet with her afterwards so that they could discuss his situation in more detail. Stories like the one the father presented are common at The Network’s meetings. Often, because parents do not speak the language, figuratively and literally, they have a difficult time navigating the complex systems required to access care for their children. It is a 24-hour job.

Within this space, empowerment toward advocacy does not work in a straight line. Much of the information given to parents by The Network arms parents with the knowledge they need, but the relationship is much more complex than that. As Chi An told me,

“What is the most important part for the parents is educating them about their *voice* and their *rights* and how the system *works*. You have to know the policies to know your rights, to know what is wrong...what you could have...how the school is supposed to treat your child...and how to know if the school is not doing their job. To survive, you have to know how to work with the system, the school, the providers just to get baseline services for your child. You have to speak their language” (Nguyen 2019).

She went on to further explain that the information The Network gives parents is only one piece of the puzzle. However, in conjunction with people like the Storytelling presenter, the MassHealth presenter, and even Chi An herself, parents are equipped to enter conversations with institutional entities and begin the process of advocacy. They become cultural brokers (Jezewski and Sotnik 2001, 2005) between the various cultural

spheres in which they travel – Vietnamese American culture, disability culture, and the culture of institutions they interact with daily.

## **Wellbeing and Worry**

Wellbeing can come in many forms – physical, mental, spiritual, et cetera. One can see a feeling of wellbeing or calm come across the face of a tired Network parent at a summertime event when their child sprints toward a friend they see. Although I became well acquainted with the parents at ease, more often than not I also saw furrowed brows, apprehensive looks, and slumped shoulders. The physical manifestations of worry were clear on the faces of many parents during meetings when difficult topics would arise -- IEPs or health insurance or the transition process<sup>15</sup>. The wellbeing and worry that parents experience is tied to information, knowledge, and empowerment. Information, the cut and dry facts that are provided at meetings, can help parents navigate systems with more literacy than before they came into contact with the group. While this can ease worry, it is when information becomes knowledge, which in turn empowers parents to action that one may see worry truly becoming wellness or wellbeing. The knowledge parents possess -- knowledge of their child, various systems, their own lived experience -- compounds the information they receive to build a solid foundation for potential advocacy.

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<sup>15</sup> “Transition” in special education jargon refers to the point at which students age out of the system. Typically this happens on a student’s 22nd birthday.

Although some may consider wellbeing and worry to exist on somewhat opposite ends of a spectrum, amongst the Network members I spoke with, one cannot exist without the other. The idioms of distress, which are understood as “a process which acts as a ‘prime mover’ in social change” (Parsons 1984), shared within this group are difficult to distinguish from the idioms of wellness. The latter is “a collection of physical, emotional and interpersonal... experiences labeled by the individual as optimal... and identified as important” (Arnault 2009). Through storytelling and the sharing of worry, one can find wellness. Within this paradigm, some forms of worry, such as worry for others, are encouraged over others. Below, I will explain the ways that information and knowledge, along with several other factors, exist on a spectrum. Throughout this discussion, it is important to consider that wellbeing and worry exist in a similar way. It may even act to increase moral wellbeing.

The difficulty in distinguishing between wellbeing and worry, in practice, within this Vietnamese family support group, may be explained by the concept of sacrifice or *hy sinh*. This entails a “moral expectation that persons anticipate and fulfill others’ needs and wants ‘intuitively,’ by sanguinely forgoing certain comforts and freedoms themselves for the sake of an intimate other” (Shohet 2013). A common worry, based in this expectation of moral conduct, expressed by members of this support network is that of worry for others, and more specifically worry over children. Extrapolating from this, then there are also acceptable forms of wellbeing that are based in the community and are based on

one's relationships with others. For example, when asked about their personal definition of wellbeing, each member of the family circle I spoke with began to tell me about someone else, typically a child. Perhaps this is because the parents' day-to-day lives are so enmeshed with that of their child. In a conversation with a woman who regularly translates during the Network meetings, when I asked about her definition of wellbeing, she began to explain things in terms of her friend's children:

*Well for the children, they have the Boys and Girls Club. We don't have to worry about them if they're there. But they grow up so fast and then go hang out in friends' basements while Mom is at work. ... You know, Mom might work at the nail salon down the street – ten- sometimes twelve-hour days. They don't get home until late, so what do the kids do? When the kids go there [BGC], they stay out of trouble. Their parents know where they are.*

Chi An identified two reasons why parents come to group meetings and stay involved with The Network, long term. First, “they [the parents] have each other. They inspire and encourage each other. They think ‘I see you at the meeting, I feel less alone’” (Nguyen 2019). For the parents in this support group, a large part of the support they receive from this group comes from the camaraderie they experience and the common worry they share with other parents. Chi An says that the support network and the events they put on are so important for parents because:

Parents worry about being in a public place with a child that embarrass them. Neighbors might curse at them when they realize they have a child

with special needs. Especially for the men, it affects their image. When people find out, they might not want to be friends with you. Don't want to be your in-laws or marry into your family. A lot of stigma; and it's very severe against people with special needs and their relatives (Nguyen 2019).

Coming together in this way allows them to gain valuable information so that they can take care of their children, without having to worry about the prying eyes of other people who may stigmatize, marginalize, or even ostracize them. This bi-monthly safe space also allows parents the space to worry about and care for themselves and their own personal wellbeing. One study even asserts that because parents come together in this way, they are not only the most qualified to take care of their children, but they are the most qualified to care for one another (Kerr and McIntosh 2000). This in turn leads to better care for their loved ones.

The second factor Chi An identified is that the parents have increased visibility as a group that combats stereotypes. Chi An discussed the idea that people of Asian heritages are likely to go to impressive universities and work in academia – the perception of the “model minority” (Ong 1996). Ong explains that this is “the general perception of them is as possessed of ‘can-do’ attitudes closer to the white ideal standards of American citizenship” (ibid.). Chi An states that “Because the group is now larger, they can work with institutions and big groups. It shows people that ‘This is our reality, too. Vietnamese people don’t just get into Harvard and MIT. We have children who are left behind, who are stuck, sick, and left behind’” (Nguyen 2019). This visibility not only allows parents to combat the stereotypes placed on themselves and their children; it

allows them to network and connect with individuals with varying levels of institutional power throughout Boston such as community liaisons from city hall, police chiefs from the Boston Police Department, and community coordinators from organizations like The Coalition<sup>16</sup>. In sharing ideas and networking, the parents are able to become advocates for their children and their right to a full and meaningful life. As advocates, these parents are empowered to be actors; they are “trying to make certain things happen, to bring about desirable endings, to search for possibilities that lead in hopeful directions” (Mattingly 1994).

In the Fields Corner Vietnamese community, but especially among those connected with Trang and her family group, wellbeing means supporting others for the betterment of others. As one mother once told me, “It is all about the children” (Field Notes, Bailey 2019). As Mattingly writes, spaces like the one created by The Network give members a space to “to *create sense* out of situations” (Mattingly 1994, emphasis added) that are difficult to understand on multiple levels. There is an implicit understanding that while you help others, someone will in turn be there to support you. Importantly, the family network gives parents an outlet to openly worry about themselves and care for their own needs. The social aspect of the bi-monthly meetings – the empathy the parents share and the compassion they show one another – is exceedingly important.

Meetings seem to act as a social space before acting as an informational space. Chi An mentioned this when she stated that parents like to know that they are not alone.

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<sup>16</sup> All of the “individuals with varying levels of institutional power” mentioned here were present at The Network’s *Tết* celebrations.

On a Tuesday evening in this back room of the Community Health Center in Dorchester, one does not simply see parents in need of information. This is a group of friends, who talk and laugh with one another throughout meetings, who share meals with one another, and take care of each other's children. Groups of mothers cluster together around the tables and whisper as speakers present. The guffaw of one father breaks the quiet as a young woman next to him says something amusing. Before and after the meetings and at events, it is honestly difficult to tell whose children are whose, even after spending around a year working with this group. The children who run around, playing tag, at the start of the meetings will run to several different adults to say hello before settling with their parents to leave the Community Health Center. This group is not just a site where people gather to commiserate or get information. The ties of fictive kinship present in this group allow the parents access to social capital they would not otherwise have (Ebaugh and Curry 2000) as migrants to the United States.

From an analysis of the interactions I observed between Network members, two distinct facets of this group emerge. The first involves the sharing of knowledge; the second involves the sharing of information. I believe that, as I wrote in Chapter 4, knowledge and information exist on a spectrum, and it is not easy to differentiate when or if one becomes the other. This spectrum is further complicated when one considers the outcomes of the sharing of knowledge and information, especially considering the people with whom one shares (see Figure 10 below for reference). Figure 8 in Chapter 4 shows the output of a combination of information and knowledge from The Network. Once this leaves the meeting space, individuals interact with other parents who may or may not be a



part of The Network as well as individuals who represent institutions – City Hall representatives, university professors, or special education teachers. On one end of the spectrum, one may see the sharing of knowledge, the formation of social bonds, and the process of storytelling. When individuals (parents in The Network) have knowledge of a certain aspect of life (working with special education teachers, for instance), they are able to share their personal story of interaction with that knowledge (think back to the father who shared his concern over schools not implementing IEPs). If the person with whom they share this knowledge also shares a similar experience, social bonding through the sharing of narrative capital (Beneduce 2015) occurs. On the other end of the spectrum, one may see the dissemination of information, the forming of networks, and the rise of advocacy. In a similar fashion to the interactions between knowledge, social bonding, and storytelling, the relationship between information, networking, and advocacy is as follows: a Network parent may share information they gain at a Network with a community liaison from City Hall; this liaison, who has connections within the local government, may either introduce this parent to others who can directly impact their situation, or work towards helping that parent themselves. Networking between community members and local government is where grassroots advocacy movements begin.

These factors exist on a spectrum because there is no set path for the creation of social bonds or the start of advocacy. Information may become knowledge, which disrupts the neat diagram I have provided below. Furthermore, when institutional representatives themselves have knowledge of issues that plague Network parents, they

may be empowered to take up advocacy on their own, effectively cutting out the “networking” included in this diagram.

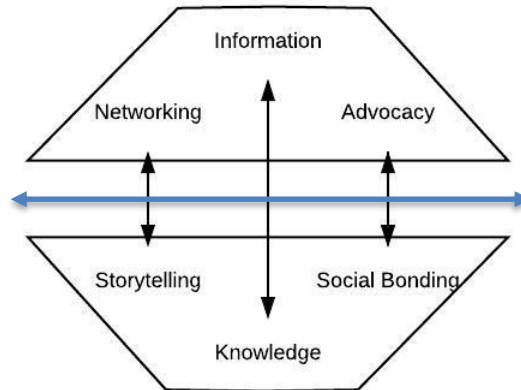


Figure 10: Networking and storytelling, information and knowledge, and advocacy and social bonding all exist on a spectrum.

The Network is a space for constructive, collective worry. The monthly meetings become a space of flourishing as parents “*create sense* out of situations” (Mattingly 1994) by locating themselves “within an intelligible story” (ibid.) that is meaningful to members and understandable to institutional figures. Some parents take the information they receive at meetings and channel it into positive action publicly by presenting at institutions and universities. Others channel this information and positivity into more private spaces, letting it impact their loved ones on a smaller scale. However, in both cases, parents are provided a space to exist in a way that would not otherwise be encouraged and a place to worry about oneself in a way that produces constructive outcomes. Through this act of advocacy through storytelling parents create purposeful personal wellbeing.

## **Surviving or Thriving**

Above, in the brief excerpt from one of my conversations with Chi An, she used the word “survive.” In order to *survive* one must learn how to navigate the system, play the game. But consider the differences between merely surviving and thriving. Additionally, keep in mind that the parents in The Network are keenly focused on promoting their child’s ability to not just thrive, but flourish. System literacy, something that The Network assists the parents in achieving at some level, is important. But in this statement, Chi An shows that it is only the tip of the iceberg. This then raises the question: at what point does surviving become thriving? At what point does thriving become flourishing?

I will explore these questions in the following chapter through a contrasting analysis of two Têt celebrations -- one for the larger Vietnamese American community throughout New England, and one specifically created by and for the parents of The Network and their children. I will address the questions above as well as discuss the importance of visibility within this group. Although it is important to maintain a level of visibility for advocacy purposes, in many ways the Network remains an invisible force for good within the community.

**Chapter 6: A Tale of Two Têts: Surviving versus Flourishing Within a Doubly  
Invisible Community**



Figure 11: A Lion Dance at a celebration of Têt, held in a local community center gymnasium (Bailey 2019)

I arrived at the Community Health Center in Dorchester a little before ten in the morning. From the outside, the building looked like many health centers in the city – grey and looming. It seemed out of place, surrounded by small businesses, a gas station across the street, and the three-story, wood-sided houses that are the norm throughout Boston. Above me, a red paper lantern hung from a light post, swinging in a cool breeze. Trang did not specify where volunteers should meet before the event, so I was not sure which way to go. I noticed a small group, dressed in their “Sunday Best” and followed them around the side of the building. I hoped we had the same destination. Inside a set of glass double-doors labeled “community center,” the crowd grew in size. I looked to my right and left and noted various corridors along the hallway with designations indicating that you could get financial assistance on one side and have your hearing and eyesight checked on the other. The signage was translated into English and Vietnamese.

Down the hallway, I found a gymnasium and a small group of Boston University undergraduate students waiting for instructions. As we milled about in the hallway, I peered through a door, propped open with a metal folding chair, and into the gym. There was nothing special about this room. The floor was the typical light brownish-yellow of a basketball court. Unlacquered plywood revealed spots where floorboards had come up due to frequent use. Basketball hoops lined the walls at regular

intervals. Clocks on the walls were enclosed in wire cages, presumably to protect against wayward basketballs. Presently, the room was filled with rows of young children clad in white karate uniforms, who followed the motions of the instructor in front of them. Once the class ended and the full team of volunteers had assembled, we entered the gym to await further instruction. We were all here for a Tết celebration, put on by Trang and The Network (Field Notes, Bailey 2018).

The Lunar New Year, called Tết Nguyên Đán (Tết for short), which takes place between mid-January and mid-February each year is an important festival on the Vietnamese calendar. This holiday is a celebration of prosperity and hope for the coming year and an opportunity to reflect on the past (McAllister 2012). This multifaceted holiday is sometimes described as having the gaiety and importance of the American/Western holidays, if they were held on one day. For example, Minh et al. describe it as “a celebration that combines the emotion of family members returning home, similar to the family gathering of the Thanksgiving holiday, plus the general frenzy of New Year’s Eve” mixed with “the hubbub and hype of Super Bowl Sunday” (2015). Hiebert writes that it is “something akin to Americans trying to compress Christmas, New Year’s, Thanksgiving, and everyone’s birthday into one giant holiday” (1996). Vietnamese people throughout the world consider it to be “the main occasion for families to reunite” (Malarney 2002).

In this chapter, I will compare a large Tết celebration in Dorchester with The Network's own smaller one. The contrast between the two reveals the ways Vietnamese parents of children with special needs in Fields Corner strive to live their lives to the fullest, even if it is in a quasi-secret way. It is important to remember that *survival*, a term Chi An used in a conversation quoted in Chapter 5, is not *flourishing*. Survival is barely making it. This raises the questions: How do parents go from surviving to thriving to flourishing? What is living, not just surviving? And how do these various small differences show up in the lives of Network parents? I argue that The Network, its events, and meetings promote parents' wellbeing in their ability to explore and enjoy their own culture and heritage. The camaraderie and social support that parents and families receive at these events fosters a feeling of community and a sense of belonging.

## **Hundreds of People**

Tables lined the large high school gymnasium, filled with food and wares from various vendors, at this Tết celebration in Dorchester. In the center of the room, tables and rows of chairs provided seating for those who wished to watch the performances taking place on the stage at the front of the room. Large, colorful banners stood on either side of the stage proclaiming, "Happy New Year 2018," both in English and Vietnamese. A man and a woman spoke into the microphone on stage, announcing the next event of the celebration. I had arrived late so several of the vendors

packed up their stalls as I walked around the room. Some of the still-occupied booths were not selling things at all – one displayed pictures of young women, competitors in the beauty pageant that was just announced. At another booth, one could purchase raffle tickets for everything from a two-night stay at a local hotel to a wedding dress, displayed on a mannequin nearby. And, of course, there were tables selling food and drink. I did not recognize most of the foods I saw – small bundles wrapped in banana leaves and balls of dough covered in sesame seeds – along with some that I did recognize like mooncakes, stamped with a fortune in red food ink, and various teas.

Ornately carved red and gold gates, reminiscent of the one standing at the entrance to Boston's Chinatown, stood sentry throughout the room. Festival goers took pictures underneath and around the gates. As I myself passed through the gates and continued to walk throughout the room, I came across booths offering experiences. One of them acted as a portable store-front for a Vietnamese Martial Arts center. Men and women dressed in martial arts uniforms with large swords stood out front, teaching children elaborate techniques. Grass huts that reminded me of the grass Hawaiian skirts children wear for Halloween stood along the far wall of the gymnasium. It appeared that their purpose was to be a place to take pictures with a pretty background.



On the stage, a woman dressed in a purple *áo dài* began to sing. Her voice was high and nasal, but beautiful. The audience watched with rapt attention making it clear that, although I could not understand her words, she was a wonderful storyteller. It was only until other people joined the woman on stage that I began to get a sense of what the song was about. At one point in the performance, the accompanying recording rang with gunfire and the performers scattered on the stage. The singer's voice was full of sorrow, standing in stark contrast to the laughter of children coming from game stations around the room. When the performers appeared again, they boarded a makeshift boat and sailed across the stage. I understood – this was the story of Vietnamese immigration to the United States (Field Notes, Bailey 2018).

The celebration described above is a yearly event put on by an organization simply called Tet in Boston. This organization has put on Tết celebrations for the Vietnamese population in New England for almost thirty years (personal communication 2018). Starting out as a small event for a collection of families throughout the city, it has grown in size to an attendance of several thousand every year. One informant told me that the event grows in popularity, and outgrows its venue, each year because Vietnamese and Asian Americans from all over the Northeast United States travel to Boston to attend (Field Notes, Bailey 2018). It is the largest celebration of its kind in the area and vendors and community members pull out all the stops to make it a grand event. I soon learned that each aspect of decoration at these events has a purpose and meaning based in ritual,

symbol, and tradition. I argue that these facets of the large celebration allow people to maintain cultural identities in a society that encourages acculturation and helps ethnic enclaves make places for themselves in well-established cities.

### *Symbols, Cultural Identity, and Placemaking in Boston*

Culture, as portrayed in symbols and rituals, is evident in the two field note excerpts above. Every aspect of these Tét celebrations represent important details in Vietnamese history, culture, and identity that are key to the establishment of place for Vietnamese Americans who live in Boston. Symbols, cultural identity, and placemaking are all facets of daily life that, while often taken for granted, are essential to living a full life. Culture, as defined by Ann Swidler, “consists of such symbolic vehicles of meaning, including beliefs, ritual practices, art forms, and ceremonies, as well as informal cultural practices such as language, gossip, stories, and rituals of daily life” (1986). Expression of these symbols amounts to cultural identity<sup>17</sup>, which in turn allows individuals to establish a place within a society. All of these, with the possible exclusion of gossip, were clear in my experiences at Lunar New Year celebrations.

Between the two years and four celebrations I attended, the structure of each was essentially the same. They each included some sort of pageant, food, and a lion dance. Many of the symbols were similar between events, as well. The animal representing that year of the lunar calendar (the pig in 2019, the dog in 2018) was present in cartoon and

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<sup>17</sup> Assuming a person’s cultural identity based on observation of the expression of symbols has the potential for stereotype. It is important to consider that not every person adheres to or identifies with the cultural practices of their heritage.

realistic forms as decoration throughout the events. Red, yellow, and gold – all colors representing luck and prosperity – decorate every surface available. The prescriptive nature of the event was ritualistic. Symbols, which are often part of rituals, are visual representations that either exemplify a culture's belief or history. The symbols that cultures embrace and utilize in various ritual events are the means through which people express "social processes of sharing modes of behavior and outlook within [a] community" (Swidler 2001).

## **In Secret**

During the Lion Dance, the men inside the red, yellow, and golden lion costume jumped and pranced around the old gymnasium. Children laughed and leapt back as the lion lunged toward them. The faces of parents lit up as their children fed yellow envelopes filled with wishes for the New Year into the open mouth of the beast. The lion moved from side to side, slowly inching around a semi-circle formed by awaiting children and parents.

At the end of the dance, Trang, Chi Anh, and several other now-familiar faces lined up at the front of the room, where a makeshift stage was fashioned out of a tarpaulin taped to the floor, lined with flowering trees and a large banner proclaiming Happy New Year in Vietnamese. Each person took turns speaking, some requiring translation into Vietnamese from Trang or Chi Anh. A person who I recognized as a

representative from city hall presented Trang with a certificate and a letter from the Mayor, proclaiming how her parents circle was an inspiration and an asset to the city of Boston and recognizing all of its members for their service to the community. Trang accepted the accolade with a nod and a smile, stepping up to shake the City Hall representative's hand and take a picture. She then handed the microphone to a man dressed in a floor-length blue robe and matching hat, both decorated with a beautiful design of golden swirls reminiscent of clouds. He opened his short speech with an excited *Chúc Mừng Năm Mới, Happy New Year*. He thanked everyone for attending and gave a brief overview of the activities for the rest of the afternoon - a fashion show for the kids, games, arts and crafts, and dancing. Standing on the opposite end of the hall, I did not hear the entirety of his speech as the sounds of children laughing drowned out much of what he said. However, as he concluded, the noise died down as he intoned, *This day is an important time to come together, not just as a community, but as a family* (Field Notes, Bailey 2019).

In the last weekend of February 2018, one week after my first Tết experience, Trang and her parent support group put on a special celebration for the children and families who are a part of the extended Network in the Boston area. This inclusive event provided games for children of all ages and abilities, face painting, balloon-animal-

making, a fashion show (the children themselves acted as the models), giving of lucky money (*li xi*), music, dancing, and so much more. In words of Chi An:

The Tét celebration is one of the highlights of the year. They [the event's planners] try to mobilize every resource to make the event touch the needs of each individual child while the parents don't have to do much. All they have to do is be there. I'm in it for the kids – it is the most important thing for them to be able to be involved and get to know their heritage.

Other researchers have suggested that social avoidance is common for Vietnamese parents and families of children with special needs, and that "...parents frequently avoided taking their children to public places to avoid unfriendly stares, rejection, and excessively sympathetic reactions" (Saenz et al. 2001). This event, then, acts not only to raise awareness of and destigmatize special needs within the Vietnamese community, but also give parents and children a place to practice their own traditions and celebrate holidays together with family.

The attendees at this smaller celebration were almost entirely comprised of families with young children. Some brought grandparents and even great-grandparents. The families tended to stay together, sitting at tables or following children around to the various activities set up around the gymnasium.

### *Multigenerational Families*

Within any household, there is some form of an economy which, at its most basic form, is a system of production and consumption. Actors within this micro-economy

may contribute to it through chores, growing food in a back garden, or providing an income to pay rent and other bills. Whatever the case, it is clear that the more individuals contributing to one household economy, the easier it may be for that household to thrive. While, traditionally, Vietnamese households were patriarchal, this was not what I came to understand about those I worked with in Fields Corner. The support group, which contained many of the people I informally interviewed, was filled with women who were the heads of their families. One non-support group member I shared this with seemed surprised, as it was not what they were used to. Others who were familiar with the group confirmed my finding. There is more to the household economies of Vietnamese families than purely production-driven motive, however. It also runs on a set of expectations and honorifics.<sup>18</sup> According to one study, this respect is “premised on a Confucian understanding of the...debt (on) children owe their parents (especially mothers)” (Shohet 2017) sometimes including repaying parents for a college education and taking care of them in old age. Reasons for this feeling of debt are cited as “giving birth to them and enduring hardship uncomplainingly to provide material care and support for them throughout life” (ibid.).

Because of the obligations a child has to contribute to the household economy, things change when a child is not able to contribute in a way that is considered normal or accepted by families and subvert the “ready-made standardized scheme of the cultural pattern” and bring into question the “unquestionable guide in all the situations which

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<sup>18</sup> Honorifics refer to names of respect given to individuals based on their relationship to you. For example, someone might call an older woman *chị* (meaning elder sister) or *bà* (meaning grandmother).

normally occur within the social world” (Schuetz 1970). This includes, but is not limited to, children who are mentally or physically not able to contribute to the household in traditional ways. I argue that this contributes to the stigma that impacts the members of the Dorchester Vietnamese community with disabilities, including those whose parents were a part of the support group.

### *The Importance of a Smaller Tet*

The two Tết celebrations are similar – they both utilize symbols and rituals that are based in cultural traditions and practices. They both encourage placemaking for Vietnamese individuals living in the Northeastern United States and promote a shared identity amongst all attendees. However, The Network’s iteration of this event is special. Because of the stigma discussed above, many Network parents do not feel welcome at the larger celebrations. Although it is never explicitly expressed that they are not welcome, parents worry that, because the event is not specifically created to accommodate children with disabilities, their children will not be able to participate. Participation is an important aspect of Tết as people are encouraged to join in the pageant at the large celebration and children in the fashion show at The Network celebration. Moreover, the sensory sensitivities that some children experience make it difficult for them to be in spaces with loud noises, many people, and limited space, all conditions of the larger celebration.

The smaller Tết is necessary for parents and children to express their cultural identities. Traditionally, Tết is a time to reflect on the past but also prepare for the

coming year. Because of this, it is such an important festival on the Vietnamese lunar calendar. In the smaller, inclusive celebration, The Network has created an alternative space for cultural expression. This is a time for families to be together, but also a way for people within the community to be seen as participating. The former is important for family bonding; the latter is necessary to establish oneself as a part of The Network's web of connections. This is an event for networking and making the connections discussed in Chapters 4 and 5 that promote advocacy and social connectivity. Finally, The Network's Tét allows parents to assert an alternate identity. One where they can be members of a community of similar parents and celebrate holidays with family – it provides an afternoon of normalcy in a life that is anything but.



## Chapter 7: Conclusion – In/Visibility and Medical Silence

### A Unique Group?

After explaining the research and subsequent ethnography that arose from its analysis, a question I am often asked is how is anything that I found unique to the Vietnamese community? In truth, it isn't. Families all over the globe struggle with the task of accessing healthcare for children with special needs. Expatriate communities form globally, and Vietnamese immigrants settled in many more places than just the United States. Language barriers, similarly, are not just barriers to healthcare for parents in Fields Corner. While the health systems in the United States are complex, they are in other areas of the world, as well.

The parents of The Network struggle at times with accessing care and adequate education for their children because of the many touchpoints they encounter in the processes. However, the fact that they are still able to is an enormous boon to their ability and their children's ability to flourish. Because of the structure of the American Health Care System, and the complex insurance that goes with it, people *are* able to access healthcare if they are taught to navigate the system. I think of stories, told to me by other researchers, of countries with only one psychiatric hospital. In these places, people with disabilities may be institutionalized alone with those with severe mental illnesses because it is the only place they can potentially receive treatment (personal communication 2018). In low-come countries, cost often proves to be the most prohibitive factor when accessing healthcare. In fact, "32-33% of non-disabled people are unable to afford health care

compared to 51-53% of people with disabilities” (WHO 2018) and that they are three times more likely, than their able-bodied counterparts, to be denied care completely.

Even though the findings presented in this thesis could be extrapolated to just about any group of parents caring for children with special needs throughout the world, these findings are unique and *important* because of the context in which they are found and because of the impact The Network has on people’s lives. There is something about the way this Vietnamese community exists in Boston that tears down barriers for these families. Vietnamese immigrants to the United States are less likely to seek higher education than other immigrant groups, overall (Alperin and Batalova 2018). Maybe there is something about being in a city like Boston, with its 35 universities, colleges, and community colleges (Lima, et al. 2011) that gives them access to important information? Is it that these parents are simply resilient? Is it that centers of education and research are more likely to have resources for parents like those in The Network? Does gentrification which prices families out of good neighborhoods and quality housing act to build barriers to care and education?

## **Future Research**

Due to the length of time I worked in the field – a mere three months of intensive field work and a little under a year of part-time field work – this study is limited in the scope of its analysis. Because of this, I believe that more research ought to be done within Vietnamese communities, within parent support networks, and with Vietnamese parents of and children with disabilities.

The questions I pose above ought to be considered in future research by medical anthropologists and public health researchers. What is it about this community, or Boston itself, that creates a space where these families can do so much advocacy work but still remain *doubly* invisible? Additionally, I recommend that researchers focus on the barriers to care within underserved communities, the Vietnamese community included. Although, in Boston, there are mobile outreach programs that attempt to provide in-community healthcare to the poorer areas of the city, Fields Corner and the Vietnamese American population there are consistently overlooked. Research on how and why this happens is essential to the future public health of this community. I would also suggest further study by medical anthropologists, specifically, on the structure and function of parent support groups and the ways they impact the community, at large.

## **Summary**

In this thesis, I have defended the argument that social support networks, as materialized in this circle, can act as sites of social change through advocacy. Parents advocate for their children's ability to flourish within major social institutions and in society. This particular network is a site where the "personal" and "institutional" intersect and, if only for the length of a meeting, exist on the same plane. This allows parents to act as vectors of consciousness to raise awareness for specific action. Within this context of advocacy and social awareness, parents are enabled to fight for their definition of a life worth living, the wellbeing of their children, as well as their personal wellbeing.

In Chapter 4, titled “I Cannot Only Be a Mother: Parents as a Part of the Health Care Team,” I introduced The Network, this community of parents all striving for a good life, and how its members navigate the complex systems relating to health and wellness for children with special needs in the United States. Through an analysis of literature, I explained how parents are an essential part of the health care team. I believe that Trang herself acts as a community health worker for the parents of the group she has created. I explained this connection using quotes from two interviews, conducted with Trang and Chi An.

In Chapter 5, titled “‘To Survive... You Have to Speak Their Language’: Wellbeing in the Context of a Support Network,” I covered how The Network supports and promotes wellbeing between members and throughout the larger Vietnamese community and the city of Boston. In this chapter, I presented an argument that a local sense of wellbeing and a related worry that permeates the experience of raising children is important to understanding the act of empowerment to advocacy that occurs within this organization. Through observations from Network meetings and discussions with community members, I showed how this network utilizes community resources to overcome struggles to support their personal wellness. This chapter includes a discussion of the theoretical definitions of wellness and resources and how telling one’s story may be the starting point of advocacy.

In Chapter 6, titled “A Tale of Two Têts: From Surviving to Flourishing Within a Doubly Invisible Community,” follows the story of two separate celebrations of the Vietnamese Lunar New Year, Têt, over two years. By comparing these two events, one

large and one small, analysis revealed the importance of maintaining cultural identities, which is especially meaningful for parents in The Network. This chapter explored how the concepts of ritual, symbolism, placemaking, and cultural identity play into definitions of surviving, thriving, and flourishing. I supported the argument that The Network and the events and meetings it puts on promotes parents' wellbeing in their ability to explore and enjoy their own culture and heritage. These events foster a feeling of support and a sense of belonging.

## **Closing**

In closing, I would like to address the title of this thesis. What does it mean to be in/visible? Additionally, how do the structures that exist act to medically silence the parents of this support group? The anonymity that comes with existing as an immigrant community in the United States is something that impacts the Vietnamese Americans living in Dorchester daily.

Demby and Northridge (2018) write that when “families are forced to live under unrelenting stress with respect to their immigration status” they avoid seeking medical care. These authors cite fear of interaction with staff of both public and private organizations for the avoidance. Because of this fear, families are silenced from participating in medical discourse. This extends past medical care and into more facets of daily life, including grocery shopping and going to work. In the fall of 2018, the current presidential administration released a statement “that Vietnamese immigrants who arrived in the United States before the establishment of diplomatic ties between the United States and Vietnam...are all eligible for deportation” (Dunst and Calamur 2018).

With news like this in the headlines of many major newspapers, people were afraid to leave their homes.

Stigma exists in the Vietnamese community surrounding both mental illness and disability. While the latter was thoroughly covered in Chapter 6, it is important to note that the reasons for stigma of visible disabilities are similar to those for less visible ones, such as some mental illnesses. The author of a study on mental health awareness writes that while “many Vietnamese Americans meet criteria for psychiatric disorders, only few seek treatment due to stigmas that mental illness is a sign of weakness or the result of karma due to past wrongdoings by one’s self or ancestors” (Bui 2017). When thinking of stigma, Chi An’s statement, quoted in Chapter 6, comes to mind. She told me “Parents have to deal with their image and don’t want to be in a public place with a child that might cause a scene – mess up their clothes, have outbursts, draw attention. There is a lot of stigma. It’s very severe against people with special needs and their relatives” (Nguyen 2019). These two factors together are what create “double invisibility” – invisibility from the outside looking in and from within their own community.

All of the aspects of membership in this family network that I discuss above lead to a person’s ability to flourish. Some are more general, such as knowledge, information, social support, and culture, and can apply to anyone’s ability to live their life to its fullest potential. Arguably every person utilizes knowledge and information to navigate life and achieve goals. This inherently comes with social ties and networks, formed from social bonding and information sharing. For The Network’s members, specific to the socio-politi-cultural context in which they live, the other factors come into play. Being a part of

the health care team is specific to the lives of parents who are profoundly involved in their child's health care. Especially in instances where guardians care for loved ones with special needs, the level of involvement is extreme because, in some cases, the child cannot fulfill the sick role of their diagnosis.

The ability to navigate systems, the healthcare system included, to the extent that one becomes a part of the team gives a sense of satisfaction to parents. As Trang said, the ability to effectively coordinate care for her daughter alleviates some stress because she knows each step of the process. While belonging to a culture is not specific to this group of parents – it can be argued that everyone belongs to at least one – the way this culture impacts their daily lives is what is important. As many of the parents in The Network were not born in the United States and many are recent transplants from Vietnam, ties to culture and others from similar backgrounds can be very important to their happiness and wellbeing. The Network provides parents an opportunity to make connections and friendships which fosters a sense of belonging in a new place. This belonging is tied inextricably to the concept of in/visibility. Parents are highly involved in a part of the community that tends to be forgotten, ignored, or outright shunned by the larger Boston and Vietnamese communities. Within their niche (special education, disability rights, Vietnamese Americans, etc.) they can have the social connections and interactions that are necessary to flourishing within any community. However, the larger community tends to render them invisible in ways discussed previously. The knowledge and information parents receive and share in meetings lead to advocacy for children in schools, the medical sphere, cultural experiences, and many other aspects of daily life. This advocacy

further gives parents a driving force for good in their lives. Although advocacy may seem unending, the parents of The Network do *good* for their children and others with disabilities, even if it is just on a local level. Large-scale change starts with small-scale action. This domino effect of positive action is a force for flourishing in the lives of many people, the parents in Fields Corner included.

Because of diagnoses that are stigmatized throughout the predominantly Western culture of the United States as well as more traditional values potentially held by smaller Vietnamese-American enclaves, parents of this group receive little visibility. Although this is the case, the parents are emboldened to advocate for themselves and for their children through the knowledge and information shared in Network meetings. They are emboldened to fight for their right to a life worth living – to thrive and flourish. Depending on the spheres they act in, they receive varying levels of conspicuousness. They are simultaneously visible and invisible.



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**CURRICULUM VITAE**

