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## CONVERSATIONS WITH THE COMMUNITY: AN ETHNOGRAPHY OF TWO CASE STUDIES HIGHLIGHTING COMMUNITY-RESEARCH PARTNERSHIPS IN SPRINGFIELD, MA

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CONVERSATIONS WITH THE COMMUNITY:  
AN ETHNOGRAPHY OF TWO CASE STUDIES HIGHLIGHTING  
COMMUNITY-RESEARCH PARTNERSHIPS IN SPRINGFIELD, MA

A Dissertation Presented

by

VANESSA ESTHER MARTINEZ-RENUNCIO

Submitted to the Graduate School of the  
University of Massachusetts Amherst in partial fulfillment  
of the requirement for the degree of

DOCTOR OF PHILOSOPHY

May 2014

Department of Anthropology

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Approved as to style and content by:

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Kathryn Tracy, Member

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Tom Leatherman, Department Chair  
Department of Anthropology

## **DEDICATION**

This Work is Dedicated to

My Great Grandmother

*America Alers vda de Velez*

(My Tata, who passed away before

seeing me graduate with my

doctorate)

## ACKNOWLEDGMENTS

There are many people to thank for making this dissertation possible. First, I would like to thank my parents, Linda Maria Martinez and Ramon Perfecto Martinez-Gonzalez, who shared with me a love of reading and learning, and who allowed me to ask A LOT of "Why?" questions as a young child. They were my first role models who taught me the importance of a good education. My parents saved to send my brother and me to private schools even when food was limited. Their sacrifice provided us with the necessary foundation to excel in education. When I have struggled, my mom has listened, given me advice, and taught me what it means to be a strong woman. Throughout this process, both my parents provided feedback on my dissertation chapters that has made this project even stronger. No tengo todas las palabras para expresar lo que tanto significa para mí. To my grandmother, Esther (Ita) Dorfman, who also played a part in encouraging me to do what I love, and love what I do. To my brother, Richard, who constantly calls me a civil rights activist because of all my work in anti-oppression training. And to my great grandmother, America Alers Vda. de Velez, who passed away in 2005 during my doctoral work, and whose absence has left a large hole in my life. Yo no habría llegado tan lejos sin el amor y apoyo de mi familia.

During the research phase of this process, I met a lot of local people from the Pioneer Valley who really encouraged my participation in community endeavors. I found myself struggling to ask for what I needed as a researcher because of the history of traditional research "using" the community without true collaboration. In 2012, Beth Spong, former Executive Director for MotherWoman, and a colleague from the Leadership Institute for Political and Public Impact (LIPPI) leadership training for

women, inspired me to ask for help on my dissertation and to share my professional accomplishments with others when she said to me "Remember, you are a role model. If you do not ask for help, and if you do not talk about your accomplishments, then you cannot get the support you need nor be a role model for those who come after you. It is not bragging, it is sharing your successes, and as women we need to do that more." I have never forgotten those words, and I continue to make them integral in my life. Thank you, Beth, and all my LIPPI sisters, for your kind words and encouragement to finish this dissertation.

After I started to ask for help interviewing local community organizers, I started to gain some clarity on my dissertation work. But it was not until meeting with my formal advisor, Dr. Jean Forward, and my friend/colleague/informal advisor, Dr. Tom Taaffe, that I really started to clarify my research question and feel a sense of direction. Tom helped me to create a working outline and push forward after being stuck, unable to write, for over two years. I cannot thank Tom enough for the guidance he provided me in developing a clear research question and dissertation outline to finally be able to start to write. I want to say thank you to my doctoral committee, Dr. Jean Forward, Dr. Krista Harper, and Dr. Kathryn Tracy, who supported me in this process. To my advisor, Dr. Jean Forward, who has always supported my work, my activism, and my teaching, I would like to say: You were critical to my finishing this work. Thank you for the hours spent together creating hard deadlines and giving me workable goals to meet. To Krista Harper: Thank you for your words of encouragement and I look forward to our future research collaborations. To Kathryn Tracy: Thank you for being part of my team, providing me detailed feedback, and challenging me academically throughout this

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ABSTRACT

CONVERSATIONS WITH THE COMMUNITY:  
AN ETHNOGRAPHY OF TWO CASE STUDIES HIGHLIGHTING  
COMMUNITY-RESEARCH PARTNERSHIPS IN SPRINGFIELD, MA

MAY 2014

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Directed by: Dr. Jean Forward

This dissertation is both qualitative and collaborative. It emphasizes the participant observation and ethnographic documentation of two community-researcher partnerships on community-level health interventions in Springfield, MA. Drawing upon critical theories and reflexive methods, I explore and analyze the process of building and sustaining researcher-community partnerships in an era of limited funding. Two Springfield, MA-based projects – one on healthy cooking/eating, and the other on contingency management – serve as case studies to provide a concrete picture of the complex relationships of researcher-community collaborations. I use ethnographic storytelling to provide a multi-dimensional look at two different community-research partnerships on health disparities work. I have chosen ethnography as my primary methodology because I am interested in gaining a broad understanding of Springfield as a post-industrial city – a city with both a complex support system of public health services and a community suffering from poor health outcomes. My dissertation explores the

following questions: What are the factors that contribute to successful community-research partnerships? What are the challenges to creating and sustaining good community-research collaborations? And what recommendations or strategies can build social and cultural capacity for these types of partnerships?

My experience on-the-ground highlighted a gap in the literature on community-research partnerships. I discuss the need for expanding the list of collaborators to include community college faculty and students, funding agents, and grassroots community leaders – not just service agencies standing in as representatives of the community. Given my personal and professional experience over the last twelve years, I believe that, in the end, successful community-research partnerships must build on the strengths already in the community in order to create a lasting impact in the community. For Springfield, that means bringing "everyone to the table," , in other words, a diverse group of people who all have a vested interest in improving the health of Springfield residents.

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## CHAPTER 1

### INTRODUCTION

#### *Privileged Health*

*In America, is health a basic human right? OR Do we believe it is right and just to allow human suffering?*

*Well, let us look at the facts.*

*Let's look at American history – at the American medical apartheid system.*

*Let's look at what racialized bodies were used most for medical experimentation before it was deemed unethical? Let's unearth the stories of forced sterilization to reduce the population of marginalized and perceived inferior communities.*

*Let's look at how we treat the homeless, the hungry, or the mentally ill. Rarely, do we ask what role we play in their personal struggles.*

*Let's remember the American nuclear family and the push for independence, both national and personal.*

*Let's look at the importance of money over people; profit before people...*

*Let's look at the way we talk about illness, that some illnesses are acts of God but others are preventable; and that those preventable illnesses are the responsibility of individuals; that society has no role in fixing the problems created by its people and by its laws.*

*And yet, there are some in their communities who do not believe these stories; there are some in their communities who know that there is something not quite right in the telling of American hierarchy as just and necessary.*

*These often unsung heroes of the everyday fight for equity and justice continue to scream about the injustice of allowing preventable human suffering to continue. These people, who are so rarely part of the dominant history, know there is something wrong with the dominant narrative of American liberty and justice for all.*

*For me, that day happened many years ago, during my adolescent years, visiting my grandmother in New York City, passing by the homeless people living on the street.*

*I was informed not to look, that it was disrespectful to look, that we could not help everyone and so to just walk by... but I could not just walk by, I wanted to stop, I wanted to ask, I wanted to help, I wanted to know why...*

*Why were they dirty, and sad, and hungry and begging? Why could I not help? Invite them home for dinner, give them a change of clothes?*

*I was so sad, I started to cry and even now as I remember this story, tears run down my cheek.*

*To this day, I am affected.*

*I often wonder if I am alone... It feels isolating to see the tragedies that are preventable...*

*And so I wonder why more people are not affected, why more people don't cry, don't help, don't scream, and don't seem to care... How is this possible?*

*It is not just to see suffering and do nothing? It is not just to hear pain and do nothing? And it is not enough to scream about injustice and still take no action?*

*It is not just bad choices or acts of God that cause sickness. That is what we are told but it is a lie.*

*Choices are made within the confines of social, cultural, political and economic boundaries that create illness and health disparities.*

*In the end, we must see that there is privilege in who has access to social resources. There is privilege in who gets thought of as worthy of help. There is privilege in health.*

*To overcome injustice, we will need a national shift in priorities, moving from military and national security to funding of education, housing programs, job development and basic health care for all.*

*We will need community members to continue leading their communities and working to change their circumstances.*

*Can we do this? Are we ready?*

*Do we, as a nation, care enough? I truly hope so.*

— My poem, a reflection of my academic and personal understanding of inequitable health. Dedicated to all the community collaborators I have worked with over the years.

Thank you for your knowledge and your compassion.

*"Of all the forms of inequality, injustice in health care is the most shocking and inhumane."*

*– Martin Luther King Jr.*

The United States healthcare system can only be described as a politically and economically stratified social institution. Based on a market economy, our healthcare system, operating largely on a for-profit basis, justifies policies that deny access to many in need of care, while continuing to be expensive and inefficient (Budrys 2001). The United States spends nearly a trillion dollars yearly diagnosing and treating diseases; however, hundreds of thousands of Americans die each year due to preventable causes, including substance abuse, HIV, and cardiovascular disease. While research clearly has linked prevention and early diagnosis to positive health outcomes for various diseases, the healthcare system continues to make minimal investment in preventative medicine. On Wednesday, December 10, 2008, Don Wright, the Principal Deputy Assistant Secretary for Health, made this exact point to the Committee on Health, Education, Labor and Pension of the United States Senate. Wright (2008) stated that "the vast majority of health care dollars are spent on direct medical care, despite the fact that clinical care is credited with only 5 out of the 30 years that were added to life expectancy."

Why then does the U.S. government invest in an expensive and reactive system of providing medicine primarily to those who can afford it when broad agreement exists among health professionals that preventative medicine reduces health care costs? Millions of Americans suffer from preventable chronic illnesses, yet a different allocation of governmental resources could prevent poor health outcomes, provide early diagnosis, and ensure uninterrupted treatment. It is still too early to determine whether the

Affordable Care Act signed into law by President Obama on March 23, 2010, and upheld by the Supreme Court on June 28, 2012, will provide the necessary redistribution of health resources to make significant change in our current healthcare system.

In the last thirty years, substantial research has documented health disparities, particularly due to ethno-racial and income disparities (Barnett et al. 2001; Craddock Lee 2006; Healthy People 2020; Ibrahim et al. 2003, Kawachi et al. 2005; LaVeist 2005). Health disparities, as defined by the National Institute of Health, are the "differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States" (Health Disparities Defined 2013). This research has been used to advocate for a national agenda to eliminate health disparities. Since 1997, the reduction of health disparities has become an American national project; in fact, social determinants of health are included as one of the ten leading health indicators identified by the federal government (Healthy People 2020). According to the Center for Disease Control & Prevention (2010),

social determinants of health (SDH) are the complex, integrated, and overlapping social structures and economic systems that include the social environment, physical environment, and health services; structural and societal factors that are responsible for most health inequities. SDH are shaped by the distribution of money, power and resources at global, national, and local levels, which are themselves influenced by policy choices.

As research on ethno-racial health disparities has increased over the last thirty years, scholars are beginning to unlock a broader understanding of health that includes the role

of social factors in determining individual health. For example, receiving differential access to health resources, like nutritional information and prevention screenings for historically-disadvantaged groups, has had a profound impact on individual ability to make healthy choices and ensure positive health outcomes. In order to "provide new insight into the source of racial disparities in medical treatment" (Malat 2006: 313), we must move from the traditional approach of quantitative methods, which focus on individual clinical care, to a qualitative research paradigm that emphasizes population and community outcomes, participant observation, in-depth interviews and ethnographic documentation.

Through various health initiatives, the U.S. government has officially acknowledged that there are real differences in the health of different socially defined groups in America. Those groups who are disproportionately represented in high mortality and morbidity rates tend to be the poor and people of color (Healthy People 2020). *Healthy People 2020* is an expansion of previous health research initiatives, including the 1999 Institute of Medicine Report and *Healthy People 2010*, among others. This work has shaped national health priorities and has served as a basis for numerous state and community health care plans. Healthy People 2020's main goals include working to achieve health equity, eliminate health disparities, and empower individuals to take action in their own communities (Healthy People 2020). And yet, I argue that the strides made in health care coverage and health outcomes are not enough. Research from 2001 and 2007 data collected on American bankruptcies found "that illness and medical bills play an important role in a large and growing proportion of bankruptcies" (Himmelstein et al. 2009: 745). This research is particularly disturbing because the

demographic information indicates that most medical debtors were well-educated, middle class, and three quarters had some form of health insurance. Also between 2001 and 2007, "the share of bankruptcies attributable to medical problems rose by 50%" (Himmelstein et al. 2009: 744).

The impact of this research is multilayered. First, it shows the difficulties of the middle class to adequately survive with health problems. This provides a larger population of suffering Americans, including the middle class. Second, this research speaks to embedded strength of the bootstrap myth of individual responsibility and its contribution to medical impoverishment in the United States. Ironically, this mentality is almost unheard of in other high- and middle-income nations, who provide a greater national safety net for their citizens (Himmelstein et al. 2009). And third, this research lends support to the idea, as Himmelstein and colleagues suggest, that universal health care would benefit the majority of Americans, including those who identify as middle class, as well as the poor and underinsured.

On the ground, we remain hard-pressed to see the improvements in our local communities. To affect quality of care and improve outcomes at the community level, we must first start with a cultural paradigm shift that guarantees quality health care to every person in the U.S. regardless of their current health status, experience of being socially marginalized, and ability to pay. Without a broader, more complex definition of health that includes access to public transportation, basic housing, healthy food, green spaces, and other social determinants of health, the U.S. populace will continue to suffer under the limited policy initiatives currently in place.

My research has encompassed a breadth of issues, ranging from an analysis of localized collaborations on racial health disparities, to a systemic analysis of the structural conditions that regulate local, state and federal health policy decisions. Specifically, this dissertation provides an institutional, race-based analysis of the larger U.S. medical system, along with an account of a locally-relevant and community-supported ethnographic conversation about health intervention programs in Springfield, Massachusetts. Both qualitative and collaborative, my dissertation emphasizes participant observation and ethnographic documentation of community health experiences. I worked to ensure that my research addressed community needs while meeting the criteria for my doctoral program. I have been unwilling to work on a project that focused solely on knowledge-production without an immediate application in the social world. I did initial research on methodologies, models and theories to assist me in building my research project. When I came across community-based participatory action research (CBPAR) in my preliminary work, I realized that this methodology was in line with my goals; CBPAR requires research to be participatory, action-oriented and relevant outside of scientific discovery (Trotter & Schensul 1998).

CBPAR has garnered significant academic interest in recent years within public health and the social sciences. CBPAR involves the commitment by all involved to participate in joint collaboration throughout the project study and to develop an action plan for social change. This methodology is locally-specific (Trotter & Schensul 1998), requires flexibility in design as well as sensitivity to community and research needs. It provides a framework for addressing various communication needs of participants and ideally allows a more equitable division of power and resources. With time and resource

constraints, CBPAR is a more difficult research agenda to follow than conventional research given the need for transparency and collaboration in decision-making.

Participation by community and research stakeholders in the creation and implementation of health interventions encourages critical praxis studies on the role of power and privilege in medicine, in this case specifically in understanding racial health disparities.

In the last decade, medical and social science research has garnered support for innovative strategies to study and address the institutionalized effect on the physical body of social class, racism and White privilege (Acevedo-Garcia 2000; Bell et al. 2006; Borrell et al. 2006; Brondolo et al. 2008; David and Collins 2007; Fedigan 2002; Grady 2006; Jones 2000; Krieger 2003; Krieger 2005; Krieger et al. 2011; Lu and Halfon 2003; Smedley et al. 2002, Williams and Mohammed 2009). Adding to the current research on health disparities and CBPAR, this dissertation explores the challenges experienced by researchers and community members in creating culturally-competent health programs. Given that my community work is located in Springfield, Massachusetts, a racially-mixed city, I also explore the impact of institutionalized racism, classism, and color-income privilege on community health intervention projects.

I began my dissertation research by reaching out to health care professionals and community organizers in Western Massachusetts. Originally, I wanted to use ethnographic research methods to assess Latino client experiences with a diabetes management program at a community health clinic in Western Massachusetts. I was particularly interested in facilitating a dialogue between health care professionals and clients where they could share their successes and challenges. As I developed contacts within the Holyoke and Springfield communities, I was approached by community

members and asked to participate in two other health intervention programs: a health disparities roundtable forum, a healthy eating community program, and a new substance abuse harm reduction/recovery pilot program.

While working in Springfield, I began to question if a truly collaborative research model would be feasible for dissertation research. I found myself questioning the process of conducting participatory action research (PAR) in urban communities of color. Given my experiences with community engaged research, I decided to shift my research focus away from a programmatic evaluation of community health programs, and toward a critical ethnographic dialogue of the process of doing PAR. I was interested in investigating how PAR could serve as a framework for the creation and implementation of sustainable and culturally-relevant community health interventions. This research is informed by many years of personal interactions with community activists. Data was gathered and collected over a variety of mediums in the last six years while working as a full-time, tenure-track professor at Holyoke Community College. During this time, I have worked with a number of community activists, participated in trainings, meetings and planning sessions, and have conducted formal and informal interviews.

Both the health disparities roundtable and the substance abuse harm reduction pilot program serve as case studies in addressing my main research question: What is the efficacy of CBPAR as a research methodology for the creation and implementation of sustainable and culturally-relevant community health interventions?

My fieldwork in Springfield, Massachusetts, revealed a gap in the knowledge production and financial resources available in the community. I was informed by many community members that gatekeepers existed who limited the medical information and

program development available in Springfield. I was intrigued; it reminded me of Laura Nader's article "Up the Anthropologist – Perspectives Gained from Studying Up" (1969). Nader's controversial article was one of the first to call for anthropologists to study power and privilege instead of focusing on the less powerful members of different societies. She presented three reasons for the need to "study up" that I still believe hold true today. The first is anger at injustice, which can be a strong motivator for systemic change. The second is the need for scientific equity since only studying the less powerful members of society does not provide a complete picture of community and world issues. This concept is critical to my discussion surrounding Springfield "gatekeepers," those members of Springfield that hold most, if not all, of its symbolic, financial and material resources. The third is democratic relevance, which speaks to the value of the research for the better performance of individuals in society, not just scientific inquiry. Nader's framework provided the necessary questions with which to investigate the informal and formal support structures available for community-researcher health intervention programs. Her argument for a study of power provides the anthropological foundation for the critical theories I have chosen to inform my work: Critical Race Theory and Critical Medical Anthropology. Augmenting Nader's argument for an analysis of power, these critical theories explore the intersectionality of social identities and health outcomes. Combining critical theories with participatory research methods ensures that complex questions regarding community-research collaboration are pursued in multiple avenues.

## **Capitalizing on Illness**

*"We also need to say we recognize that because of inequity  
in our society, not all needs are equal"*

*– Nancy Krieger, Epidemiologist)*

As the only industrial nation where health care is a product that is commodified, the United States "ensures that large numbers of people...will be simultaneously put at risk for disease and denied access to care" (Farmer 1999: 12). And yet health interventions consistently focus on individual behavioral changes, and rarely address structural inequalities in health. Focusing on behavioral modification provides only a narrow lens with which to view inequity in population health. It assumes that individuals are completely responsible for their individual health, and ignores the social determinants of health. Larger community control over health interventions might better address structural inequities at the local level. In fact, it is community members themselves who can best identify their own needs and create culturally relevant programs to resolve their health issues. I advocate for a process by which researchers and health professionals act as mentors and support for any local health interventions within a culturally diverse community.

The U.S. healthcare system functions as a business, not a basic human right, and what ensues is unequal access to services and differential health risks/privileges for the subordinate and dominant groups. Understanding how capitalism and colonization have created a system of racial and economic dominance within American institutions,

including the healthcare system, is crucial to understanding the barriers to people of color's access to resources, and the disproportionately positive health outcomes for Whites. This history must be understood in order to investigate and alleviate the social determinants of health. If capitalism is founded on the principle that profit is good and should always increase, then social inequality is inevitable, and some people will receive more than others. Given this perspective, we see that "patterns of [social] inequality result from and perpetuate a class system based on widening gaps in income, wealth and power between those on top and everyone below them" (Johnson 2006: 45). Throughout American colonial history, capitalists used White racism explicitly as a strategy to ally White working people with White elites; therefore, any possible class alliances between lower class Whites and people of color are suppressed in favor of alliances based on race. Poor Whites were not given a better living wage; instead, they were provided with a psychological wage of Whiteness, which created and reinforced a system of superiority based on skin color. This system allowed Whites to justify atrocities they had inflicted on people of color (Buck 2001; Olson 2004; Lipsitz 2006). Even to this day, power is maintained as White privilege by limiting access to education, political representation, job opportunities, and even health care for people of color.

As a social institution, the American healthcare system continues to show a conflicted attitude toward racial health disparities. Some researchers still link racial disparities as distinctions born out of innate cultural differences. Instead, given the complexities of social identity and new research on the social determinants of health, those who conduct research should consider gender, race, and class as the main social axes that render individuals and groups vulnerable to extreme human suffering. Paul

Farmer has described this human suffering as occurring through what he calls *structural violence*. Structural violence includes extreme and relative poverty, as well as social oppression, ranging from racism to gender inequalities (Farmer 2004; Farmer 2005). Central to his concept of structural violence is the idea that poverty is the underlying factor that determines power relationships and social connections. Farmer goes on to suggest that such social factors are differentially weighted in different settings and in different times (Farmer 2005: 42). In the contemporary United States, the institutional basis of structural violence operates within a historically-embedded hierarchy of racial dominance. Paul Farmer's critical analysis of structural violence offers compelling evidence for the need to redistribute global resources based on human need, not private profit. His work provides a foundation for current, and future, socio-political policies to dismantle the dynamic class-, gender-, and race-based human rights violations worldwide.

The United States government legally sanctioned White supremacy with policies like Native American land removal, Black slavery, and anti-miscegenation laws; however, in 1964, the last vestiges of state-sanctioned legal White privilege ended with the passage of the Civil Rights Act, leaving behind a legacy of de facto practices built into the social structures. From the 1960's to the present, social indicators like infant mortality rates and infectious rates for AIDS and tuberculosis (among others) continue to show strong advantages for Whites, and disadvantages for people of color (Olson 2004). While laws have been created to stop individual racist discriminatory practices, institutionalized racism continues to be masked as a purely economic problem. For this

reason, a class analysis alone is limited, as it ignores the interactions of other socially-constructed categories that impact individual and population outcomes.

Several research studies have connected the role of racial stereotyping by Whites to poor health outcomes for populations of color (Lee & Farrell 2006; Burgess, Fu & van Ryn 2004; Burgess et al. 2007; Lipsitz 2011; Van Ryn & Burke 2000; van Ryn & Fu 2003). Given this research, we can argue that the perception of health status is affected by non-medical factors like race, and can, thereby, contribute to variations in medical care. The power to determine medical treatment remains in the hands of people greatly affected by perceived racial differences (Burgess et al. 2007; Hartigan Jr. 2010; Hunt et al. 2013; Page & Thomas 1994; van Ryn et al. 2006). A structural framework that analyzes the functions of power, privilege, and individual agency in the Western medical system is therefore critical in the elimination of racial health disparities (Buck 2001; David & Collins 2007; Farmer 2004; Farmer 2005; Jones 2000; Jones 2003).

It is clear we need a more comprehensive and intersectional analysis of health care outcomes to acknowledge the experiences of people of color. Two very important studies that address how race is a determining factor in who receives access to quality healthcare include the Institute of Medicine's 2002 study titled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* and the 2012 *National Healthcare Disparities Report*. People of color receive less access to preventative and curative services, and thereby receive a lower standard of care. Both reports state that, when controlling for other social factors, race *does* play a significant role in differential access to healthcare. This research suggests that systematic change implemented at the

national level, yet controlled at the local level, is needed before the health of populations of color can ever really improve.

By analyzing the way a class-bias influences perspectives of social inequality and healthcare, we can work towards establishing an assessment of the inequities of the US healthcare system that properly accounts for the influence of race. As we have seen, the healthcare system perpetuates inequality by having health care services constrained within a capitalistic structure. It is assumed that those who cannot afford healthcare, which is treated as a commodity, should not expect to receive it; however, this assumption continues to disguise other social factors that play into the inequities arising from the bureaucratic healthcare system structure. The discriminatory effects of racism in the US have been well-established, but the focus on race often is reduced to a focus on class. Our society masks how class is structured by race, and how race and class work in tandem to structure different population's access to quality healthcare (Gravlee 2009; Jones 2000; Kreiger 2003; Krieger et al. 2011; Smedley et al. 2003; 2012 National Healthcare Disparities Report).

Race and racism arguably continue to be relatively neglected research subjects among medical anthropologists and medical researchers. This is borne out in Clarence Gravlee and Elizabeth Sweet's review of the relative inattention given to race, racism, and ethnicity in medical and anthropological research journals. In their content analysis of a random sampling of empirical research articles from 1977 to 2002, Gravlee and Sweets, while acknowledging the skills that medical anthropologists could bring to the discussion of racial disparities, found that race was not a significant component in the research being done by medical anthropologists. This could be the result of a perspective

that holds that, because race has overwhelmingly been discredited as a biological concept, researchers should shelve it as "beyond the scope" of their social scientific work. Yet such perspectives discount race understood as a social fact that is in line with people's lived experiences. Therefore, ignoring "race" as a social fact does nothing to get rid of racism and White privilege. As Justice Blackmun stated in the Regents of the University of California v. Bakke 1978 affirmative action case, "In order to get beyond racism, we must first take account of race. There is no other way. And in order to treat some persons equally, we must treat them differently. We cannot – we dare not – let the Equal Protection Clause perpetuate racial supremacy" (1979: 407). Gravlee and Sweet cite the potential for medical anthropologists to add to interdisciplinary research on racial health disparities. My dissertation addresses some of Gravlee and Sweets' research recommendations by using ethnography as a qualitative methodology to foster and enhance community-university research partnerships, and to highlight how socio-cultural processes generate inequality in health.

Discussions of racial health disparities are incomplete without addressing the various social factors that constrain individual choices regarding health decisions. These social determinants of health—including the effects of education, poverty, sexism, job opportunities, and access to health resources—are critical to promoting health and limiting disease. While researchers debate the most important factor affecting life expectancy, most agree that better wages, housing, job security and working conditions, civil rights laws, sanitation, and other protections that enlarged the middle class were central to expanding average American life expectancy (McKinlay & McKinlay 1977; Arno et al. 2011). And yet, funding for social programs continues to be cut year after

year. Within a political climate of limited funding, it has become more crucial to study the social determinants of health as evidence upon which health strategies for improved population health can be based. This research on social determinants of health provides us with a more comprehensive picture of health in America.

### **Organizing the Dissertation**

*"Every decision within the research process acts as a site for ethical decision making and an enactment of the world we wish to inhabit."*

*– Abby Templar, AAG abstract 2011*

This dissertation is a critical ethnographic monograph that analyzes the effectiveness of using community-based participatory action research (CBPAR) as a research methodology for the creation and implementation of sustainable and culturally-relevant community health interventions. By using critical theories and reflective methods, I explore and analyze the process of creating and sustaining community health programs from the perspective of the different stakeholders involved. I conceptually link my personal experiences explicitly to theory and propose a blending of anthropological research methods. My use of ethnography places narrative in social context. Ethnography, I argue, is a useful way of exploring the complexity of using CBPAR to intervene on health initiatives at the community level. I evaluate my experiences by compiling emails, meeting notes, personal notes, field notes, and records of interviews with community members. My various social statuses place me in a unique position to

discuss how structural and institutional factors privilege some personal narratives over others.

This dissertation is divided into six chapters. This chapter introduces my research project and highlights my research questions. Starting with Chapter Two, every chapter is framed and paired with research stories to provide a concrete picture of the complex relationships of research-community collaborations. In Chapter Two, I present the main theories and methods that frame my research questions on CBPAR, researcher-community health interventions, and health disparities. This review of literature on CBPAR and health disparities provides a context for the following chapters, in which the focus shifts to my ethnographic fieldwork on the healthy eating and substance abuse intervention pilot programs in Springfield. Chapter Three introduces Springfield, Massachusetts, as a multi-racial space blending together issues relevant to urban spaces with complex health disparity problems and community programs. Chapters Four and Chapter Five use ethnographic storytelling to provide a multi-dimensional look at community-research partnerships on health disparities work. In Chapter Four, I explore my community-research partnerships with Jamilah Ali Alexander on the creation of a substance abuse community health intervention. Chapter Five tells the snapshot story of Universal Community Voices Eliminating Disparities effort and our collaboration on a healthy eating initiative in Springfield. Chapter Six offers an analysis of the similarities and differences in resource allocation between the healthy eating program and the substance abuse intervention. This concluding chapter also provides a framework for building and sustaining research-community partnerships in community health interventions.

## CHAPTER 2

### WHO AM I? WHY AM I HERE? WHAT AM I DOING? THEORETICAL AND METHODOLOGICAL APPLICATIONS TO MY RESEARCH

*"Knowing is not enough; we must apply.*

*Willing is not enough; we must do."*

—*Goethe*

#### **Introduction**

This chapter of my dissertation describes the interdisciplinary theories and mixed methodologies used to ground my research in self-reflection, community advocacy, and social justice. The central concern of this chapter is to explore how theoretical choices and research methods are informed by a researcher's social identity, life experiences, and academic background. Relevant to this concern is the fact that I come from a background where I am both privileged and subordinated in different settings, and, at the heart of everything I do, resides a strong desire to advocate for equity. I find I must constantly reflect on positionality in my research, and this has strongly impacted the way the research has taken shape.

#### **Research Story/Vignette 1: Who are you and why do you care?**

Early on in our researcher-collaborator relationship, one of my collaborators, Betty Agin, asked me why I was a part of Universal Community Voices Eliminating Disparities (UCVED), a grassroots organization whose membership was mostly Black. In fact, she said "why would a White girl like you want to work in Springfield with me?"

I am often perceived as White by both people of color and Whites; I simply smiled and responded that "this Latina is invested in working with communities of color in Springfield to address health and other community problems." Betty expressed her surprise and replied "But you look so White." I explained the history of the colonization of the island of Puerto Rico and that, while I could pass for White, I chose not to pass whenever I could. She paused briefly to consider what I said and quickly moved forward with, "Okay then. Let's get started."

### **Positioning Myself in the Field**

This experience with Betty was not unusual. In fact, I have spent most of my life navigating the space between my light skin and my Boricua background. Boricua is a Taino term used by some Puerto Ricans to self-identify our indigenous roots. I was born in Mayaguez, Puerto Rico, but consider San Sebastian de Pepino my hometown. I learned Spanish first, and only converted to English when I went to kindergarten in Columbus, Georgia. My parents have an old cassette tape that recorded my transition from a Spanish household to a predominantly English speaking one. The tape spans a few years and captured some of my frustration with learning a new language. My younger brother, Richard, had to learn Spanish and English simultaneously, and struggled with both languages. His difficulties forced our parents to choose to either maintain an important part of our cultural heritage or assimilate into an English-only environment. Their reason for choosing English as the new sole household language was simple: we were living, not in Puerto Rico, but in Columbus, Georgia, where English was the dominant language and assimilation would make life easier for us kids in the long run.

And so I learned standard, unaccented English, and only spoke Spanish with my great grandmother, Tata, on phone calls or visits to San Sebastian.

My light skin and unaccented speech allows me to pass racially as White in American society. As a young child, I found my light skin frustrating and ugly, preferring my cousins' olive and darker complexions to my pale one. I did not understand the privilege granted to me by my light skin. It was not until many years later when a colleague called me out on my privilege that I truly began to understand the matrix of oppression and intersectionality of social identities (Collins 2000; Johnson 2006). I began to struggle with questions about my identity as others perceive it. How could I be light-skinned and also proud to be a Boricua? How could I be angry over the colonization of my beautiful *Isla del Encanto* while being able to speak "perfect" American English?

My light skin and mastery of the English language opened doors for me to distinguish myself as a White woman. Even before I had a language for the privilege I was granted, I knew something was different. I could see that I was watched when I went out with a Black male friend from school, but not when with a White male. I could tell that people would blink twice at my name, confused by the obviously Latino marker it provided. As I got older, I investigated for myself what these glances, comments, and experiences meant for me and others like me.

It became clear to me in high school that there existed a space between worlds – White and non-White. I attended school in Columbus, Georgia, where the vestiges of legal segregation were on display every day. Students divided themselves along racial lines in the cafeteria and gym. My high school was racially mixed, mostly White and

Black, but, according to the director of the college prep program, I was "free," as school officials were only required to count the White and Black students.

I had friends in all groups, but regularly found myself decoding racial messages. One of the most eye-opening moments came when a Black female friend told me she could no longer be my best friend because she needed to be with *her people*. At the time, I was frustrated because I also wished to be with *my people* and still be her friend. Unfortunately, I was the only Latino student in the program. This moment helped to define my racial consciousness and provided a foundation for asking questions about how to work collaboratively with people different from myself. I was determined to make every person I met *my people*, while at the same time understanding why others might not be inclined to see things my way. I realized early that the concept of racial unity does not exist in a social vacuum; instead, anyone working for this ideal must understand the double consciousness of people of color and the unmarked privilege status of Whites (DuBois 1903).

Embedded in my ethno-racial story is a class consciousness that begins with being born into a lower-middle class family, one with a non-commissioned officer father and a counselor mother. While both parents worked, my mother was the primary caregiver. I remember how boxed Kraft macaroni (complete with the powdered cheese), rice, and eggs served as staples in our house because they were inexpensive. My parents saved money to send my brother and me to private Catholic schools through grades K-8. Education was a priority in our lives because both parents recognized it as the only way to ensure success for their children. Education was viewed as the great equalizer: my parents raised me on a motto of "Hard work in school pays off." Yet it was not until

much later, in graduate school, that I understood the connections between race and class in America.

Overall, life was stable, even though we moved around while I was growing up. My parents' love of travel was infectious and formed in me a love of difference, movement, and people. Through my family and school experiences, I emerged from my parents' home with a clear understanding of morality, compassion, equity, and justice. I knew the world was not yet what I wanted it to be and that I could actively create social change.

In my sophomore year of college, I took an introductory course in cultural anthropology that inspired me to choose anthropology as my career. At its core, anthropology argues for a complex understanding of human nature that included time, space, and cross-cultural analysis. I was very interested in anthropology's goal to study the complex relationship between individuals, culture, and the natural environment. I was most interested in studying how social factors impact the distribution of resources in general, and healthcare and education access more specifically. For this reason, I pursued graduate work in applied cultural and medical anthropology. I realized that what I needed was an interdisciplinary lens that allowed me to work with, and provide solutions for, real world social problems. And so now, many years later, I have challenged myself to create a dissertation research process that was compassionate, just, and collaborative.

In 2002, I moved to Western Massachusetts from Atlanta, Georgia, specifically for my PhD program. I spent the first four years of my program working on my coursework and professional statements of field. In 2006, I started to engage in campus and community organizing while working full-time as an anthropology instructor at

Holyoke Community College in Holyoke, Massachusetts. My community work and teaching experiences allowed me access into urban communities of color through student mentoring and participation in community events. This professional experience, along with the fact that I am *Boricua*, provided me with a very real and personal connection to the people of color in the communities of Holyoke and Springfield. I had to juggle the demands of my research project, potential funders, my PhD committee, and my full-time job while actively collaborating with community-based organizations to ensure my project met the needs of all involved.

In order to ensure that my research is self-reflexive, I have allowed the research to flow organically using grounded theory. My research questions came out of months of working side by side with two community advocates, Betty Agin on the health disparities roundtable and Jamilah Ali Alexander on the substance abuse pilot project. Betty Agin is a strong, Black, middle-aged woman, originally from the South, who has done community work in Springfield over the last ten years. Jamilah Ali Alexander is an energetic White woman employed as a case worker at the Baystate-Mason Square Neighborhood Health Center for HIV/AIDS Care (BHCH) based in Springfield, Massachusetts. Both women are passionate about alleviating the community health problems in Springfield. Their compassion and energy are inspiring and contagious. It was important for my research to be community driven; in essence, the research needed to meet the needs and support the work already being done in the community by community leaders themselves. For this reason, my research is based on countless community meetings, roundtable discussions, trainings, one-on-one interviews, and direct observation. In order to frame my ethnographic story of two community health

interventions in Springfield, I used critical theories that highlight differential power dynamics, hegemonic structures, human agency, and race. Following these parameters, I chose to focus my theoretical analysis using Critical Medical Anthropology and Critical Race theory.

### **Critical Theory**

As a researcher, I have struggled to ensure that my work is relevant to the discipline of anthropology, while also having a larger impact on social problems –this is essentially the definition of applied anthropology. To do both well, I believe we must ensure that we act ethically by making our research politically relevant. By grounding myself within a critical theoretical perspective, I ensure that my research involves an analysis of individual and collective agency within the constraints of social institutions. My philosophical and conceptual analysis is framed by two critical theories that span two academic disciplines – Anthropology and Legal Studies. As critical theories, Critical Medical Anthropology and Critical Race Theory both offer critical examinations of power and privilege in determining access to varying resources including health. Application of methods to real world social issues will be discussed in greater detail later in this chapter.

Community-engaged research highlights different sources of opinion within a community; therefore, it is necessary to establish a way to engage the multiple stakeholders in discussions around embedded hierarchy and power. A critical theoretical perspective is needed to challenge the dominant institutions of society through the development of *multiple standpoint epistemologies* (Angrosino 2007). Ethnographers who ground their ideas in a critical lens favor research methods that are counter-

hegemonic, heterogeneous, and collaborative. One form of critical research, Community Based Participatory Action Research (CBPAR), attempts to involve the community as active partners in the creation and implementation of academic research. For this reason, CBPAR is the methodological theory I use in my research; it will be discussed further later in this chapter.

Within the field of medical anthropology itself, research has focused primarily on the folk health beliefs and behaviors of individuals within different medical systems. This early research has been criticized by critical medical anthropologists as "...ahistorical and atheoretical... [because it ignored] the structure and functioning of the broader health systems within which the particular problems or facet under study occurs" (Singer 1990: 179). Historically, research on how American social movements have played a critical role in how people receive access to services, foods, and health information, was rarely addressed in anthropological research studies. Instead, this critical research has been undertaken mostly by social epidemiologists, psychologists, and medical doctors (Jackson et al. 2012; Jones 2000; Krieger 2003; Lu 2010; Lu & Halfon 2003; Lu et al. 2010). Consequently, what became known as critical medical anthropology (CMA) arose out of the inadequacy of theories which explained health-related beliefs and behaviors solely as products of human personalities or environmental influences, and ignored the impact of social systems and restricted access to resources on individual and population health.

As a practice-oriented theory, CMA seeks to understand and find solutions for health problems within and across multiple levels of the healthcare system, including individual, community, national, and global experiences. Critical medical

anthropologists ask research questions that address how the historical elements of a society exert direct or indirect domination over the political, economic, social, and cultural expressions of citizens or residents, including minority groups (LeCompte & Schensul 1999). Singer & Baer state that "CMA emphasizes structures of power and inequality in healthcare systems and the contributions of health ideas and practices in reinforcing inequalities in the wider society" (2012: 39). Given the constraints of funding and community disempowerment, my dissertation, incorporating these concepts, must include a critical analysis of how access to preventative and reactive healthcare services is stratified by social categories, including the social class, race, gender, and sexual orientation of participants. While my dissertation focuses mostly on the interconnectedness of race and class in determining health access and outcomes, these social categories are by no means the only ways that resources are unequally distributed. By studying the social origins of illness, my research adds to the contemporary dialogue on the social determinants of health specifically by questioning the way in which social factors contribute to poor health outcomes at the population level.

Critical medical anthropology expands upon research that explores the interplay between social structures and human agency, highlighting how "people develop their own individual and collective understandings and responses to illness and to other threats to their well-being" (Singer & Baer 2012: 40). This occurs within the context of a socially inequitable world that shapes the nature of their experience. CMA is interested not only in studying resistance by individuals and groups to dominant health structures, but also in understanding how individual and collective decisions often reinforce positions of dominance and subordination. My research highlights the complex relationship between

Springfield residents, the local government, and the academic community. In Springfield, we see resistance to dominance through the visibility of local organizations fighting for economic and social justice ( like Arise for Social Justice, No One Leaves, and Universal Community Voices Eliminating Disparities). Within these organizations, student and academic leaders work with community members to address different social needs. A comprehensive discussion of health that encompasses access to other resources – including jobs and adequate housing – is seen in their communal resistance. My research reveals that the gatekeeping of information takes place, and this limits the spread of ideas and data, and reinforcing social identity markers of difference, disempowering the community, and reemphasizing the community identity of marginalization.

By defining power "as a fundamental variable in health-related research, policy and programming" (Singer 1995: 81), CMA provides the theoretical foundation to analyze health experiences and outcomes within a social justice framework committed to reducing health disparities and ensuring community engagement. CMA has seen a number of its proponents take action and work with communities to address health disparities and other poor health outcomes. Research done by critical medical anthropologists currently supports innovative community intervention programs in the areas of substance abuse, HIV prevention, and youth education (Berg et al. 2009; Li et al. 2012; Radda et al. 2011; Singer 2008; Singer 2009; Singer & Baer 2012).

Both critical medical anthropology and critical race theory (CRT) grew out of critiques of an apolitical status-quo in the foundations of their disciplines. As critical theories, CMA and CRT focus on issues of power and privilege as essential to resource distribution. Critical Race Theory complements the work of Critical Medical

Anthropology by providing a theoretical lens that continues the latter's investigative questions regarding the power of healthcare professionals, administrators, high-income patients, and health policy makers in the medical system. Both theories are tools that researchers can use to define, expose, or address health inequity linked to racism, whether internalized, interpersonal, or institutionalized. In emphasizing the personal narratives of people of color within the healthcare system, CRT examines "how socio-temporal notions of race inform the naturalization of oppression and the normalization of racial inequality" (Duncan 2005: 94). As a storytelling method, CRT can assist critical medical anthropologists in documenting the oral history of health experiences and interventions. For this reason, I have found this theoretical perspective to be a powerful tool in the collection of data regarding health interventions in Springfield.

CRT began as a response to a missing racial analysis within critical legal studies theory (Parker & Lynn 2002). In response, "CRT scholars...began to take up seriously the question of race and racism in the law by calling for a complete reinterpretation of civil rights law with regard to its ineffectiveness in addressing racial injustices, particularly institutional racism and structural racism in the political economy" (Parker & Lynn 2002: 9). CRT pioneers Derrick Bell and Richard Delgado argue that racism should not be viewed as acts of individual prejudice, but rather as a defining, stratifying, and systemic element that determines the social, political, and economic subordination of people of color. This perspective centralizes race and racism as a means to understand institutional discrimination within the historical framework of American society. CRT also highlights how definitions of race and legalized racism have shaped the U.S. criminal justice and legal systems.

CRT has three main goals. First, it emphasizes the value of personal narrative and storytelling as legitimate research strategies that complement ethnography as a methodological tool for documenting institutional, interpersonal and internalized racism (Duncan 2005). Previously silenced by the dominant narrative of the bootstrap myth, it is the voices of the oppressed that are privileged by this theoretical perspective. This theoretical perspective lends further credibility to utilizing anthropological methods to work with populations of color on their health needs. Second, CRT argues for the end of racial oppression while simultaneously reexamining race as a socially, not biologically, valid and flexible concept continually shaped by socio-political forces. In order to undo racial oppression and privilege, we must first understand that race stratifies American society through the unequal distribution of resources. The third goal of CRT is to promote research that addresses the intersections between race and other social categories, like class, sexual orientation, and gender (Duncan 2005).

Critical Race theorists work to change the dominant rhetoric that success is always achievable through individual merit, social equality, and the free market. It is CRT's storytelling that provides the counter-narrative to meritocracy that is so deeply embedded and widely accepted by the larger society. The CRT narrative has important implications for qualitative research in healthcare since a power analysis of relationships and systems is needed to understand individual and group experiences in the medical system (Parker & Lynn 2002).

Critical race theorists' emphasis on personal narratives of the historically disadvantaged has drawn criticism and disapproval "given the conservative nature of the federal court rulings on questions of race, as exemplified in the bevy of anti-affirmative

action decisions and laws that have sprung up around the country in recent years..." (Parker & Lynn 2002: 17). Critics of CRT argue that storytelling is one-sided, lacks analytic value, and ensures a level of empathy that automatically causes the researcher to lose objectivity (Duncan 2005). CRT theorists challenge this idea by arguing that storytelling provides the researcher with another medium for data collection and a means to write themselves into the story more clearly. Given that researchers always remain products of enculturation, true objectivity is not possible; instead, we must advocate for acknowledging that a researcher's perspective influences the work in some way. CRT proponents advocate for the position of the researcher to be more clearly defined in the research; for this reason, I chose to start this chapter on theory and method by positioning myself clearly in the dissertation narrative.

Critics of CRT also maintain that CRT has yet to prove how subordinated perspectives are different from privileged experiences in traditional research. Is the story being told by a man of color about his health experiences really that different from a White woman discussing her visit to the doctor? Recent chronic disease research supports an affirmative answer, and highlights the importance of racial health inequities, differential access, and poor outcomes for people of color (Jones 2000; Krieger 2003; Krieger et al. 2010; Krieger et al. 2011; Williams 2002). A study by Rathmore and colleagues found that two patient actors with identical health statuses, but different racial classifications, were perceived differently by White medical students and medical students of color (Malat 2006). Medical students of color perceived the Black female and White male similarly, while White medical students assigned lower health status to the Black female actor (Lee & Farrell 2006).

Given this research, we can argue that the perception of health status is affected by non-medical factors like race, and can thereby contribute to variations in medical care. The power to determine medical treatment remains in the hands of people greatly affected by perceived racial differences (Page & Thomas 1994). Continued research and community programs that analyze and address the functions of power, privilege, and individual agency in the Western medical system are therefore critical in the elimination of racial health disparities (David & Collins 2007; Krieger et al. 2011; Lu & Halfon 2003). CRT is a theoretical perspective that lends credence to the idea that application of theory is necessary for its real world use in community interventions.

Traditional research and health policies focus primarily on modifying individual cultural behaviors, and thereby ignore the social determinants of health and illness that mask "the ways that the dominant group exercises privileges, eliminating the dominant group's responsibility for the source of the problem" (Malat 2006: 308). Responsibility for issues of health and illness then falls to those afflicted. This blaming-the-victim mentality is rooted in the American cultural values of individualism, freedom of choice, and meritocracy. Anthropology, as a discipline, historically has at times shown a clear focus on victim-blaming, for example, in the work of Oscar Lewis on the culture of poverty. His book, *La Vida: A Puerto Rican Family in the Culture of Poverty- San Juan and New York*, exhibited a negative stereotype of Puerto Rican women as prostitutes (1966). Yet, because Lewis was viewed as a credible source as a known academic, his book was given substantial weight and received the National Book Award for non-fiction in 1967.

Lewis focused on individual behaviors that created what he called a culture of poverty (1966). This popular book reinforced a popular stereotype that is still with us today. His analysis of poverty as a self-inflicted phenomenon arising from the specific behaviors of a subculture masked the roots of poverty as structural violence. New findings in the medical and public health literature that acknowledge the importance of the social determinants of health have not translated into a larger cultural movement to make radical changes to the American economic and social system. Even with significant research supporting the need for greater social services to improve American life, the average American is unaware of the impact of society on individual health and overall life.

Discussions of power and privilege must acknowledge "the racialized social structure that produces race-based class inequality" (Malat 2006: 309). Through the use of critical theories, I argue for improved research on racial health disparities by bridging historical facts with contemporary examples of differential resource allocation based on racist ideology and White privilege, within and outside the healthcare field (Gravlee 2009; Gravlee & Sweet 2008; Dressler, Oths & Gravlee 2005).

Both CMA and CRT incorporate the use of an empowerment model that highlights a vital need for researchers to have an understanding of social, historical, political, and economic factors. It also calls emphasizes the researcher's role in changing the dynamics of a study by being a participant-observer. These two theoretical perspectives, founded on resistance of systemic oppression and giving voice to historically-silenced populations, provide this research with a unique grounding in history and praxis.

Power is often rooted in economic systems. This requires an interrogation of who owns and has access to knowledge production and knowledge distribution relating to health and healthcare. Looking at non-White risk, as determined specifically by economic, structural and personal barriers to care, holds not only the individual, but also society as a whole responsible for health problems. These theories will be used to guide data analysis in the pursuit of themes and patterns. By using theoretical and methodological models that are empowerment-centered, I ensure the voice of the community in dialogue over their health needs. In conclusion, CMA and CRT provide a complex social framework from which to reflect upon my collaboration experiences and discuss the process of doing participatory action research.

### **Methodological Theory**

My dissertation blends multiple public health and anthropological methodologies together in a critical ethnography. In order to gain the most complex and accurate data from my research, I used a multilayered triangulation approach to provide "a more detailed and balanced picture of the situation" (Altrichter et al. 2008). Multilayered triangulation allows me to answer questions about human behavior, the meaning attributed to human behavior, and the beliefs attached to human behavior. Ethnography and CBPAR are used to engage with the data in a meaningful and organic way.

I chose CBPAR as my theoretical methodology because it shares the same goals as my critical theories: to promote a more equitable research and community agenda. This is radically different from the traditional research model that tends to use communities as human laboratories for data collection. This collaborative method provides a more secure and concrete way for research-based innovations to become part

of community interventions. Historically, "research based innovations make their way slowly, if at all, into community practice," (Hacker 2013: 2) highlighting the disconnect between academic and community-based healthcare practitioners.

CBPAR has evolved as a popular methodology in recent years, originally arising out of a critique of previous research methods for studying a given population without addressing the needs of their participants. Sometimes called "collaborative ethnography," "street science," "participatory community research," "community based participatory research," or "action research," CBPAR is a methodology built out of the need to critically acknowledge that academic research is politically located within a particular historical context of differential power between researchers, community organizations and community members (Chevalier & Buckles 2013; Hacker 2013). Even as researchers have found value in collaborating with community members on community driven projects, funding support for these programs is difficult to sustain. It is critical, therefore, for researchers to reflect on their position as outsiders and recognize that their research may affect the various project stakeholders in different ways. CBPAR requires that academics and community members act as co-researchers to ensure results are community-centered, community-driven, and locally relevant (Flicker 2008; Resnick & Kennedy 2010).

In practice, CBPAR is rarely a fifty-fifty collaboration. Academic write-ups of community-researcher partnerships tend to highlight the accomplishments and ignore the challenges of this type of research. Further discussion on this issue takes place in Chapter Five of this dissertation. While there is a strong academic interest in this methodology, critical analysis and evaluation of researcher–community collaborations

are needed to consider how different stakeholders or community–researcher partners benefit from CBPAR. Morris and Luque (2011) assert that anthropologists play an important role as intermediaries between agencies and community members; they are often asked to drive research relevant to community needs and facilitate community action. The costs and benefits of university-community partnerships must be assessed and agreed upon by all parties, especially given the conflicting interests, power dynamics, and knowledge production. Since 2008, Margaret Everett, a medical anthropologist whose work focuses on Latino health initiatives in Oregon, has been a member of the north Portland Healthy Eating Active Living (HEAL) Coalition. In her capacity as a health researcher, she has seen how "anthropological skills in participatory research, mediation, and evaluation are useful to community members in coalitions, while opportunities for local engagement and development of ongoing collaborative research opportunities are beneficial to anthropologists in this symbiotic arrangement" (Morris & Luque 2011: 4).

CBPAR involves the commitment by all involved to participate in joint collaboration throughout a project and develop an action plan for social change. This methodology is locally specific (Trotter & Schensul 1998), and requires flexibility in design and sensitivity to community and research needs. For this reason, researcher and community partners must establish a common language and plan for collaboration. Ideally, this methodology allows a more equitable division of power and resources since community members are actively collaborating to build the project with researchers. What remains unclear in the literature is the role of the community partners in the evaluation and final reporting of CBPAR projects. With time and resource constraints,

CBPAR is a more difficult research agenda to follow given the need for transparency and collaboration at all levels of decision making. Participation by community and research stakeholders encourages critical praxis studies of the role of power and privilege in medicine, specifically in understanding racial health disparities.

CBPAR has been used by social scientists and health researchers. CBPAR is similar to the critical theories I employ, which challenge the idea that knowledge building lies only with privileged, elite researchers; instead this methodology "supports the premise that knowledge should be developed in collaboration with local experts" (Wimpenny 2010: 91). Community members are, therefore, expected to become active stakeholders in the research process and guide researchers on the issues relevant and urgent to the community.

CBPAR starts from the premise that research should be conducted *with* research participants. They challenge the idea proposed in standard academic research that the only relevant data is purely objective research. Participation in the production and generation of research knowledge is required of all of the participants for a truly collaborative project that relocates the power of research in the hands of many, instead of in the hands of the primary researcher. CBPAR requires critical self-reflection of stakeholders, including an acknowledgment that people have different ways of thinking, interacting, and working (Wimpenny 2010). Anthropologists, specifically, bring complex interdisciplinary research skills and "an important understanding of the interaction of physical and social environmental conditions" (Everett 2011: 12) to community-level interventions. Given its goal of collaboration, CBPAR would benefit

from the use of thick description to emphasize the multiple voices involved in a critical ethnography (Geertz 1973).

CBPAR shares much in common with critical ethnography and critical theories including "...a concern with global connections and relations of power and attention to issues of power within the fieldwork" (Hemment 2007). While more anthropologists are advocating for mutually collaborative relationships between research partners, anthropology, as an academic discipline, has rarely engaged in CBPAR (Hemment 2007). This, however, does not mean that anthropology has not engaged in community-research partnerships. In fact, the field of applied anthropology was founded on many of the principles inherent in PAR. For example, the Society for Applied Anthropology website clearly states that "anthropologists demonstrate a particular capability in helping to solve human problems through building partnerships in research and problem solving; acknowledging the perspectives of all people involved; focusing on challenges and opportunities presented by biological variability, cultural diversity, ethnicity, gender, poverty and class; and addressing imbalances in resources, rights, and power" (Society for Applied Anthropology 1999). The field of applied anthropology was founded on the principles of building equitable research and advocacy partnerships; more recently, academic anthropologists have started to also promote a public and community-engaged agenda. Community-research partnerships in anthropological research must therefore include a look at public and applied anthropology.

## **Data Collection**

For anthropology, the ethnographic process is essential in that it "involves the collection of information about the material products, social relationships, beliefs, and the values of a community" (Angrosino 2007: xv). Beginning in the 19<sup>th</sup> century, ethnographic thick descriptions of the human experience became an important fieldwork strategy for understanding the developing world. Participant-observation became "a way for conducting research that places the researchers in the midst of the community he or she is studying" (Angrosino 2007: 2). The search for patterns in the data gathered through careful observation of human behavior and from detailed interviews is a hallmark of ethnographic fieldwork. This methodology requires long-term commitment to the community and the triangulation of multiple fieldwork methods in order to formulate practical and theoretical findings of the research. The product of ethnography is, therefore, a narrative dialogue analyzing the complex relationships between people, the community, and the researcher. Raymond Madden describes ethnography as "a way of writing about people, a way of being with people, and in combination, a way of theorizing about people" (2010: 7).

The basic design for this research consists of a multi-level ethnographic analysis of two case studies involving Springfield community health intervention programs. To investigate complex researcher-community relationships involved in constructing research, I use a variety of qualitative research methods, including semi-structured interviews, document analysis, participant observation, and CBPAR. I have chosen ethnography as my primary methodology because I am interested in gaining a broad

understanding of Springfield as a post-industrial city with a complex support system of public health services and containing communities suffering from poor health outcomes.

Participant--observation of several Springfield public health and community programs has been critical to understanding the impact of differential access to information on the poor health outcomes of community residents. Data was collected over the course of six years. In the development phase of my dissertation, I took time to identify and share my experiential knowledge with community members. I also took the time to get to know individuals on a personal level in order to build rapport. The bonding and personal connection allowed consistent contact with community members throughout the research and was particularly helpful when reflecting on long term work together.

The inclusion of multiple voices in the research process, according to Schensul (1999), provides a basis for mutual trust and conflict reduction. Informal engagement with Springfield residents through community events dealing with healthy eating, the Criminal Offender Record Information (CORI) reform laws, environmental health concerns, among others, has contributed to my understanding of how health information is dispersed, how a "community event" is defined (i.e., Is it a community event when it is attended by mostly academics and service providers?), and the importance of face-to-face engagement with community members. I attended monthly meetings and regular trainings , organized occasional executive committee meetings, planned and attended community events, and coordinated college student participation in the Springfield community. I interviewed both key collaborators and other Springfield organizers to obtain a broader understanding of the complex history of limited sustainable health interventions being promoted in Springfield. Pseudonyms have been given to community

members who did not give permission to have their names used in my dissertation.

Changes will be noted with an asterisk (\*).

In my dissertation, I highlight the challenges of doing truly collaborative CBPAR at the grassroots level of a socially and politically marginalized community with limited funding. Gathering information from individuals at different power levels in the Springfield community provided a unique history of the city that supplemented the current research on health disparities and health policies on communities of color. In order to address ethical considerations, certain ground rules were discussed and established where necessary, including confidentiality, anonymity, and informed consent.

### **Activist Anthropologist: Navigating Conflicting Goals**

*"Those who have the good fortune to be able to devote their lives to the study of the social world cannot stand aside, neutral and indifferent, from the struggles in which the future of that world is at stake"*

– Bourdieu

In the article "Anthropological Advocacy: A Contradiction in Terms?" Kristen Hastrup and Peter Elsass (1990) discuss the role of anthropology in influencing social change. Their argument stems from the idea that anthropology must remain neutral in order to better comprehend the context of local interests, and that advocacy would require the pursuit of one particular interest. Their ideas stem from a tradition of cultural relativism and an attempt to not perform one's cultural bias. Yet, I argue that their ideas fail to address the fact that not all interests start out equally validated within a society. For this reason, neutrality remains a tool of the oppressor, ensuring the status quo runs

smoothly. What happens if I am both a social scientist and community activist? How can I work toward ensuring the collection of valid and reliable data, while at the same time feeling a responsibility to work for social change and human equity? This is complicated further by how I define my ethical obligations. Do I agree that "to be ethical, one must act and be politically effective" (Baba 2000: 27), or is this a conflict of interest, as most social science research seems to argue?

I argue that the idea of the researcher as a neutral observer is a myth that has been perpetuated for centuries in social science research. A researcher's social location always influences research, whether or not this impact is acknowledged. Pure observation is still influenced by the socio-cultural lens of the researcher. Informants have often been found to omit or embellish truths when studied. I agree with Bourdieu's assessment of the need for action by researchers who study society. Neutrality on the part of the researcher assumes that being unbiased is necessary for important knowledge gathering. I do not believe neutrality can exist in a paradigm where the researcher is to gain the rapport of their informants and be authentic to the researcher's work. When studying real world social problems, how can a researcher remain impartial, considering the unequal distribution of power and resources? This would assume the researcher is only a gatherer of knowledge without a role in the distribution of knowledge; I argue that the researcher has an obligation to ensure that research serves a useful purpose in society, and thus the researcher cannot be neutral. I have spent a lot of time navigating the roles of neutral observer and active participant. I agree that observation is important, but I cannot just observe; I must apply, and I must do.

My time in Springfield has meant daily reflections of my role in the community. I spent the first year and a half with UCVED watching and listening, rarely speaking up. I did not want to come in with the traditional research model of "researcher knows best." Instead, I listened to community members as they discussed the gatekeepers of Springfield, the health problems of residents, and the projects they were trying to get off the ground in Springfield. I just listened. I learned. After about a year, community advocate Betty Agin asked me to take on more of a leadership role, as she saw that I was invested in Universal Community Voices Eliminating Disparities and the Springfield community. My connections to other community organizations, like Western Massachusetts Jobs with Justice and ARISE for Social Justice, provided me with "street credibility" and suggested that I was more than just another researcher looking to take from the community. My consistent presence and eagerness to help gained her respect and her trust. I knew it was only a matter of time before she would ask me to step up, be a board member, and offer some organizational training for the group.

My interest in understanding human nature and passion for medicine led to my career path in medical anthropology. I was fascinated by the ability of anthropology to provide the cultural context with which to view biomedicine and study healthcare stakeholders as participants in the United States' medical industrial complex (Page & Thomas 1994). Yet, most research surrounding the dyadic relationship between health professional and patient has emphasized understanding the patients' interpretation and value of health information (Hunt & Arar 2001). This gap has left medical professionals as unexamined socio-cultural agents existing within specific political and economic hegemonic spheres.

Unlike most medical research on compliance, anthropological research can provide us with information regarding the clinical encounter that does not privilege the viewpoint of the medical professional over the patient (Hunt & Arar 2001). Through community involvement, anthropologists can work to redefine patient health compliance as a complex issue that highlights individual human agency in the decision making process and promotes a non-hierarchical structure that does not assume patient inferiority (Hunt et al. 1989; Shaw et al. 2008; Trostle 1988). In order to gain a clearer view of the healthcare system and patient experiences, greater focus must be placed on the role of the medical professional as privileged gatekeeper in a corporatized health institution/system.

In summary, anthropology, through its origins in the study of the "other," historically promoted the construction and essentialization of oppressed groups and the disenfranchised. Therefore, it is critical that socially-conscious anthropological research focus on subordinate groups with the purpose of exposing privileged groups. Navigating the line between objective science and subjective storytelling, anthropologists must acknowledge the changing narrative of experience based on the positionality of the researcher and the geographic space. Reminding ourselves of the ethical implications of human subjects research, anthropologists must act to ensure the research is relevant to the discipline and ethically sound. A recent development within the field of anthropology is the creation of a sub-discipline, Public Anthropology, which promotes the notion that research should be more readily available to the larger public. This sub-discipline draws upon the work being done by applied anthropologists.

One relevant question remains – should anthropologists act as neutral observers or as reflective participants in the research process? I would argue that objectivity assumes

that the status quo is what should and will happen. If I had chosen to be a neutral observer in Springfield, my research would look significantly different, and I would have had a more difficult time gaining access to the community. Instead, I went into the community to learn about it from the people and had the community tell me how I might be able to assist them in their work. As someone who assumed the community had a wealth of knowledge, I watched and became a member of organizations for months before ever adding my academic expertise. I made my research and student status known to everyone I met to ensure that I was acting ethically.

In working with different organizations, their staff and community members, I have found myself negotiating my social roles as researcher, displaced community member, activist and Latina. As a researcher, I was painfully aware of my need to collect data and write-up my data analysis. Living in Sunderland, working as a community college professor in Holyoke. Engaging as a community organizer in the Springfield community left me feeling like a displaced community member. I was not originally from, and did not work or live in, Springfield. I was not Black nor a Latino immigrant. And yet, I felt a connection to the city. I believe in advocacy and fighting for equity and social justice. I am Latina, but light-skinned, which means I am often assumed to be White. All of these social identity markers have made reflexivity an essential component within my research. I am constantly questioning my role as participant-observer and interviewer. I share what I have learned with the community organizers with which I work on these projects. Raymond Madden said it best when he argued that reflexivity in ethnography "is not really about 'you, the ethnographer'; it's still about 'them, the participants'" (2010: 23). Thus, sharing my story and reflecting on my positionality

within the research process ensures the creation of a more reliable narrative of the community.

## CHAPTER 3

### (RE)IMAGINING SPRINGFIELD, MASSACHUSETTS: A COMMUNITY OF COMMUNITIES

#### **Research Story/Vignette 2: Walking through Springfield**

On July 19, 2011, I participated in an educational walk around the North End of Springfield, an area rife with structural barriers to positive health outcomes for its residents. The North End of Springfield is a "food desert" and one of the most socioeconomically disadvantaged neighborhoods in Massachusetts. Originally, the Environmental and Health Coalition had planned a bike event that would allow community members and local leaders to identify structural violence in the community, understand the history of Springfield's poor health indicators, and discuss strategies for improving Springfield residents' health outcomes. After learning about the event, I suggested to Betty Agin, my community collaborator, that the event could also be done as a walk, providing people without bikes the opportunity to participate. She thought it was a great idea, and so she contacted the organizers, who agreed to promote the event as a bike/walk health event. The day of the event, I arrived wearing workout clothes. I only note my clothing because Betty was dressed as always in her Sunday best, only changing into her sneakers to walk.

The organizers chose to start our journey at the Pioneer Valley Transit Authority diesel bus garage in the North End neighborhood. The North End may not have a toxic waste dump or a factory emitting smoke into the sky, but the diesel bus garage is a major contributor to air pollution that can pose a serious challenge to human health. Participating in this Springfield community event provided me with a new understanding

of the dangers experienced by Springfield residents every day. These dangers are not only those we hear about in daily news reports, which emphasize violence and poverty; rather, these dangers stem simply from being pedestrians in a city. The creation of a highway had split the North End neighborhood in two. This is not unique to Springfield, in fact, many urban centers faced this during Urban Renewal of the 1960s and 70s. However, a consistent thread in the Urban Renewal story across urban America highlights that the newly created highway systems ensured that getting from neighborhood to neighborhood was difficult if not impossible. This remains true today where, in some areas, people have to risk crossing railroad tracks or highway entrances in order to get to another neighborhood.

While I walked around Springfield that day, the most prominent features that stood out to me were elements of hope and community existing in an urban area that was rife with structural violence. I noticed the vertical ghetto across from the Springfield Riverwalk and Bike Path; this poor community could look across and see the bike path only a few yards away, but the highway divided the community from the river. The only way to access the river would be to walk miles across the city. I was so frustrated that I looked on in amazement, searching for hope. We kept walking and I noticed that this same community had a small community garden that was tended to by adults and youth alike. Hope.

When we reached the Gerena School, a community elementary located at 200 Birnie Avenue and built in 1972, our Springfield tour guide discussed the environmental problems experienced by school personnel, students, and community members. The school was built directly under Interstate 91 and adjacent to roadways, a railway, and an

industrial plant. An underground tunnel was created within Gerena's property as "a passageway for pedestrians after the construction of Interstate 91 removed the original connecting streets between Memorial Square and Brightwood neighborhoods" (Santana 2012). Construction of the highway system severed the Connecticut River from the rest of the city, just as the railroad had done a century earlier.

Recent community outcry over the school's need for repairs has resulted in local government officials redirecting money for structural repairs. The school suffers from transportation-related indoor air exposures, flooding, moisture, mold, and filth, all resulting in an unhealthy environment for children. Currently, the EPA is conducting a Health Impact Assessment to determine changes needed to make the school safer and healthier. As we continued our walk past an industrial plant, I had to use my inhaler several times for my asthma.

On our walk, Betty introduced me to Zaida Luna, City Counselor for Ward 1, which includes the North End. Meeting a City Counselor who was committed to the community and showed her support at community events like these was very powerful. As our walk continued, our tour guide pointed out, not only what we could see, but what was missing. We saw limited green spaces, barriers to reach the riverwalk, limited pools and family friendly spaces, and a lack of established walking and bike trails. I could not help but think about a framed art piece on my wall with a quote taken from Martin Luther King Jr's speech "Beyond Vietnam," an address delivered to the Clergy and Laymen Concerned about Vietnam on April 4, 1967, in New York City; "A nation that continues year after year to spend more money on military defense than on programs of social uplift is approaching spiritual death."

I began to wonder about the future of the Gerena School, the North End, and Springfield as a whole given that their future was tied up in a narrative of historical oppression, urban renewal, and community action. Furthermore, I asked how the media-driven narrative of personal responsibility was mediated by the lived experience of structural and symbolic violence in poor communities? Who was this event really for? Was this experience primarily for the researchers participating in this environmental walk/bike journey to learn about the everyday life experiences of Springfield residents? Was this a healthy event for community members to learn how social factors impact their everyday health choices? Did one's position as stakeholder change the purpose of the event? The fifty people gathered may have come to the event for different reasons, but, at the end of the walk/bike event, people seemed eager to take what they had learned and experienced to their fellow community organizers and take action on the disparities existing in their neighborhoods.

### **Defining Community**

Most research done that discusses local health intervention strategies uses the concept of "community." Often the term is used without a clear definition, thus allowing for both flexibility and confusion. Government and health professionals tend to define "community" based on the physical location of a population; for example, Holyoke and Springfield would be considered two separate and bounded communities using this definition. This definition also assumes that identity is defined solely along geographical lines. Alternatively, the concept of community can be defined "based on affinity, similarity, and belonging, rather than spatiality" (Chappell et al. 2006: 119). This

definition is popular in the social sciences, and is similar to the anthropological concept of "culture."

Earlier sociological research by Anthony Cohen defined "community" as "a system of values, norms, and moral codes which provides a sense of identity within a bounded whole to its members" (Cohen 1985: 9). This symbolic understanding of community builds in the importance of human beliefs, values and agency. Combining spatial and non-spatial definitions can provide researchers with a clearer picture of what a community looks like, and how individuals function within their community. Yet blurring both definitions into one can create a problem for operationalizing the fluid boundaries of communities. "Despite the rise to prominence of the community concept in health promotion research, and the importance placed on subjective experiences of community, to date little attention has been devoted to the measurement of community" (Chappell et al. 2006: 120). Some researchers argue that community health interventions, even those that have strong community participation, have failed to yield effective and generalizable results. This requires a reanalysis of definitions of community and community engagement (Merzel and D'Afflitti 2003; Horowitz and Lawlor 2008).

Chappell, Funk, and Allen's research findings suggest that community participation in health interventions require that a community be "rich" in both an "aggregate sense of belonging and income" (2006). Their preliminary conclusions are tentative and require further testing; however, if new research supports their findings, then a redefining of community boundaries using both psychosocial and structural dimensions could provide a more complete understanding of community participation in health programs. Their research provides a different context for arguing that social determinants of health impact the ability for a community to be effective partners in the research and problem solving process.

Within PAR, people seem scared of the questions asked about who the "community" is and what it means. Randy Stoecker argues that there are two main reasons people fear asking the question *who is the community?* Some argue that the question itself is divisive and would produce conflict, while others, even subconsciously, know that those on the outside are not part of the community. Stoecker defines those on the outside as academics, foundation personnel, government agencies, and most non-profits (2013). His argument, which I agree with, is that "by and large, those organizations are not controlled by people who live, eat, and sleep with the problems that participatory action research models are designed to attack" and therefore, community must, Stoecker argues, be defined as "the people with the problem" (2013: 63). This definition of community is supported by literature in CBPAR, public health (Community Toolbox 2013; Flicker 2008; Maiter et al. 2008).

The neighborhood and community in which one lives can have a positive or negative effect on healthy resource access and individual health outcomes; this means, therefore, that your community "often determines safety, environmental conditions, access to resources such as healthy foods and social capital" (Budrys 2010: 209). This reinforces the concept of structural violence and the lived experiences of poor communities and communities of color. Hofrichter argues that the "sources of inequalities in health outcomes remain deeply embedded in the structure of major economic and social institutions. Social determinants of health inequity themselves are not causes of social injustice and inequity. They reflect deeper social divisions that generate multiple social risks, reproduced over time" (Hofrichter 2010: 10).

Early on in my own research, I struggled with defining community. I knew something was not quite right about defining community only in terms of social service agencies and non-profits, but did not have the language for my ideas until writing this chapter. I chose to integrate my research knowledge with what I experienced on-the-ground. Therefore, so for the purposes of this dissertation, I am defining "community" as *a group of people who share common goals, cultural understandings, and, usually, a geographical space*. Taking into consideration the role of social determinants of health, this research understands community as a complex and multi-layered phenomenon that recognizes how members live with structural barriers to health and limited resource access. Given that the concept of community is subject to multiple and complex definitions (Abbot 1995; Wayland and Crowder 2002; Morris and Luque 2011), researchers must be aware of the potential impact that varied definitions of community might have on the effectiveness of building research-community coalitions on health intervention strategies.

### **Research Story/Vignette 3 - Who in the "community" is missing?**

A fellow anthropologist and friend, Julie Skogsbergh, also works on community-engaged dissertation projects in Springfield, and our conversations often provide us with some great ideas for research and analysis. Because we work in the same city, our conversations allow us to understand the landscape a little better. In one discussion in June 2013, the conversation changed from our lives to our work. I was discussing how this chapter compelled me to consider my understanding of how community is defined in Springfield and who decides that definition. I had observed, by attending numerous community events, that "community," as Stoecker defines it, consistently seemed to be

missing in our local interactions. Presumably community events were instead merely a gathering of the same familiar healthcare professionals and community organizations. Rarely did community members not linked to these agencies attend the events. In fact, I often wondered where the "community" actually was, and why they were not at these events. This conflicted with my strong conviction that community-research collaborations on health interventions should do their best to ensure that community events reach the larger community, individuals and families with a vested interest in improving their health and quality of life.

My experience over five years working in Springfield is that community events rarely have, as Stoecker calls them, "the people with the problem," represented. Where are the Mason Square residents interested in getting a full-range grocery store in their local area? Or even Springfield residents interested in fixing errors in their criminal offender records, or promoting and learning about healthy eating? My colleague Julie, whose project is on Safe Sleep practices, was also asking many of the same questions. She shared with me her frustration at the lack of community engagement in Project Baby/Proyecto Bebe, and her desire for a community advisory board made up of parents and grandparents interested in promoting safe sleep behaviors in their communities. Together we wondered what community engagement would actually look like in Springfield? The question remained: "Can we do community engagement without all of the community?" For Julie, as well as myself, we continue, in both our projects, to push for greater capacity building, leadership, and empowerment among Springfield residents in order to produce more effective solutions to community challenges. We promote this by creating partnerships with community leaders and consistently reflecting on, not only

who is included in the conversations or events we are holding, but also what that means for those missing from the conversation.

### **History of Springfield**

The cultural and political factors challenging the creation and implementation of collaborative health interventions among researchers and community members in Springfield can best be understood through an ethnographic analysis. When assessing the intimate relationship between urban spaces, health disparities, and community work, it is imperative to expose the historical processes that have contributed to the poor health outcomes of Springfield residents.

Springfield is located in western Massachusetts, and is the third largest city in Massachusetts, after Boston and Worcester. Located on the eastern bank of the Connecticut River, Springfield is known as the *City of Homes*, a nickname referencing the Victorian residential architecture erected during the industrial revolution. Springfield became the site for the National Armory, and is best known as the site of Shay's Rebellion in 1787. Daniel Shay was a poor White farmer who organized his neighbors to seize weapons from the Armory in an effort to stop Massachusetts courts from taking their lands for unpaid taxes. This radical event shaped the course of American history in that it influenced wealthy landowners to support the idea of a strong central government in the new Federal Constitution (Zibbel 2009).

From the early 1800s to the 1960s, Springfield's population steadily increased. Notwithstanding a slight spike in the 1990 Census, Springfield's population growth basically ended in the 1970's. In Springfield people of color make up the majority of residents. As of the 2010 Census, people of color made up 63.3% of its population;

Blacks made up 22.3%, Latinos 38.8%, and 3.1% consisted of other races, including American Indian, Asian, and Pacific Islander. Non-Hispanic or Latino Whites were in the minority at 36.7% of the total population.

Since the 1980s, the number of families in Springfield living below the federal poverty line has consistently increased. In 2010, the figure rose to 22.6% of all families. Poverty is concentrated in 10 of the 17 Springfield neighborhoods. In these neighborhoods "the percentage of residents living in poverty exceeds the percentage for the overall city population" (City of Springfield 2013: 24). Poverty can be directly tied to the following statistical observation: while the cost of living in Springfield Massachusetts is 20% higher than the national average (Partners for a Healthier Community & Pioneer Valley Asthma 2012: 5), Springfield residents on average have a household income that is 20% less than the national average.

In a recent University of Michigan study titled *New Race Segregation Measures for Large Metropolitan Areas: Analysis of the 1990-2010 Decennial Censuses*, the Springfield metropolitan area has been classified as "one of the most residentially segregated metropolitan areas in the country" (City of Springfield 2013: 10). The Springfield metropolitan area includes all cities within Hampshire, Hampden, and Franklin counties. Using a "dissimilarity index," this study analyzed and ranked the 102 U.S. metropolitan areas with populations over 500,000 for the degree of racial and ethnic integration in the specific city. This study identified the metropolitan area of Springfield as #1 in the country for Hispanic-White segregation, #22 for Black-White segregation and #57 for Asian-White segregation. In an article titled "Local Media Struggles to Understand Segregation," Aron Goldman, Executive Director of the Springfield Institute,

wrote that "while segregation and inequality persist within the city, it [segregation] is even more profound in the context of the quintessential White flight suburbs that surround it, and the relatively affluent Five Colleges Area to the north, behind the 'Tofu Curtain'" (2013). The high level of racial segregation in the larger Springfield area is both a problem for the local city and a larger Pioneer Valley regional issue. Amaad Rivera, Director of Housing Policy for the Mass Commission against Discrimination, argues that the city of Springfield can lead the rest of the Pioneer Valley in lowering racial and class segregation by working together to create comprehensive policies for new job opportunities, affordable housing, and to reduce foreclosures in the city itself (2013).

Despite being the home to almost 30% of the jobs in the Springfield metropolitan area, the city of Springfield has the highest unemployment rate in the region: it was 11% in 2012, according to the Massachusetts Department of labor and Workforce Development. This rate is 30% higher than for the rest of the state, and can be traced to some historical roots (A Preliminary Discussion of Environmental Health in Springfield, MA 2012). The steady decline of livable wages in Springfield is part of a larger global shift from an economy based on material production to a service-based economy. As corporations moved production overseas in search of cheap labor and higher profit margins, the U.S. lost millions of unionized skilled manufacturing jobs. "In cities like Springfield, the higher paying, manufacturing jobs that previously dominated the city's economy were slowly replaced by low-wage service jobs, occupations that provided little economic security and no health benefits" (Zibbell 2009: 42). The steady move toward deindustrialization left many American cities, including Springfield, suffering from increased unemployment and poverty.

Zibbell (2009:43) uses findings from Macek's (2006) research to describe this decline of the inner city as caused by three interconnected processes;

First, the suburbanization of business and manufacturing along with the postwar suburban exodus of much of the white population; second, the so-called Great Migration of America's black population to inner city ghettos; and third, the restructuring of the American economy and its disastrous impact on wages and economic prospects of American workers (Zibbell 2009: 43).

The creation of the suburbs was, in part, due to the rise of the automobile and the federal highway system. While working class, minority neighborhoods, and minority-owned businesses were forced to sell their homes at "market rate" to make way for the highway, racist federal housing policies were created to increase the number of White owner-occupied homes across the country. The use of "redlining," or marking neighborhoods with majority people of color or low-income residents as risky lending areas, ensured little to no financial backing from the federal government to build homes. Therefore, "urban blight" in low income neighborhoods, i.e., the divestment from the inner city, is a direct reflection of discriminatory restrictions on loan eligibilities and not the result of group social pathology (Zibbell 2009). This is clearly reflected in the earlier example of the Gerena School and the North End neighborhood.

While Title VIII of the Civil Rights Act of 1968, otherwise known as the Fair Housing Act, prohibits *de jure* discrimination in the sale, rental, and financing of housing based on race and other social identity markers, it did not change *de facto* discriminatory practices. This can be seen in the most recent housing crisis and the predatory lending practices of the banking industry. Research done by Jacob S. Rugh and Douglas S. Massey at Princeton found that

the greater the degree of Hispanic and especially black segregation a metropolitan area exhibits, the higher the number and rate of foreclosures it experiences... [In fact,] by concentrating foreclosures in metropolitan areas with large racial differentials in sub-prime lending, segregation structured the causes of the crisis, as well as the geographic and social distribution of its costs, on the basis of race (2010: 644).

Further urban blight in Springfield can be seen in the 10.8% housing vacancy rate for 2010, according to the American Community Survey data for 2006-2010. This means that one in every twelve housing units in the city was vacant. Certain neighborhoods had higher rates of vacancy, which negatively affects home values and destabilizes neighborhoods. According to a 2013 report analyzing the structural factors that impact fair housing practices,

residential foreclosures in the city of Springfield accounted for almost 50% of all residential foreclosures in the Pioneer Valley region [in 2010]... While the economic recession and rising unemployment undeniably exacerbated the increase in the number of foreclosures, it is well-understood that predatory, sub-prime lending was a leading factor in our city centers and certainly in Springfield (City of Springfield 2013: 32).

This practice of predatory lending to people of color and low-income households is a prime example of a regional unfair housing concern.

Community organizations, like Arise for Social Justice and Springfield No One Leaves/Nadie se Muda, work to fight back against the recent housing and foreclosure crisis. These organizations teach homeowners and renters about their rights and mobilize average citizens to take back their homes. These organizations push the city of Springfield to support their residents. In the Spring of 2013, a survey done by the city of Springfield classified 1,162 properties as blighted, vacant, or condemned (City of

Springfield 2013). According to this report, "as of March 2013, a total of 990 families were on the Springfield Housing Authority's waiting list for federally funded public housing" (City of Springfield 2013: 35). Given its urban destabilization, the housing crisis, and the large number of families in need of public assistance, Springfield is a local example of a national healthcare crisis linking the social determinants of health, including housing conditions, to larger population health and healthcare policy. According to a Robert Wood Johnson Foundation Issue Brief on *Housing and Health*, poor and inadequate housing contribute to individual and population health problems, including infectious and chronic diseases, workplace and home injuries, and poor physical and emotional development for youth (2011). In fact, housing quality is directly tied to social and economic circumstances; This makes it our society's responsibility to address public health issues associated with residential issues.

Springfield is among the poorest performing cities in Massachusetts in terms of health outcomes (Caceres et al. 2007). The most recent Regional Health Status Indicators for Western Massachusetts shows the majority of health indicators are statistically worse in Springfield than the state average (2007). Springfield has poorer birth indicator rates (low breastfeeding, high teen birth rate, high smoking during pregnancy, low adequacy of prenatal care, and high infant mortality rate) than the rest of the state. For chronic disease outcomes, including obesity and diabetes rates, Springfield has statistically worse rates than the state average. HIV/AIDS rates for 2003-2005 show Springfield suffering at 15.9 per 100,000 people, five times the Massachusetts rate. There are also higher numbers of emergency room visits and hospitalizations for Springfield asthma sufferers (Caceres et al. 2007). These health indicators show significant human suffering in Springfield.

While these rates are startling, they need to be understood within the context of the history and socio-political climate of the city.

### **Structural Violence & Community Resilience: Springfield in Context**

*"We need to develop a plan for an economic development model  
that does not put people's lives at risk."*

- Tom Taaffe, (former) Chairman of the Pioneer Valley Asthma Coalition

Understanding the structural violence experienced by Springfield residents is only one part of the research scholars should undertake; we must also incorporate people's agency and community resilience into the analysis. It is necessary to analyze the interplay between structure and agency. According to sociologist William Cockerham, "proponents of structure emphasize the power of structural conditions in contouring individual dispositions and behavior along socially prescribed lines, while advocates of agency accentuate the capacity of individual actors to choose their behavior regardless of structural influences" (2005: 55). But it is not one or the other that determines health, rather, both. This section is devoted to exploring some of the governmental and community support programs and community initiatives that are in place to address the social needs of Springfield residents.

To protect fair housing choice, the city of Springfield has programs to acquire and redevelop foreclosed homes, assist homebuyers and homeowners with down payments, provide classes, and to reduce homelessness, including a 10 year plan called Homes Within Reach. The Springfield Redevelopment Authority has partnered with Develop Springfield in attempts to revitalize and reinvest in the city. Efforts target the creation of green spaces and public facilities, including a full-line grocery store in the Mason Square 'food desert' neighborhood. The Springfield CARE project, funded by the U.S.

Environmental Protection Agency, is an emerging coalition of community, health, local government, and academic institutions committed to developing a healthy environment and improve quality of life for all residents. The local non-profits Partners for a Healthier Community (PHC) and the Pioneer Valley Asthma Coalition (PVAC) collaborated on a report titled *A Preliminary Discussion of Environmental Health in Springfield, MA* that documents the link between social class, racism, and environmental (in)justice in Springfield. The report was presented at community stakeholder meetings in January 2012. It highlights the negative environmental health impact of Springfield's history as an industrial city, and it explores the impact on the city of its 'food desert' neighborhoods. This report also attempts to provide a foundation for further discussion and a way for community members, local government, and academics to identify problems and work together to provide solutions for the socio-economic and health-related deficiencies in Springfield. An updated report is still unavailable. But PHC has helped quantify the need in Springfield for targeted efforts to improve health outcomes by defining specific criteria for what they term an *environmental justice community*: "1) a median household income of less than 65% of statewide median; 2) 25% or more minority residents; and 3) 25% or more residents are lacking English proficiency" (Partners for a Healthier Community & Pioneer Valley Asthma 2012: 5). Springfield clearly meets such criteria: Springfield residents earn 64% of the statewide median, Springfield has population made up of 62% people of color, and 30% of Springfield residents speak a language other than English at home (Partners for a Healthier Community & Pioneer Valley Asthma 2012).

One of the organizations I collaborate with, Universal Community Voices Eliminating Disparities (UCVED), is part of the PHC / PVAC alliance, and the fact that UCVED had not been provided updated material from the January 2012 report as of this writing brings to mind some important issues. Several key informants and community members have highlighted the key issues of differential access to knowledge and gatekeeping. Differential knowledge production and distribution is a central problem acknowledged by Fair Housing stakeholders in the April 8, 2013, document entitled "Analysis of Impediments to Fair Housing in Springfield." It also appears prominently in the project document of Springfield CARE organization, mentioned above. The Fair Housing document acknowledges that, while Springfield has many services and support available for housing, "there remains a lack of awareness of the fair housing laws and an understanding of the services available" (City of Springfield 2013: 64). Similarly, the Springfield CARE project acknowledges the good work being done in Springfield to improve health conditions, for example, the growing community garden movement and robust public health networks. However, this document fails to explore the relationship between Springfield's continued poor health outcomes and the unequal access to information and services across the city. My case studies provide some ethnographic support and recommendations to address the conflicting narrative between the presence of available government resources amidst the socio-economic deprivation of the city.

How can we better understand the connection between population demographics, resource distribution, power, and racial health disparities in Springfield? Why does the Black community in Springfield have significantly higher rates of infant mortality and diabetes when compared with non-Latino Whites? Analyzing why certain populations in

Springfield have higher infant mortality rates, higher incidence of diabetes, and shorter life expectancies requires a complex look at multiple factors. At a general level, these include how individual behaviors are constrained by group social status, and the previously discussed structure/agency issue. At a more basic level, we must ask the following questions: 1) How are poor health outcomes affected by limited access to social and economic resources? 2) What part does the individual play, and what role does society play in addressing these social inequities? 3) What role do communities play in addressing the social problems they see on the ground? 4) What are the roles of human agency and community level interventions in determining individual health outcomes?, and 5) How can we increase the participation of communities that have experienced historical marginalization given the lack of trust many feel for government and medical professionals?

Bergstrom's 2012 report entitled "The Community Engagement Guide for Sustainable Communities" discusses the complexity of community participation in research collaborations. Their work not only discusses the explicitly discriminatory policies that have marginalized low income populations and populations of color, but also explores the way that traditional public participation processes do not allow for communities to participate in *their own ways*. Instead, these processes are "artificial and do not include spaces to share stories, lift up community assets and knowledge, or include community members and organizations in shaping the agenda, the process, and the ultimate decisions" (Bergstrom et al. 2012: 6). Therefore, we need to redefine community participation in health interventions as complex, flexible, and truly collaborative, which requires us to start with a conversation about who is the

"community" in the first place, as discussed earlier. Community members should have more influence in decision-making in order to increase capacity and leadership among residents, similar to the work being done through The Sustainable Communities Initiative.

For this reason, I set out in this dissertation to create an ethnography that documents, in part, how and why Springfield struggles to improve access to better health information, resources, and services, and the role that researchers play in reproducing this struggle. In the process of documenting researcher-community partnerships, this ethnography provides a detailed analysis of some of the challenges experienced by Springfield community members to sustain healthier resources and programs to their communities. Springfield's political environment has a direct impact on the health outcomes of different populations. Research has shown that "if elected officials do not share the concerns of these communities; even the best-intentioned and executed participation processes may fail to translate community priorities into policy" (Bergstrom et al. 2012: 6). In truth, if policies and/or problems raised have no relevance for local residents, and furthermore, do not include the local community in the solution-making process, these can further alienate communities from public officials and planners. Subsequently, if communities are alienated from their local government officials, what types of local action are then being done to improve healthcare resources at the grassroots level? Chapter Five includes a larger discussion of the work of the non-profit Universal Community Voices Eliminating Disparities as an example of grassroots organizing around health outcomes.

Contextualizing Springfield within the larger American healthcare system is critical to understanding a number of factors. How is Springfield a product of the larger US healthcare system? The city of Springfield is not alone; many racially mixed American cities with large populations of color show similar trends in poor health outcomes and limited resource allocation. Ecological research has reported that mortality rates are significantly higher in metropolitan areas and counties with higher proportions of Blacks (Cooper et al. 2001; Deaton & Lubotsky 2003; Mellor & Milyo 2004). Another study found that racial/ethnic disparities are much greater in some neighborhoods than others, even across class lines. In one study, researchers found that "neighborhood level poverty directly contributes to the greater geographic heterogeneity in mortality rates for Blacks [and therefore] suggests that the consequences of neighborhood deprivation may be particularly exacerbated for Blacks, compared with whites" (Subramanian et al 2005: 263). This research supports the need for local action to drive national policy changes.

### **Introducing Two Community-Researcher Partnerships**

The following two chapters, Chapter Four and Chapter Five, explore how community-engaged research can be used to address health disparities at the local level. By examining researcher-community collaborations in two health interventions in Springfield, Massachusetts, this dissertation demonstrates the importance and challenges of using CBPAR as a social change strategy for addressing health disparities in communities of color. Engaging community members and organizations as collaborators in academic research provides a way for differing stakeholders to share their experiences and knowledge to create more mutually beneficial and sustainable health programs. Both

case studies, the Recovery Sweepstakes & UCVED collaboration, show unique and similar findings related to the financing of grassroots projects, differing stakeholder needs and participation, and support from larger community stakeholders.

## CHAPTER 4

### "WHEN SUBSTANCE ABUSE ISN'T THE ONLY PROBLEM": RECOGNIZING THE NEED FOR ALTERNATIVE RECOVERY SERVICES IN SPRINGFIELD

#### **Research Story/Vignette 4: Teaching about Substance Abuse**

"Substance abuse isn't the only problem," I say, frustrated at some of my students. I am standing at the front of my Holyoke Community College classroom responding to a student's question about how substance abuse is a social problem. The class is called Social Problems, and this week we are discussing substance abuse. I continue "Let's be clear about something, we have a culture that promotes legal and illegal drugs. Just take a look at our media, our values, and how we treat poor versus rich drug users. So why punish some people for doing what is culturally accepted, but not punish others? If you are rich, you go to rehab and get help; but, if you are poor, you are sent to jail and stigmatized." As a class we look at statistics and research done on legal and illegal drug use. I add a follow-up question, "Why do we criminalize some drugs but not others?" A female student raises her hand and states emphatically, "Illegal drugs are more dangerous." Several other students nod in agreement. Another student responds "That's not always true, look at how dangerous alcohol is and it's legal; plus you never hear of a marijuana user killing someone, but drinking and driving is always in the news." I use material from Merrill Singer's work with illicit drug use and community health to address the class.

As Singer notes, the answers to why some drugs are legal and others illegal "lie in an examination of complex social forces, ethnic prejudices, vested interests, and historic events and involve an assessment of how particular drugs come to be embroiled in

tensions across gender, ethnic, and class boundaries" (Singer 2008: 29). Tensions continue to rise as we discuss the cultural and structural factors in the criminalization and stigma of substance abuse. We discuss the interplay of structural barriers and human agency in the experience of drug abuse, and how addiction is correlated to other social issues like poverty, racism, healthcare access, criminalization, and more. When the class ends, I am left hoping the silence present is in response to their learning and processing of new material.

### **Overview of the Problem**

Substance abuse, defined as excessive or inappropriate use of a drug that results in some form of physical, mental, or social impairment (Kendall 2009), is a major public health concern as it causes harm to individuals and society. American society is affected, whether directly or indirectly, by drug abuse and addiction at many levels. For the individual, drug abuse is linked to increased health risks for disease, injuries, mental illness, and death. Additionally, families of substance abusers are affected both psychologically and physically by their family member's addiction. Children, in particular, suffer in-utero from exposure to smoking, cocaine, and alcohol. At the local level, communities like Springfield, Massachusetts, are also largely affected by illicit and licit drug abuse because of the close relationship between drug use, homelessness, crime, increased mental health, special education needs, and loss of workplace productivity. Drug abuse is also linked to various medical problems, including cardiovascular disease, fetal alcohol syndrome, stroke, cancer, HIV/AIDS, hepatitis, and lung disease.

At the state and national levels, policies that determine which drugs are legal, which drugs are illegal, and how they might be policed, have a direct effect on

historically disenfranchised groups, primarily poor communities and communities of color (Singer 2006). Drug abuse also adds a financial burden, not just on individual drug users and their families, but also on harm-reduction and recovery programs that focus on lessening the burden of drug addiction. Often individuals are blamed for their choices, thereby leaving the complex social structure that helps to determine their choices unexamined. Individuals exist in a larger society that they participate in every day. The burden of poverty, racial segregation, and loss of job opportunities are all a part of the boundaries by which people make decisions about their daily lives (Singer 2006). Therefore, the health experience of drug users needs to be evaluated within a social framework which contextualizes the social and political factors that have previously impacted, and continue to affect, individual and group health outcomes.

Currently, our healthcare system is based on a curative model of care that emphasizes diagnosis and treatment over prevention. Historically, drug treatment has been primarily defined as the use of medication and/or behavioral therapy in order to limit, if not end, the individual's abuse of drugs. Since the mid-1970s, scientific research has shown that drug treatment is effective in reducing the frequency of drug use when administered and followed appropriately (Cartwright 2000; Rhodes & Gross 1997; Singer 2006). Unfortunately, addiction often goes untreated. According to the Substance Abuse and Mental Health Services Administration's (SAMHSA) National Survey on Drug Use and Health, among the 23.1 million people needing drug treatment in 2012, only 2.5 million received treatment, leaving 20.6 million people needing services but not receiving them (2013). Given current knowledge of drug addiction as a complex chronic illness that affects multiple dimensions of an individual's life, treatment is complex. Focusing

on drug treatment alone ensures that a cycle of drug abuse will form in many families. It also means that non-profit health agencies are providing the brunt of prevention and support services.

If the healthcare industry moved to a prevention model, drug education and support programs might be able to provide high risk populations with the necessary assistance to limit the social destruction caused by because of drug addiction. While the benefits of the prevention of infectious and chronic diseases have been documented by scholars, the medical system has yet to fully invest in changing the focus to preventative medicine. Given this climate, it is important to discuss the various elements involved in drug treatment and prevention. Treating drug dependence as a chronic disease could be a step in the right direction (McKellan et al. 2000).

Another issue to consider is program institutional inertia. Drug treatment and prevention programs, once established and routinized, are difficult to change. Merrill Singer's research with drug addicts highlights how "prevention programs tend to get stuck implementing models that may have proved effective at a particular time and place but are no longer useful due to the changes that have occurred in the drug scene" (2006: 10). Given that drug use is constantly evolving, programs need to be able to adapt to the changing drug market.

How then can we create sustainable intervention programs that are adequately funded, adaptable, and evidence-based? According to a CDC-funded project, being done by the Hispanic Health Council in Hartford, critical components to effective community substance abuse intervention programs include:

- (1) implementation of a locally grounded system for monitoring changes on the drug scene;
- (2) assurance that this monitoring system includes the collection of quantitative data from existing data collection sources, periodic interviews with active drug users, and ethnographic observation of drug use behaviors and social interactions;
- (3) a mechanism for transferring and translating findings from drug monitoring for rapid use by public health officials, clinical personnel, drug treatment providers, and community organizations;
- (4) adequate funding to sustain monitoring over the long haul; and
- (5) periodic evaluation to identify strengths and weaknesses in the monitoring and referral systems, thereby insuring a basis for continued growth and development (Singer 2006: 234-235).

What is not explicitly stated, and therefore might be missing altogether from this Hispanic Health Council project, is the collaborative voice and participation of the larger community in sustaining these community substance abuse programs. Their work does include a community advisory board that consists of representatives of the community, including healthcare professionals, drug specialists, and community based organizations. This is a start; however, I believe there is a critical group missing from this definition of community. Where are what Stoecker calls, "the people with the problem" (2013: 63)? Where are the people in addiction recovery, their families, and other everyday community members to serve on this and other advisory boards? Given the complex problem of addiction, community intervention programs created to reduce substance abuse must attempt to include all community voices, complex community-research partnerships, and program assessment and revision.

It is also critical to understand the differential impact of drug treatment and prevention programs specifically on socially-marginalized groups given that the numbers of new AIDS cases disproportionately affect women and people of color. (Amaro et al.

2001; Rothman et al. 2007). Research shows that excessive drug use can increase HIV-transmission risk-taking behaviors among both infected and uninfected individuals. Substance abuse programs based in affected communities have been shown to reduce HIV risk-taking behaviors among their predominantly male participants (Amaro et al. 2001; Rothman et al. 2007). In fact, "few programs have been evaluated that address both substance abuse and HIV for women or adolescents" (Amaro et al. 2001). Programs must highlight the social intersectionality of race, class, gender, and sexual orientation (Cao, Marsh & Shin 2008). The use of culturally competent preventative services has been shown to enhance substance abuse treatment and decrease client HIV risk behavior (Cao, Marsh & Shin 2008; Weeks et al 2009; Trimble & Beauvais 2001).

This research linking drug treatment, prevention, and culturally-competence supports my collaborative efforts to get a substance abuse harm reduction program off the ground. This project is founded on the belief that a collaborative social justice approach to community health is critical for effective intervention. This case study/health intervention works to connect drug users, various healthcare professionals, community members, policy makers, and funding agents in a dialogue regarding the effectiveness and sustainability of a pilot contingency management and peer education program.

### **Establishing an Initial Community-Research Partnership**

In February 2010, Jamilah Ali Alexander, a physician assistant who is the HIV Care Coordinator at Baystate Mason Square Neighborhood Health Center, contacted me and asked to collaboratively create a pilot substance-abuse treatment program using prize-based incentives to reduce substance abuse behavior. The concept for the pilot program had been in development for 20 years, and was based on Jamilah's work as a

medical provider for the HIV infected, substance abusing, homeless, and seriously mentally ill populations. At the 2008 Harvard University Continuing Medical Education conference, she received an 'Honorable Mention' award for the concept in the professional category for "Publishing Books, Memoirs and other Creative Nonfiction." She was interested in collaborating with a researcher to create and implement this harm reduction project, and was given my name by a mutual colleague. I was intrigued by both her passion for the topic and the potential to make a local harm reduction program that could reduce drug abuse and high-risk HIV behaviors. We met a few times at Mason Square to discuss her idea. She was uncertain about the research available to support or refute her idea. The partnership grew over time as we both realized our commitment to each other and the program idea.

I was excited to work with a healthcare professional that believed in public health prevention and was interested in developing new ideas to address current problems. A logistical problem arose right away in managing our individual work schedules. From the beginning our collaboration was difficult given both our busy and complicated work schedules. Research and community partnerships are complicated as different stakeholders provide different expertise and have different reasons for the collaboration. Partnerships are rarely fifty-fifty, and when both parties are already over-committed, it means that the work is slow at best. Early on, we received verbal support from Jamilah's supervisors at Baystate. While we have received accolades and interest in the project from academic colleagues, medical professionals, and HIV clients, this interest has not come with the financial and structural support for the development of this program. Thus

trying to develop a well-crafted program proposal that would garner funding support has been an added challenge for us.

We have both spent our "free time" trying to secure grant funding for this program. I was interested in the initial project details; however, it was Jamilah's passion for her clients that truly drew me in. And so I began a review of the literature surrounding contingency management programs and their application at the community level. Here, I thought, I would have true collaboration with a healthcare provider and community representative who understands social inequality and is a native to the area. We decided to approach Baystate with our initial project proposal. I spent countless hours juggling several activities: my full-time job teaching community college students, my community work on this project, and my other community-engaged project with Universal Community Voices Eliminating Disparities. I read numerous research studies on contingency management in order to put together a project proposal for Baystate officials. I studied the details and challenges of other harm-reduction programs in order to prepare for our meeting with Baystate.

#### **Research Story/Vignette 5: Meeting with Baystate**

In preparation for the meeting, Jamilah and I discussed the potential reservations Baystate might have with the pilot project. We knew going in that the idea of an incentive program for health behavior was controversial, even though it was supported by scientific data. I had done a lot of research on the programs that already existed in other cities and their overall effectiveness, and Jamilah had received some verbal support from colleagues at Mason Square. Jamilah and I walked into the conference meeting room on the first floor of the main Baystate Health Center building on April 16, 2010. We were

greeted by six Baystate officials, including the Medical Director of Mason Square clinic, the Associate Medical Director of Mason Square, a Vice President of Baystate, a Public Relations representative, and two other officials. The majority of the Baystate representatives were middle-aged White men, with the exception of the Mason Square personnel, one of which was a White woman and the other a Black man. To begin the meeting, the VP asked everyone to go around the room and provide their name and credentials. We did, and immediately following this, he stated that he was uncomfortable with the proposal because "it sounded like gambling to him."

Jamilah was asked to elaborate on the proposal but was not prepared for some of the research questions that were asked. I had done the research alone due to my experience and her work schedule. So I took over and addressed all their questions by pointing to the information packet in front of them. I carefully chose my words and highlighted a number of research articles that clearly support contingency management as an effective evidence-based strategy for harm reduction. It felt a bit like what I imagine the Spanish inquisition might have felt like. We tried, unsuccessfully, to change the preconceived minds of the leaders of Baystate. They continued to repeat their concerns about the project. First and foremost, was the issue that the public might perceive Baystate as condoning gambling. The Baystate administrators mentioned that monetary and prize incentives could lead to more dangerous crimes taking place in what one Baystate representative called an "already questionable neighborhood." Both Jamilah and I felt there was an undertone of hostility for substance abusers and racism regarding affected population by the Baystate personnel. After the meeting, the Medical Director of the clinic caught up with us outside. He stated that the project was innovative and

worthwhile, but he believed it did not meet the mission statement of the clinic. Leaders at Baystate Hospital are among the power players in Springfield and serve as gatekeepers in the community. Baystate had transitioned their drug and alcohol treatment services to the Behavioral Health Network, a community health service provider for drug and alcohol treatment. This was used by Baystate to effectively ignore issues of substance abuse and its impact on other health concerns. Another excuse we were given, as mentioned above, was that the awarding out of prizes for healthy behaviors would be seen by the public as promoting gambling. Baystate could not support a program, even for a stigmatized population, that might provide an image problem for the hospital. Research on contingency management shows that it does not create gambling addiction, but this research was not enough to sway Baystate (Festinger et al. 2005; Festinger et al. 2008; Petry et al. 2006). In the end, the perception that contingency management would be seen as a gambling program killed the possibility of running the program through Baystate with funding.

Ironically, three years later, gambling seems to be looked upon favorably by many large players and residents who voted in favor of a proposal to build a new casino . Yet, despite their stated concerns over gambling, we question whether Baystate would change its mind in light of the interest that many key leaders in the city have in bringing a prominent casino to "develop the area" and "create jobs." It seems unlikely because, at a broad level, American society is embedded in the excess and materialism arising from capitalism, and so many are generally blind to the way such roots are implicated in people's poor health. Evidence-based data supporting our proposal for a contingency

management program was not enough to overcome such factors, and to overcome the socio-political stigma surrounding substance abuse and gambling.

### **Finding another Community-Research Partner**

After Baystate Medical Center turned down our proposal, we looked to community agencies for support. We discussed the proposal at a Universal Community Voices Eliminating Disparities Saturday roundtable meeting. The organization was interested in the work, but could not provide the staff or money we needed. We realized we needed an established community social service organization with some stable funding sources to be able to get this idea off the ground. We looked into three organizations: Northern Education Services, River Valley Counseling Center, and Tapestry Health. Northern Education Services (NES), one of Springfield's oldest and best-known social services agencies, was having some severe financial problems and had been in the news for financial irregularities about loans never disclosed to government. Thus, we decided against contacting them.

After looking into the River Valley Counseling Center (RVCC), Jamilah and I agreed that they might be a good organization to collaborate with on the proposed project. We called RVCC twice to discuss the possibility of collaboration on the project, and both times we were told that they would get back to us, but we never did hear back. In the meantime, we also contacted Tapestry Health about the proposal. We were directed to Tim Purrington, Director of Prevention Services for Tapestry Health Systems. We sent Tim a working draft of our two-page Executive Summary proposal over email for review and to gauge his level of interest.

## **Research Story/Vignette 6: Meeting with Tapestry**

On September 3, 2010, at two in the afternoon, Jamilah and I met with Tim at the Tapestry regional offices. The offices are on the 2<sup>nd</sup> floor in a 150,000 square foot brick and mortar building located at 296 Nonotuck Street in the Florence section of Northampton, MA. Originally a silk plantation and processing plant built in the 1830s, the property has a rich history. In December 2007, Environmental Compliance Service (ECS) purchased the building as part of a local redevelopment project, and Tapestry moved in soon after.

The inside of the offices were clean, and the waiting area was quiet. We walked in a few minutes early, both Jamilah and I anxious to get started. We discussed the paperwork we had brought with us while we waited a few minutes for Tim to be available. Tim walked in as formidable as ever, a tall White man, about 6 foot 5. When I saw him, I realized I had met him the year before when he presented at a conference I attended, The Reproductive Rights and Social Justice Conference at Hampshire College. I was excited to make that connection, which I believe allowed us to build collegial rapport more quickly. When we sat down at his office table, we discussed Tapestry's current programs, including the Needle Exchange in Northampton, HIV counseling and testing, and La Voz, while exploring where the project might work best. Tapestry Health's La Voz program in Springfield, a neighborhood-centered and culturally-competent HIV prevention initiative, seemed to be the best location for our harm reduction pilot program. Tapestry already had a research-community partnership established with Boston University's School of Social Work that was working well, so

this experience with community-based participatory action research provided the groundwork for a new potential collaboration.

During our meeting, Tim asked questions about the project details and Tapestry's role as the community partner. Tim seemed cautious given the amount of work that creating and implementing a pilot project requires. He was worried about requiring new work for the La Voz program managers in addition to how we would fund this new initiative. We discussed our different roles in the project. As we talked, it became clear that the research component would fall to me, and that the development of the program would fall to Jamilah and me. Tim and Tapestry would provide feedback along the way.

In reality, we realized this project would take months if not years to develop and fund because all three of us were over-extended and new to the research and development of contingency management. I assured Tim that the research on contingency management was evidence-based with positive results. I informed him that I would send a revised larger proposal within a week. The larger project proposal had the research on contingency management, and would provide the necessary academic support for our idea. At the end of the meeting, Tim said he liked our idea, but that he needed to discuss the collaboration with Tapestry's Executive Director, Leslie Tarr Laurie, before he could make a decision. Jamilah and I left the meeting hopeful that this would be the beginning of a long-term collaboration with Tapestry Health.

### **Moving Forward With Tapestry**

We didn't hear back from Tim for two weeks, but the wait paid off. I followed up via email to check in about his conversation with Leslie. When he emailed back a few weeks later, Tim had spoken with Leslie, and she felt there were a number of concerns

which would make moving forward difficult. After doing some further research on contingency management programs, I made some suggestions to Jamilah about the necessary steps we might need to take in order to secure Tapestry's support. It took a few more project revisions, including taking out the idea of having participants buy tickets for the prizes. Instead, we decided to have clients register for the program and participate in healthy activities (including a 12 step program, counseling, yoga, an HIV risk questionnaire, and volunteer activities) that would give them tickets to win the prize. This idea was more consistent with the literature on contingency management and had been a sticking point with Baystate as well (Fulbrook & Maloney 2003).

Necessary adjustments were made in a series of meetings and discussions. On November 7, 2010, I drafted and sent a short email to Tim regarding the changes we had made to the program. My email included a new revised proposal and face-to-face meeting times for the following two weeks. I got Jamilah's feedback before sending the email to Tim. The next day we heard back from Tim that he approved the modifications. We were then able to schedule a follow-up meeting with Tim and Leslie to secure the collaboration with the November 19, 2010, meeting at Tapestry. As it turned out, Tapestry was a better fit for our collaboration. Tim' seemed excited about the possibilities of such a new and different program targeting people with substance abuse problems. We discussed the potential for the program to support already established programs in Springfield, including those at Tapestry. We discussed the parameters of our research partnership at our follow-up meeting on November 19, 2010.

As I stated earlier, partnerships are rarely 50/50. In fact, after meeting with Tim, I realized we would all fall into specific roles with limited overlap. I was the researcher

whose role focused on the reading and synthesizing of contingency management research for grant funding purposes. Jamilah was the idea person whose passion for this harm-reduction strategy brought all of us to the table. Jamilah and I also worked through the logistics of designing the program. Tim was interested in being the community organization representative who would provide input on the almost finished product. He stated early on that he was unavailable to work collaboratively on the logistics and start-up details of the program. Instead, he asked to be kept in the loop with occasional meetings and being cc'd in email conversations about program research details. He would respond to emails that asked for direct information from Tapestry.

Acknowledging this division of labor was critical to understanding the community-research partnership we developed during the creation of this community intervention. One question that arose for me out of this experience stemmed from the obviously unequal distribution of project labor – Is the research still community-based if the "community" or organization is not part of all stages of the research and project development ?

### **Logistics of the Project**

We originally titled the project "Recovery Sweepstakes: Pilot Contingency Management Program as an Alcohol/Substance Abuse and HIV Transmission Reduction Tool." This title, while catchy, has elicited an unfavorable response from within the medical community. Baystate Medical officials, along with Nancy Petry, a longtime proponent of contingency management, cautioned us about the impact of social perception on project implementation. They believed that if people perceived the program to promote gambling in any way, the program would remain unsupported. For

this reason, the title was changed to "Road to Recovery Springfield: Pilot Contingency Management Program for a Novel Alcohol/Substance Abuse and HIV Transmission Reduction Tool." The goal of this harm-reduction CBPAR project was to implement a set of already-proven prevention and treatment initiatives, including prize-based incentives, peer education, and healthy behavior changes (Fulbrook & Maloney 2007; Lussier et al. 2006; Higgins, Alessi & Dantona 2002; Weeks et al. 2009).

This project had been several years in the making, something typical of CBPAR projects. Over time, we have made significant revisions to the original idea, created collaborative relationships with community organizations, and contacted/applied for alternative revenue and grant funding. At this time, the program is still unfunded. Once funded, Road to Recovery Springfield will provide access to a harm reduction community-based program for eligible participants in the Springfield area. We are providing a culturally-competent program that includes incentive-based activities for reducing drug use, which will help prevent the HIV burden from increasing in the community. Our contingency management/health education model will ensure that the personal buy-in of at-risk populations is attained through their participation in a number of healthy activities, including exercise, meditation, substance abuse support groups, and more.

This case study documents the complex process of implementing a contingency management model as a substance abuse and HIV prevention intervention in Springfield, Massachusetts. My personal observations and interviews with collaborators provide some insight into the need for a critical cultural paradigm shift that views substance abuse as a social problem, rather than an individual character flaw. Thinking of substance

abuse as a complex social problem that is in constant need of re-evaluation based on changes in cultural, political, and economic drug policies would more accurately allow us to envision multiple solutions to drug problems. This alternate perspective would provide important support for socially marginalized communities given the different structural barriers to appropriate healthcare access and positive health outcomes that exist for these populations. If research supports contingency management as an effective strategy for harm reduction, then how can we change perceptions in order to create viable and sustainable support for such a program in Springfield?

The Road to Recovery Springfield community intervention project attempts to bridge the gap between current drug abuse programs and recovery programs. It seeks to improve individual health outcomes and decrease the risk of HIV transmission. Given the fact that drug and excessive alcohol use can increase HIV transmission risk-taking behaviors among both infected and uninfected people (Amaro et al 2001; Caetano & Hines 1995; McCusker et al. 1996), this pilot project aims to provide an HIV harm reduction tool for drug users. A prevention and/or treatment program that reduces drug and excessive alcohol use behaviors is likely also to reduce the risk of spreading HIV. In fact, treatment for substance abuse has been the most endorsed intervention tool for HIV prevention in the United States (Auerbach et al 1994; Cao, Marsh & Shin 2008; Cooper 1989; Gerstein & Harwood 1990; Hubbard et al 1989; Metzger & Navaline 2003; Mitchell & Oltean 2007; Sorensen & Copeland 2000).

This program offers a healthy option for people who may not be abstinent every day, but would like to limit their overall health risks. This program can be used by Twelve Step fellowship to support abstinence. The goal of the Road to Recovery

Sweepstakes program is to foster recovery from hard drug and excessive alcohol use by providing a prize-based incentive within a comprehensive community-based and culturally-competent substance abuse intervention.

According to Nancy Petry (2000), contingency management programs should follow six specific steps for success. First, the program should choose a behavior they want to reinforce. Being specific provides participants with clear guidelines and greater likelihood of successful behavioral change. For example, participants can be requested to have a negative toxicology screen and legal blood alcohol limit for a two-week period. Second, the program should decide on the behavioral reinforcer. Our program, for example, has decided on raffling off prize-based incentives like \$100-\$250 gift certificates to local grocery or chain stores. These gift certificates would provide a clear financial incentive to stay clean and potentially win a prize to assist with basic necessities (i.e. groceries) or luxury items (i.e. non-essential clothing). Third, programs should utilize behavioral principles to monitor participant behaviors frequently. Having healthy behavior options for de-stressing (exercise and mediation) while providing job training and financial counseling would allow for a greater likelihood of individual success in the program. Our long term goal for the program is to include a peer health educator component for participants who have successfully used the program and can advocate for others to do the same. Fourth, programs should draw up a behavioral contract with details about behavior expectations, how behaviors will be monitored, and how prize incentives will be applied. Monitoring will be done using the Addiction Severity Index and HIV risk behavior index for all participants. Winners chosen for incentive will also be asked to submit to tox and alcohol screening. Fifth, programs must be clear about

assessment; the means of monitoring the behaviors of participants under behavioral contracts must be clear. Our program will gather both quantitative (BAL & toxicology screenings) and qualitative (Addiction Severity and HIV risk behavior indexes) data for program evaluation. Finally, Sixth, programs should keep clear and comprehensive records of what works and what does not in their respective communities. These records are needed for program review and revision to ensure that specific community needs are met by the program.

Our program has addressed all of Petry's programmatic steps in some way. Unfortunately, this program has been unable to gain enough financial and grant support. This has temporarily delayed our ability to implement this harm reduction program. Jamilah, Tim, and I continue to be in touch about this initiative. One possible direction we are considering is to reassess our original approach to the work and instead create a community taskforce for Substance Abuse & HIV prevention, or join an already established task force in Springfield. I am currently in touch with a community leader in Springfield who has a background in substance abuse prevention and treatment. I am trying to determine if a suitable taskforce already exists. A taskforce would allow us to have a more direct impact on the work currently being done, and possibly provide us with the larger support needed to implement something new in Springfield. Also, VA hospitals and other community and health professionals who work in substance abuse prevention should be contacted to gain their support as potential stakeholders.

### **Components to the Program**

The project was to be located at La Voz, a program of Tapestry Health, an organization with experience working with the target population. The organization

appears to provide an ideal setting and backbone for the Road to Recovery Program. Community agencies that are possible collaborators and referral sources include River Valley Counseling, Gandara, and New North Citizens Council. The project has also been endorsed by Universal Community Voices Eliminating Disparities, a Springfield grassroots community organization. Local colleges, college professors, and students will also partner with the project to ensure community investment in this public health project. Holyoke Community College students have participated in some of the initial concept development for this project. New collaborative partnerships are being established on an on-going basis.

Substance abuse prevention education is a necessary component of harm reduction because it helps break the cycle of individual and generational abuse. Providing participants with clear reasons, formal support, and informal support to stay clean will reduce the number of family members needing treatment. While we recognize that our program cannot "do it all," the program was conceptualized to provide a comprehensive and community-specific response to the substance abuse crisis in Springfield. Our program will provide another space for the needs of an at-risk community to be voiced and addressed. Participants will receive a listing of a number of city-wide resources, including Tapestry programs; Needle Exchange; 12 Step programs; church resources; community organizations like Universal Community Voices Eliminating Disparities; mental health resources; financial and career assistance; job training; and wellness and exercise opportunities.

We will provide a class about different factors that impact drug use behavior. The class will provide an analysis of drug addiction as a social problem instead of the all-too

common approach that frames addiction as solely due to the failure of the individual. Elements of our educational training could be used outside this setting to promote a more complex understanding of individual choices being influenced by society. An explanation of agency and structure will be included using interactive activities like those from the Community Action Poverty Simulation (CAPS) program. Expanded partnerships with community organizations across the Springfield area is key to programmatic success. Partnered organizations will provide continuous support for healthy behavioral changes by allowing for more individualized support in a wider set of programs. Partnering lends mutual support for partnerships and health agencies already established in the city. Any success at the community level requires the inclusion of all stakeholders in program development, implementation, and assessment. To address the common issue of missing stakeholders from the local community, this project will have a community advisory board. This group will guide project policy and consist of healthcare professionals, community organizers, substance users in recovery, and other community members.

This program is designed with a registration process that includes information sessions to detail participant inclusion criteria. Recruitment and retention of participants will begin a month before the official start of the program at Tapestry. Information about the pilot program will also be made available to the public through word of mouth, social media sites, and individual recruitment via Tapestry's already established programs. Our program inclusion criteria are based on recent criteria established in previous research studies: participants must be over 18, have a photo ID and current contact information, have no indicators of gambling addiction, and must be willing to participate in the

Addiction Severity Index assessment, in the HIV risk behavior Index assessment, and in alcohol and drug testing. Our reason for excluding people with a gambling addiction is to help ensure that our program does not promote harm reduction from one addiction only to swap out that addiction for another one. Research by Festinger and colleagues on drug abuse outpatients in three treatment programs in Pennsylvania found that "neither the magnitude nor mode of incentives had a significant effect on rates of new drug use or perceptions of coercion" (2005: 275). Their research also shows that there is no data to support the concerns of the medical community and others that contingency management programs are a form of legalized gambling or monetary coercion (Festinger et al. 2005; Festinger et al. 2008; Petry et al. 2006). Pre- and post-interviews will be conducted with participants to assess program effectiveness and make necessary adaptations. Pre-interviews will be done during registration and post-interviews will be done at the end of the three month pilot project. As part of their interviews, participants will be asked to take the Addiction Severity Index and HIV risk behavior index.

Registered participants will be urged to use varied evidence-based treatment modalities and wellness programs to assist them in reducing their drug and alcohol use. Each participant can earn individual reward incentives by making every day healthy behavioral changes. For example, attending mental health and substance abuse/harm reduction support at the Tapestry Health La Voz program would allow participants to earn tickets. Other possibilities for earning tickets include attending various recovery support groups (including Twelve Steps) and making other behavioral changes (attending nutrition and health education classes, doctor appointments, yoga class, meditation, etc.). Each reward incentive ticket earns a chance to win the \$100-250 gift certificate. If the

person holding the chosen ticket has a negative toxicology screen and minimal BAL (breath alcohol level) result, they win the prize for the week. If the person does not have a negative toxicology screen and minimal BAL result, then another person is chosen as the winner, and their toxicology screening is checked. This continues until we find a participant with the minimal requirements we set. We hypothesize that our pilot study will mirror research done by The National Institute and Drug Abuse's study titled "Motivational Incentives for Enhanced Drug Abuse Recovery" which found that "even the occasional chance of winning a prize for producing a clean urine sample is resulting in longer stays in treatment and a longer period of continuous abstinence" (Alcoholism & Drug Abuse Weekly 2004: 1).

Community organizations, healthcare providers, wellness experts, and career training specialists will provide varied activities for healthy behavioral changes to reduce the overall health risk for the individual, their families, and the larger society. To help make behavioral changes long lasting, it is important to have a variety of choices for individuals to use. The public health model argues for saturation, that is, providing people with information in a variety of ways, with a variety of options, and over long periods of time. As a pilot project, we will have limited time to show behavioral change. But we believe that the more healthy options that are provided, the more likely people are to stick with this new program. If we also integrate this program into already-established substance abuse research programs, behavioral interventions, and wellness activities, then participants will have the formal support they need to continue with the behavioral modifications, even if the program is unable to sustain funding over long periods of time.

If the program is associated with other well-known community projects and recovery programs, it increases the likelihood of sustaining the program.

Another critical component to the program is its focus on HIV prevention. As mentioned above, drug and excessive alcohol use can increase HIV transmission risk-taking behaviors among both infected and uninfected people (Conigliaro et al. 2003; Metzger & Navaline 2003; Mitchell & Oltean 2007). Thus, a program that reduces harmful drug and alcohol use behaviors is likely to reduce the risk of spreading HIV. Research supports the use of culturally-competent preventative services to enhance treatment and decrease client HIV risk behavior. Therefore, we will include HIV and Hepatitis C prevention in our health education courses. This is intended to improve the layperson's health literacy and promote prevention through increased knowledge.

Qualitative and quantitative assessments of this program will be done. The qualitative phase will consist of an ethnographic program assessment. Research supports this type of process evaluation of pilot interventions (Higgins et al. 2005). Interviews and field notes will be gathered and focus groups will be conducted with community members, substance users, and medical personnel to discuss program experience and open-ended feedback. I will record the information observed and gathered resulting in a large body of data to be organized and analyzed. Qualitative data analysis consists of interpreting this body of data by organizing material, finding patterns, and drawing links between concepts and themes emerging from the research. For the purposes of this project, I would use either NVivo computer software or MaxQda to aid in the data analysis phase. This would allow me to systematically record information, organize texts, and code texts. It would thus make it easier to see the links between different

materials. Quantitative data to be collected includes the number of program participants, the number of weeks participants were actively earning tickets, and the types of health activities being used for recovery and program participation. If a program like this could be funded and sustainable for Tapestry Health in Springfield, then this study could be used as a community harm reduction intervention model for other urban settings. An informative website would also be created regarding program goals and results.

### **Feedback from the Expert**

Over email, Jamilah reached out to Nancy Petry, a lead researcher on contingency management, to get feedback on our proposal. We asked to meet with her about our project with the hope of gaining insight into the creation of contingency management programs. A lot of what happens in the creation and implementation of community-research projects does not get written into the research articles. We were interested in the complications that arose and how to best address funding agents about the project. Unfortunately, Dr. Petry was unable to meet with us in person because she went on medical leave. Instead, she provided us with some feedback via email. She recommended a change in the original name of our project that would direct us away from the sweepstakes idea. She also recommended that we provide smaller, more regularly reinforced prizes instead of one large prize.

At first Jamilah was resistant. Given that I wanted my dissertation to be community-driven and organic, I did not want to force my community partners into anything. And given that this project was Jamilah's brainchild, I was uncomfortable pressing the issue even though I agreed with Petry's original recommendations. This caused some partnership conflicts as the research already done by Petry and colleagues

suggested that we needed to revisit some of our original program characteristics. Over time, and after feedback from Baystate on our grant proposal, Jamilah and I agreed that Petry's recommendations needed to be addressed more directly in our work. We brought Petry's feedback to Tim, who also agreed that we needed to make our project more similar to other contingency management projects that had already been funded.

### **Research Partnership on Hold**

Sometimes life seems to throw you into a perfect storm of disappointments. After finding that Tapestry's funding was cut and we had received a formal rejection letter from Baystate regarding the funding our project, Tim sent us an email ending our collaboration with Tapestry on this project. In his email, he wrote that, while he believed the idea was good and he was interested in using contingency management, he could not devote time to this project until/if funding opportunities became available. He expressed appreciation for our effort and dedication, and, although leaving the door open for future collaboration, said he needed to devote time to established projects and to finding more sources of funding to make up for cuts. We understood this decision, and hope to approach him in the future as we revise our proposal and increase our collaborations. Losing our community partner meant that Jamilah and I needed to suspend the overall project itself. We needed to reassess both our partnerships and our approach to this project. We needed to consider new ways to establish multiple research and community partnerships to increase the likelihood that the program would be funded.

### **Analysis**

In another attempt to gain more knowledge about established community-research partnerships, I submitted a project proposal to the UMASS Symposium on Community

Health and Research: Making the Connections. On November 4, 2011, I presented our project proposal at their Poster event held in Shrewsbury, Massachusetts. I created a poster which included our abstract, background information, project details, and my larger research connections regarding the sustainability and challenges of community-research partnerships in health interventions. The poster received good feedback at the conference, and people seemed interested in the possibilities of such a program. I met researchers and community health workers from across Massachusetts, all working on community research teams. Although verbal feedback across the board was good; follow-up proved difficult; people rarely responded to email or followed up after I left phone messages. Making frequent unannounced trips to Boston was not feasible.

Many well-established research-community partnerships were located in Lawrence, Massachusetts. This possibility again showed how difficult collaboration can be if you do not quickly establish a mutually beneficial relationship. I contacted individuals with the hope of interviewing them and discussing how to improve our project, but without advocating for how we might be able to assist them. Without establishing how our own project might support or improve their own, already-established research-community partnerships had no buy-in to respond to my inquiries.

Even though the Road to Recovery Springfield program itself has yet to be implemented, the community-research partnership has been established and maintained, at least in part. While our more formal collaboration with Tapestry is on hold, the three of us (Jamilah, Tim, and I) run into each other at Holyoke political and social events. We continue to be dedicated to community interventions and interested in finding a way to

make this program happen in the future. My work with Jamilah and Tim has highlighted some of the challenges in community and academic partnerships.

In line with a research and community intervention program interested in following a CBPAR model, we attempted to meet the basic requirements of this collaborative process. I was originally contacted by Jamilah regarding the idea for this pilot program. She asked me to be the primary researcher on the project while she remained the program originator and health consultant. We worked diligently to flesh out the original ideas before bringing a proposal to Tim at Tapestry Health. This partnership developed over several months of phone calls, email exchanges, meetings, and work visits. Jamilah spoke with many of her Baystate clients regarding the project idea and found both verbal support and community interest. She spoke with colleagues at work who encouraged her to pursue grant funding and healthcare funding from Baystate.

Six years ago, when I originally started looking into community-based participatory action research, the only real guidelines I found on how to create community-research partnerships had been established by Community-Campus Partnerships for Health. These guidelines were hundreds of pages long and not practical for on the ground to use. I felt there was a need for something that was more user-friendly and interactive for community-research partnerships. The Executive Summary was helpful; although still not accessible enough to share with community partners. A recent conversation with a colleague from the organization, MotherWoman, mentioned research that I believe would be helpful in pursuing this and future research. There is now a Partnership Readiness for Community-Based Participatory Research Model that identifies major dimensions (Andrews et al. 2011). A seventy-five page toolkit was

created and piloted at the Medical University of South Carolina's Community Engaged Scholars Program. Further testing outside the geographic region has yet to take place. I believe this type of research and collaboration training would improve the probability of intervention implementation by assisting us in networking new and sustainable partnerships. Realistically, I wonder how often people use these resources and how they get used. Do researchers use them to learn how to best establish and implement research-community projects? Are the resources then shared by researchers with their community collaborators? Is the material shared and presented in collaboration meetings to build trust and to establish roles? Or is the material used only when problems arise? Curriculum established by a few schools has provided me with some new insight into CBPAR and new ideas for revising this project.

Earlier in this chapter, I asked a question about the complexities of defining an activity as community-based research. The question asked whether research can be community-based if the community or representatives of the community (i.e. a service agency) was/were not part of all stages of the research and project development, but had agreed to this type of collaboration? Given my experience and the research on university-community partnerships, I would say that research that does not have community partners as critical and valuable team members with direct involvement is not truly collaborative. Different stakeholders should have similar access to the research and knowledge regarding the project goals, and without full participation, this does not happen. Without this mutual understanding, collaborations are difficult to maintain long-term. For this reason, establishing all collaborators as knowledge producers and real team members is critical to long-term sustainability of community-based projects.

Our project is a harm reduction program that is evidence-based and could make significant contributions to already-established Springfield substance abuse intervention programs. Our ability to move forward on this project is highly dependent on larger collaboration and funding. Collaboration can be seen in Springfield, but it is often incomplete or disconnected. Springfield also suffers from a negative reputation that depicts healthcare programs and community organizations often working alone instead of together. Working together and creating innovative solutions are both critical to addressing community needs. It is imperative to look at functioning partnerships that can help us improve our own research-community collaborations.

With an interest in locating on-the-ground creative intervention strategies with real world implications for health, I found a Chicago youth-violence prevention program titled "Becoming a Man" (B.A.M.). This program is a "school-based counseling, mentoring, violence prevention and educational enrichment program that promotes social, emotional and behavioral competencies in at-risk male youth" (Becoming a Man). It was created to address the youth crime rate in Chicago's toughest neighborhoods, and the social factors that create high youth crime rates, including lack of male role models, limited social support, and low educational opportunities. By noticing that, instead of jail time, young men needed more formal support, Youth Guidance's Anthony DiVittorio created B.A.M. to provide a safe space for young men to receive emotional and educational support. According to Youth Guidance's Chief Executive Officer Michelle Morrison,

The University of Chicago Crime Lab study shows that Youth Guidance's B.A.M. program reduces youth violence, increases school achievement and helps Chicago's young men reach their

full potential. 'Becoming a Man' helps young men find evidence of their worth, strengthen their connection to and success in school, and help build safer communities (Becoming a Man)

A randomized clinical trial was done to assess this type of prevention program. Data was collected from the Chicago Public Schools and the Illinois State Police which showed that the B.A.M. program works and is cost-effective. Results showed that social-cognitive skills were strengthened, violent crime arrests were down by 44 percent, and graduation rates increased by 10 percent (Becoming a Man; University of Chicago Crime Lab).

I use this program as an example because the stigma of youth violence is similar to the treatment of substance abusers. This program shows that creative interventions for community-level problems can work when provided the necessary funding and community-research support. It is this idea that moves us forward and has us pushing to create a unified public health agenda that places community at the center of the research and before doing interventions. Our idea for a contingency management program in Springfield is supported by the research literature; however, we still need to establish a strong community voice, clear healthcare professional partnerships, and a strong funding stream in order to move forward.

The Road to Recovery Springfield program has also shown me the importance of taking into account the role of funding agents as collaborators in the process of doing community level health interventions. Funding agents rarely are discussed as a necessary component to community-based participatory action research in the published reports. If they are discussed at all, they typically are mentioned in the acknowledgements for funding the research. But what happens when you have an idea that is supported by

research, but you cannot get it funded? What are the factors that determine financial support of evidence-based programs that are not well known? Obviously, from Baystate we learned that the perception of a program was more important than the supporting research. But what other factors, besides perception and stigma, determine grant funding?

My research into contingency management highlighted a number of problems with getting grant funding that were compounded by the challenges to doing community-based research and program development. At the local level, funding for pilot and community intervention programs was limited by numerous agencies fighting for the same resources. A lack of wide-spread knowledge about contingency management programs nationally meant that, at the local level, agencies would have to take a chance on a program still considered an alternative to the already-established norm. The cost of this type of program is substantial, so even if the research and American cultural norms were to support this type of intervention, the likelihood of funding support is limited.

In the end, we created a harm reduction program that has yet to be implemented. We all continue to agree that there is a real need for this type of program in Springfield, but given our differing needs as stakeholders, have had to put the push for funding on hold. We remain dedicated to the process, and continue to fight for implementing the program through alternative revenue strategies. Indeed, it is the dedicated individuals like Jamilah and Tim that make health interventions successful. While this project remains incomplete, it is critical to ethnographically evaluate the effectiveness of community-research collaborations through personal observations and interviews with main collaborators. The ethnographic case study of the substance abuse research-

community collaboration provides further data on the successes and challenges of creating and sustaining community-research partnerships. And while this case study remains an unfinished story of commitment and concern for a largely stigmatized part of the Springfield community, we learned a lot about what it takes to create and implement a substance abuse harm reduction program with limited resources.

## CHAPTER 5

### HOW CAN WE FIX WHAT'S BROKEN IN OUR COMMUNITIES? ADDRESSING THE DISPARITY IN HEALTHY EATING AMONG SPRINGFIELD RESIDENTS

#### **Research Story/Vignette 7: Trust is Earned**

On the evening of February 15, 2012, I sat in the conference room that Universal Community Voices Eliminating Disparities (UCVED) shared with other organizations in their (previous) office building at 640 Page Boulevard in Springfield, Massachusetts. I was waiting to interview Betty Agin, the community leader who founded UCVED in 2009. Prior to this I had co-led monthly health roundtable discussion groups and monthly community conversations with another community leader, Juan Montoya\* and a health professional, Dr. Joseph Frames\*. That day, Betty arrived in a frantic state because she was late, and then proceeded to inform me she had to leave early. We would only have about 60 minutes for the interview, but she said she would be available again if I wanted. When Betty sat down next to me, she told me "to begin." I asked her some questions about her life, her work as a community organizer, and her passions. I ran the interview informally, probing her for more details throughout the interview. I have observed Betty and her facilitation style for over two years and was interested in getting more information about why she was a community organizer trying to improve health disparities and increase community involvement in Springfield.

The most salient part of this discussion was when we discussed the idea of collaboration and trust. At first, Betty said that she did not "really think about trust, it's intuitive." Yet, as we continued the interview and discussed the concept of trust, a

pattern arose that, while she wanted to trust people to do the work she did, it was actually really hard for her to trust them. In fact, when I asked her if she wanted my help, she said yes, but when I asked if she would allow me to assist in my own way and without her micro-managing me, she hesitated. She said she "likes things done her way, because she knows how to do it (i.e. organize) in her community." Her hesitation comes from a history of working with people who did NOT step up to the leadership roles she asked of them.

As a researcher collaborating with community leaders from historically marginalized communities, I am aware of the past negative experiences community members have had with academics. I try to walk the walk of true collaboration. I remember the legacy of grave robbing and of medical experimentation on Black bodies and other marginalized populations. And this history is never truly forgotten, nor do I believe it should be. In fact, the misinformation and stigmatization of people of color continues with our media today. And so I believe it is up to the researcher to show the community that they are there with the best of intentions and with the goal of collaboration. The concept of reciprocity also comes to mind. Betty needed to see, from me and others like me, that our relationship was mutually beneficial and that I was not working with her to get my research done and then leave. And so, I must remember that I am both an academic (outsider in the community) and a woman of color (an insider or part of communities of color). And both of these social positions influence my research, my collaborations, and my power in the community.

## **Establishing UCVED as a Community Partner**

As I stated in earlier chapters, I wanted to make sure that my presence as a researcher did not dictate my project's research questions or the community intervention projects associated with it. I struggled with a desire to finish my dissertation quickly and making sure it was relevant and useful to the community I worked with. I did not want to force my research questions, and instead spent over a year working in Springfield, watching and participating without driving any of the community meetings. This time was helpful to me. It allowed me to watch as coalitions were built, grassroots initiatives were begun, organizations lost members, and gatekeeping strategies were used to limit the flow of information and resources in the larger Springfield community. I became most interested in how Springfield Health Disparities Project, later called UCVED, defined health, the social determinants of health, and community-research collaboration. I was interested in seeing the health equity dialogue took place at the community level. I wanted to explore how community partnerships are built and sustained. I wanted to learn how community members maintain their own passion and drive for the social issues they are working to address, especially when projects often take years to develop and gain support. I saw the potential for the development of multiple partnerships through a grassroots organization like UCVED. And so for the first year, I participated in meetings, community events, and a healthy equity conference as a member of UCVED. Everyone knew my affiliation to UMASS and HCC, as graduate student and professor. I made sure that I was transparent about my interest in the organization and my desire to use my work with the organization as a foundation for my dissertation.

## **Meeting Betty & UCVED for the First Time**

On April 11, 2009, I attended my first Springfield Health Disparities Project (SHDP) Roundtable discussion at Tapestry Health, 365 Bay Street in Springfield. I was invited to attend by my good friend and colleague, Julie Skogsbergh. She had received an email about the event through a listserv. The information about the roundtable read "Addressing existing disparities in healthcare and outcomes, and the underlying racism, poverty, and homelessness. Info: Betty Agin, 627-4028, [betagi7@verizon.net](mailto:betagi7@verizon.net)" (Email correspondence Julie Skogsbergh 03/31/09). Considering our common interest in health equity work, Julie and I decided to check out this roundtable health discussion. We arrived a little early and introduced ourselves to the three organizers: Betty Agin, Dr. Joseph Frames\* & Juan Montoya\*. Betty, with whom I have worked closely for four years, was the first friendly face. Right away, I was instantly charmed. Betty was dressed in her Sunday best, and I was reminded of my many visits to Black churches over the years. She had on a billowy hat, a dress and heels. Betty looked to be in her 60s, but with very few wrinkles on her face. She was formidable, and I appreciated that, for we had that in common. Dr. Frames\*, a White doctor who also collaborated on this project in the first 2-3 years, was dressed in dress pants and shirt. He looked a bit out of place since the meeting was attended mostly by people of color, with a larger representation of Blacks. Juan\* was dressed more casually in jeans and a t-shirt. Julie and I were also dressed more casually, in jeans and nice blouses, but knew we had to pull out our Sunday best for the next event. We sat down as the meeting was about to begin.

On the agenda for this meeting were community health updates, a presentation by the Springfield Food Policy Council on Hunger and Nutrition, and information about

upcoming SHDP activities, including the Healthcare for All annual conference on Health Disparities taking place on June 19, 2009. The meeting ran smoothly. Community event information was dispersed and collaborations were established. There were 18 people who signed in, including representatives from Western Mass Jobs with Justice, Health Care for All, SHDP, Springfield Health Department, Food Bank of Western Mass, The American Cancer Society, Springfield Partners for a Healthier Community, other healthcare professionals, and unaffiliated community members. Excitement over the upcoming health disparities conference was palpable. People remained respectful of the presenters and the time.

Originally, the meeting was scheduled to range from 9:30am until 11am. However, given the amount of information being discussed and the number of community representatives at the roundtable, we ended closer to 11:30am. We then decided as a group that staying an extra half hour once a month would be fine. The meeting ended with a short evaluation sheet asking for participants to provide feedback for improved group facilitation. As we got up to leave, Betty approached us again and asked us to return again next month. We said we would.

### **The History of UCVED**

Universal Community Voices Eliminating Disparities originated as a community effort called the Springfield Health Disparities Project (SHDP). The original mission statement of the Springfield Health Disparities Project stated "bringing community people & leaders together to learn & work to achieve health equity for all" (Springfield Health Disparities Project Handout 2009). It started with a small group of people who were concerned about many different health issues coming together to address the

difference in health access for poorer urban communities. Betty Agin, the driving force behind Universal Community Voices Eliminating Disparities, originally started community organizing by getting connected to Neighbor to Neighbor in Springfield in 2006. In 2007, Health Care for All contacted her with an interest to establish a community-level initiative to work on health disparities in Springfield. Health Care for All, a Boston-based consumer health advocacy group working for a more affordable and accessible healthcare system in Massachusetts, offered to give Betty some financial support to get started. A Health Care for All team member helped Springfield and Worcester develop programs rooted within the community. Community leaders were responsible for addressing and resolving structural barriers to a healthier life.

Early on, SHDP was a very active, highly visible organization with some financial, academic and city resources. Public Health faculty at UMASS, Health Care for All representatives, Springfield Partners for a Healthy Community, Baystate and Springfield Health Department representatives were visible and participating in the work SHDP was doing. Their approach was simple: whenever SHDP members heard of community problems, they attempted to fix them. They organized Saturday roundtable discussions and community conversations on health asking questions like "Do you have transportation to get to doctor's appointments? Do you have healthy food options in your community?" The goals of SHDP were to empower community residents to become community leaders and authorities on the health of their neighborhood. Simultaneously, they would act as advocates on critical issues needing immediate attention. Betty Agin, a middle-aged Black woman originally from the deep South with a desire to help her community, decided to eventually expand the reach of SHDP and founded UCVED out

of a desire to support and empower people who did not feel they had a voice in Springfield politics.

Two examples of UCVED's community actions early on included getting grocery stores to stock fresh vegetables and convincing the Pioneer Valley Transit Authority (PVRTA) to change bus locations to improve grocery store transportation for residents with minimal access (Dias 2009; Community Catalyst 2010). This work was done in collaboration with the Mason Square Health Taskforce. In fact, the work of UCVED was included in a Health Equity Report from Boston, which stated :

Universal Community Voices Eliminating Disparities: This Springfield, Massachusetts, community-based organization determined that one factor in the poor health of some predominantly minority neighborhoods was the distance – up to a mile – of supermarkets from the nearest bus stop. The organization, along with other Springfield groups, worked with the local transit agency to reroute buses to stop near the markets (Community Catalyst 2010: 10).

These are just two examples of the power that can be harnessed at the grassroots level with leadership and team players.

### **Healthy Eating: Do We Have a Problem?**

We all know that to live a long and happy life, we need to be healthy. But what constitutes "healthy," and what is health, really? Is it the lack of illness and disease, or a state of mental and physical wellbeing, or a combination of having basic needs and wants met? No matter how you define health, scientists and medical professionals agree that combining fresh whole foods and an active lifestyle can lead to a more healthy life. Even in a high-income nation like the United States, we find that some people have limited access to quality healthcare and other necessary resources. This disparate access has a

number of negative effects on health outcomes, including obesity, diabetes, infant mortality, asthma, substance abuse and more (Healthy People 2020). Although UCVED takes an intersectional approach to health by acknowledging how social determinants of health impact all health issues in Springfield, this case study primarily focuses on the healthy eating initiative work that UCVED has done.

In many low-income communities across the United States, the only places to buy food are convenience stores and fast food restaurants that sell mostly fatty, sugary, high-salt processed products. These same communities tend to have a high concentration of liquor stores and limited green spaces. With these specific barriers and no full-line grocery stores in site, is it any wonder obesity, diabetes, and substance abuse rates remain high? Access to grocery stores with fresh fruits and vegetables continues to challenge many American communities that live in "food deserts." The United States Department of Agriculture defines food deserts as parts of the country, usually impoverished areas, which have minimal access to fresh fruits, vegetables, and other healthful whole foods. Studies also find that there are fewer supermarkets and other retail outlets selling affordable, nutritious food in low-income neighborhoods than in wealthier neighborhoods. Also Black and Latino communities tend to have fewer grocery stores. These are all social determinants of health that have an impact on people's lived experiences and the choices they make every day. In a culture that values excess and consumerism, we must acknowledge how social structures constrain people's decision making.

Studies have shown that fruits and vegetables are under-consumed by Americans from all income levels and racial communities (Grimm et al 2010; U.S. Department of

Health and Human Services & U.S. Department of Agriculture 2010). Meeting dietary fruit and vegetable recommendations is particularly challenging, however, for low-income communities and communities of color. Some of the reasons for this include limited healthy and affordable food resources, transportation and grocery store access, low wages combined with high food prices, unemployment, and inadequate Supplemental Nutrition Assistance Program (SNAP) benefit levels. Consumer choices about food spending and diet may also be influenced by the fact that healthier food is often higher in cost, lower in quantity and simply less available in low-income neighborhoods.

People of color experience more severe health outcomes for obesity, diabetes and heart disease (Healthy People 2020). Often, culture and genetics are blamed for the poorer health outcomes of people of color; however, in the last decade, more research has demonstrated how numerous social determinants of health, including racism and classism, are contributing factors to poor health (Krieger et al 2011; Krieger et al 2005; Krieger 2003; Richard & Collins 2007). UCVED's work involves a multi-faceted approach to health that is critical to better understanding how to reduce the harm being done at the individual and population levels.

### **(Un)Healthy Massachusetts: Highlighting Springfield**

*"Being Healthy is a good metaphor for everything...  
Healthy community, healthy societies...  
Here all economic disparities could be addressed  
with this idea [of good health]"  
-Jon Weissman*

Healthcare professionals and researchers agree that access to healthy food and safe outdoor areas for physical activity is a key factor in obesity, a leading epidemic in America (Healthy People 2020). In 2008, Massachusetts Governor Deval Patrick

released a Call to Action report detailing the extent of the obesity epidemic in Massachusetts. This report highlights the percentages of adults and children with obesity, which amounts to more than 50% of the adult population, and almost 33% of youth being either overweight or obese. According to this report, obesity for adults in Massachusetts had more than doubled in less than twenty years (2008). Studies have also shown that excess weight is a contributing factor to developing chronic illnesses like diabetes, some cancers, and heart disease (Ogden et al 2007; Ogden et al 2008). Obesity is preventable, with social and economic costs to the individual and society. In Massachusetts alone, obesity and obesity-related illnesses cost the Commonwealth millions of healthcare dollars each year. Obesity is also a health equity problem, as the

health and economic impact of obesity is not borne equally by all Massachusetts residents. Race and ethnicity, gender, socioeconomics, disability and geography are all factors in obesity disparities. For example, according to data collected between 2003 and 2007, in Massachusetts, Black and Hispanic adults were respectively 60 and 50% more likely to be obese than their White counterparts. The racial and socioeconomic disparities of childhood overweight/ obesity parallel those found in adults. In 2007, Black high school students in the state had the highest rates of obesity (22%) followed by Hispanic students (15%) students. This compared with a 9% rate of obesity for White students" (Mass in Motion: Call to Action 2008: 1).

In the past 5 years, Massachusetts has implemented a few programs to address this epidemic. According to a 2012 CDC report regarding Massachusetts response to obesity, the Commonwealth launched Mass in Motion in January 2009. First, Massachusetts public schools are measuring the height and weight of students in grades 1, 4, 7, and 10 to determine whether a child is at a healthy weight. Then, parents are given this information in the hope that this awareness will facilitate change in food consumption in the

household. Massachusetts is one of 21 states that routinely measures student height and weight. Second, Mass in Motion Leadership grants were provided to cities and towns interested in making wellness initiatives and healthy living a community-level priority. Springfield was one of the cities given a grant to implement a few projects that will be discussed later in this section. Third, a statewide workplace wellness program was implemented in the hopes of providing a healthier work environment and reducing sick and personal leave taken. Fourth, a Safe Routes to School Pilot program was funded to encourage children to bike and walk to school by creating safe physical environments. Fifth, a statewide resolution entitled "Board of Health Resolution: Planning for a Healthier Future through the Built Environment and Community Design" reintroduces public health concerns into the development and planning of urban land use. All of these projects were developed using a public health model of saturating the community with necessary resources and information. Unfortunately, this information is still hard to find at the community level given that the services have not yet been expanded to all schools, workplaces, and city neighborhoods.

As part of the Mass in Motion (MIM) Wellness Grants, neighborhoods in Springfield were identified as lacking safe areas for physical activity and high obesity rates. Two programs were implemented: the Open Gyms Program and the Walking School Bus project (Sacheck & Glynn 2012). The Open Gym Program created a joint use policy that promoted youth physical activity by allowing school gyms to remain open to the public during after school hours in winter. While only three of the fifty-four schools in Springfield have signed up for the Walking School Bus, this program is employs staff member monitoring to create safe walking routes to school. Expanding this

program to other schools and acquiring stipends for parents to monitor the children could provide a more successful and sustainable program. Stipends to parents would address some of the financial reasons parents may not be able to do this regularly for their own children.

Research has found large sections of Springfield to be "designated as 'food deserts,' due to the lack of quality fresh fruit, vegetables, fish, and meat. This means the population is more dependent on fast and processed food, and is at further risk for diabetes, obesity rates, and other nutrition related health problems" (Preliminary Discussion of Environmental Health Issues in Springfield MA 2012: 7). With one of the highest rates of obesity in Massachusetts, Springfield has a complex problem of poor health that is exacerbated by its increasing economic disparities, disproportionate exposure to environmental hazards, and limited access to community gardens and safe green spaces. In Springfield, 43.6 percent of its youth are overweight or obese (Sacheck & Glynn 2012). Since both access to healthy foods and a safe physical environment are challenges held by Springfield residents, it is critical to address both problems simultaneously with community action and social policies. Another social policy, Springfield's first Bike Lane, came out of the Built Resolution. It was supported by a 2 million dollar grant from the Centers for Disease Control and Prevention's Community Transformation Grant initiative to the Live Well Springfield coalition. Until November 25, 2013, there were no official bike lanes in the third largest city in Massachusetts. This initiative is a crucial component to the work being done to reduce obesity in the city. The first bike path opened in the Sixteen Acres neighborhood. Currently, further research is

being gathered by Live Well Springfield to determine the next neighborhood to receive a bike path.

According to Governor Deval Patrick's administration, Springfield has 69,612 people in households that receive food stamps, or about 45 percent of the city's population (Ring 2013). This highlights the economic disparity that plagues some Springfield communities. Similar to contingency management for substance abuse, a new pilot incentive program was created for families with SNAP benefits to promote the purchase of healthy and whole foods. In 2008, The Food, Conservation and Energy Act "authorized funds for pilot projects to determine if financial incentives provided to Supplemental Nutrition Assistance Program (SNAP) recipient at the point of sale increased the consumption of fruits, vegetables, or other healthful foods" (USDA Healthy Incentives Pilot Interim Report Summary 2013). The Healthy Incentive Pilot (HIP) program operated between November 2011 and December 2012 in Hampden County. 55,000 SNAP households exist in Hampden County and "of the SNAP households in Hampden County, 7,500 were randomly assigned to the HIP group and the remaining households to the non-HIP group" (USDA Healthy Incentives Pilot Interim Report Summary 2013).

The HIP program conducted pre- and post-surveys to assess participant attitudes, shopping patterns, and preferences for healthy food items. EBT transaction data was collected to determine participant spending and incentive earnings for the first 6 months of the pilot. Preliminary findings suggest that having a financial incentive in place for buying fruits and vegetables does work for some families, with two-thirds of the HIP group earning incentives during the first 6 months. Also the participant satisfaction

survey showed that ninety-five percent of participants wanted to continue participating in HIP. I postulate that this could mean that, given more time, even families that did not earn an incentive early on might over time shift their buying focus.

Over the past five years, the "percentage of the state's public school students who are overweight or obese has significantly dropped," according to newly released data by the Massachusetts Department of Public Health. This new data suggests that "the childhood obesity epidemic may be receding" (Lazar 2013). "Researchers are still analyzing the data — based on annual weight and height screenings — to determine which of many school- and community-based nutrition and physical activity programs may have had the greatest impact" (Lazar 2013). This is not the time to stop, but instead, this should give us the drive to continue the community level and state-side interventions. This positive outcome may provide us with further insight to address the problem of adult obesity in Massachusetts.

### **The Original UCVED Transformed**

Having three co-facilitators from very different communities within Springfield was both a strength and a challenge for UCVED. Dr. Frames\* represented the primarily White, formally-educated, medical establishment. Betty Agin, representing the Black community in Springfield, had a strong reputation of making things happen. And Juan\*, being Boricua and bilingual, had a strong presence in the Latino community. Given their racial backgrounds and differing speech patterns, Betty, Juan\* and Dr. Frames\* remained an odd collaborative team. They often seemed to struggle to speak each other's "language." Dr. Frames\* was a bit stiff and had more formal education and greater access to resources, whereas Betty and Juan\* seemed to come from a more working class

and grassroots organizing background. All three had very different speech patterns: Dr. Frames\* spoke in a standard New England English, Betty's English dialect had southern overtones, and Juan\* was an English as a Second Language speaker. Little by little, the dynamics of the organization changed. First, Dr. Frames\* and Juan Montoya\* left the organization sometime in early 2009 and late 2009, respectively. Dr. Frames's\* departure was briefly explained by Betty as due to a difference in educational background and leadership styles – Dr. Frames often "talked down to her and other community members." Juan Montoya\* left due to personal reasons and to spend more time with his parish. Health Care for All remained associated with the Springfield Health Disparities Project until July 2010.

By 2011, Betty was running UCVED with a Board of Directors. During this time, I was an active participant in meetings and events and a strong team player. The main focus of the organization at this time was the Saturday roundtables, which were informative community meetings providing members with health information not readily accessible in the community. These meetings happened every second Saturday of the month, and all discussed some aspect of population health. Health and other social disparities were linked with presentations being held by the Fetal Infant Mortality Review (later name changed to Project Baby/Proyecto Bebe), the Food Bank, the Pioneer Asthma Coalition, Tapestry, UMASS Food Sciences, Western Mass Jobs with Justice, and more.

Community members and representatives of other health organizations came and went, and only a few UCVED members consistently attending meetings. Membership in the organization was free, and there did not seem to be a clear revenue stream. Betty facilitated all meetings for the first few years I attended. As time progressed, she

proposed that others step up and facilitate the meetings. At the first meeting I facilitated, she attempted to have me do it "her way." Having facilitated meetings, presented at conferences, and taught numerous classes, I knew how to facilitate a meeting; just not her exact way. I realized I would have to push back a bit in order to gain her respect and trust. To lead a meeting, she said, you needed to be strong and take charge. At first, she was apprehensive, but over time, she did allow for me to have a leadership role and be my own person. Because she is older than I, I had to walk a fine line between standing up for myself and respecting her authority. I have managed that line fairly well most days.

### **Collaboration with UMASS Food Science**

In 2011, I began to take a more active role in UCVED by creating a Healthy Eating Taskforce group. I started these efforts after seeing a presentation given by some undergraduate and graduate students of Dr. Kalidas Shetty, a UMASS Food Science professor originally from India. His interest in community-engaged research allowed for a collaboration between Dr. Shetty and his UMASS grant funding resources, a few UCVED community members, Holyoke Community College students, and myself. Dr. Shetty got involved with UCVED through one of our other members, Bessie Crenshaw. Bessie introduced Dr. Shetty to Betty and UCVED so that Dr. Shetty could do some community engagement work in Springfield. In an interview with Dr. Shetty on March 15, 2012, he said that he was "endeared by her [Betty's] demeanor and her open heart." In the interview, he also highlighted what he believed was needed to do good community engagement. First, he emphasized the need for researchers to feel a clear and empathic sense of engagement with the community. Second, he discussed the need to find a

"nucleus" of passionate people willing to work together. And finally, he linked the idea of community to specific spaces, personal alliances, group empowerment, and a sense of global connection.

He also spoke about his strong connection to Springfield and the Black community even though he lived and worked in a predominantly White middle class area in Amherst. When I asked Dr. Shetty about the challenges that exist in doing community engaged research, he spoke about the need for researchers to *show up* for the community, to be "clearly empathetic," to show they can interact with the community outside of their research. He spoke about many of the ideas that I have found in doing this work – the need for funding, the need to put your financial and social resources into the project as a researcher, the need to educate, and the need to use what is available effectively. For example, Dr. Shetty spoke about plugging Hadley farmer surplus into lower income communities, facilitating more small scale urban farming, and networking across communities.

Dr. Shetty and his UMASS student team, Betty, UCVED, and I, along with my students, Linda Sickler and Nicole Ouimette, made a strong collaborative team. The collaboration was based on our mutual strengths and our definitions of community. Dr. Shetty said it best when he said that community needed to be connected to the idea of empathy, worldwide. He said that to build collaboration, we needed to have a clear empathetic engagement and build trust between researcher and community. It was Dr. Shetty and my empathetic and community connection to Springfield that allowed for Betty to trust we were there to collaborate with her community, not take from it. The Healthy Eating Taskforce met regularly at the UMASS Food Science Building (Amherst)

and the UCVED offices (Springfield) to discuss creating healthy eating/cooking community classes in Springfield.

The following was written and submitted by me to the American Public Health Association Public Health Education and Health Promotion (PHEHP) Section newsletter on February 20, 2012 for publication in their Winter 2012 edition.

Director Betty Agin along with a few community members (David Gaby, Leroy & Bessie Crenshaw, Linda Sickler, and Vanessa Martinez) all members of Universal Community Voices eliminating Disparities Inc. (UCVED) have teamed up with Professor Kalidas Shetty from the University of Massachusetts Food Science to put together a *Cooking Healthy* program for the Springfield MA community. This new collaborative program will address the current disparity in fruit and vegetable consumption in Springfield, which is less than one fruit/vegetable per resident per day. We believe that a multi-pronged and long-term approach is necessary to adequately address this health issue. Since June of 2011, we have been doing the groundwork for creating a monthly cooking and eating healthy program in Springfield with cooking demonstrations, healthy adaptations to culturally important foods, and the support of community members. Our first event took place at St. John's Church with 50 community members participating in July 2011. Further steps to be taken include creating recipe cards for home use as well as starting a newsletter to go out to community members through regular mail and email. Currently, we are finalizing the location for our first *Cooking Healthy* demonstration and dinner program which is tentatively scheduled for late April 2012. We will also be adding a Cooking Healthy program to the CORI event that is organized through UCVED each summer at Block Park in Springfield. We invite other organizations to join us in this initiative and to feel free to adapt these ideas for their own communities (Martinez 2012: 15-16).

This article was designed to highlight some of the work that UCVED was doing on Cooking & Eating Healthy in Springfield.

Saturday April 21, 2012, the Cooking Healthy event was held in the conference room at 640 Page Boulevard in Springfield (where the UCVED office was previously located). Healthy food was prepared prior to the event, and recipes for all food were given out with nutritional information attached. My former student Linda Sickler, a non-traditional student with a culinary background, was essential to the Healthy Eating Taskforce team. With her culinary skills and passion for teaching and learning, the program was able to successfully hold the April, 2012, Cooking Healthy event and the Healthy Eating collaboration with the CORI reform event in June, 2012. To prepare for the Cooking Healthy event, we met multiple times in varied locations to decide on the menu. We knew we needed to start slowly and merge traditional foods with healthier options to make the event successful. We had a taste testing of the food for UCVED members prior to the event to ensure the menu was something community members would eat.

We had some difficulty merging healthier options with traditional/more familiar foods. Community members were a bit put off by certain healthier food options with names they had never heard of and which had unfamiliar flavors. We struggled to find a menu that was healthy, familiar, and tasty to them. We noticed different ideas of what was healthy, and ended up having to choose healthier items, but not the healthiest items. In the end, our menu consisted of oven-fried chicken, black beans and brown rice, corn bread, spinach, yogurt, salad, and pear dessert. Since our funding for the event came from Dr. Shetty's small research grant from the Pear Council, we made sure to include a delicious and healthy pear dessert. Channel 22 news arrived early to interview Bessie Crenshaw and me for a news report on the event. Ironically, the news report states that

"there's a group of women on a mission to give the gift of nutrition to inner city families" (<http://www.wvlp.com/news/local/hampden/ucved-holds-nutrition-cooking-class>). This editorial comment was made based on an assumption that, because women were serving the food and being interviewed for the event, no men actually helped out. This is not true. My husband, Bessie Crenshaw's husband, and Dr. Shetty all participated in some way to help out planning the event, cooking for the event, and setting up the room. It truly was a team effort, although Linda Sickler did the majority of the cooking. Leftover food, donated to some of the homeless shelters in Springfield, was dropped off by a former HCC student and her mother who also helped out at the event. We had hoped to have a greater turnout, but we knew that getting our name out would take time. Having events in different locations across Springfield would help us with name recognition and community participation.

After the April event, we needed to focus on the upcoming CORI reform event that we had decided to merge with the Healthy Food Initiative. Keith Peters was in charge of coordinating the CORI event, while Linda and I were in charge of coordinating the healthy food for the event. Coordinating this event was much more stressful than the April event. It was a much larger event to plan for. Difference in planning styles became difficult to manage. Linda and I both like to have all aspects of an event planned out while Betty and Keith seemed to have a more flexible attitude. Since we were doing new things at an event that had happened previously, I think it was difficult for Keith and Betty to make any changes. For example, Linda and I wanted to use some of the funding we had from Dr. Shetty to rent a large grill or two to cook the food. That way we would know the size of the grills, be responsible for their transportation, and be able to set up

early. But we were told by Betty and Keith that the grills would be there, and that no grills had ever been rented before. In the end, we deferred to the community organizers who had done the event before. We did not know who would be bringing the grills and in the end, that was a problem.

### **Research Story/Vignette 8: Merging Healthy Food & CORI Reform**

Poor eating habits are never just about limited access to healthy food; they are also about tradition and familiarity. People eat some of the foods they eat because they are used to it, they might have an emotional connection to the food, and because it is what they were raised with. So what happens when access to healthier foods increases? Do people automatically make the healthier choice? No. This was evident at the CORI event in Blunt Park on June 30, 2012.

Preparing for the CORI event was difficult. The CORI Independence Day event is an annual family event that provides information on recent CORI law changes and pro bono legal services to seal your records improving your job opportunities. Other community organizations could table at our event for a small monetary donation to the organization. Meetings to organize the CORI event took place over the course of 5-6 months at the UCVED office shared conference room. A flyer was recycled from the previous year with the CORI Independence Day event information specific to this year's event. I was also asked to translate the flyer into Spanish and be the contact person for the Spanish flyer as no one else knew Spanish at UCVED. Several Holyoke Community College students volunteered their time to call restaurants and businesses for monetary donations. These donations, along with Dr. Shetty's grant, provided us with the funds to

put together the event. Baystate donated bottled water and paper products for 300 people. I paid for ice out of my own pocket.

UCVED members were concerned about having healthy food options at the event; they agreed that healthy food should be provided as part of our mission, but they had a hard time letting go of the familiar and more processed items from years past. They argued that kids would not drink water, but needed juice or soda. They said that moving to chicken sandwiches complicated matters because uncooked chicken required getting a health permit to prepare and serve it. Our desire was to provide healthy chicken sandwiches instead of highly-processed hotdogs and hamburgers that had previously been served at events. We decided to add some veggies to the sandwich by having lettuce and tomato slices available. When doing the grocery shopping for the event, it became obvious that we did not have the money to buy enough chicken and whole wheat buns for 300 people. And with community members saying they wanted hamburgers and hotdogs available, we decided to have both options.

The day of the event, a few of us arrived early to set up. The grills were supposed to be on site an hour prior to the event at 10am. When we arrived, we set up the tables and organized the food. We had multiple coolers, some with food and some with drinks. We wanted to have some food prepared by 11am, but the grills did not arrive on time. In fact, the first grill did not arrive until 11:15am, and was very small. When we realized grills were not arriving, we started talking to community members helping set up for the event to see if they had a grill we could borrow. Because the grills arrived so late, food was not ready until around 12:30pm. People kept asking when the food would be ready and many of us were stressed.

Luckily, I had asked some HCC students and my husband to help out at the event. Dipayan, Dr. Shetty's graduate student, and Dr. Shetty's son both helped out with the food. My husband, Jamie Locklar, and Linda ran the grills while I ran errands, did set up, spoke with people, and handed out food. Our Healthy Cooking & Eating team ran fairly well, especially given the constraints and stress we were under. If Linda and I had been in charge of making sure the grills arrived, I believe we would have felt a lot less stress. Because the grills arrived so late, 1-2 hours late, it caused the food preparation to be delayed, and community people seemed quite frustrated by having to wait. Also, the hamburgers and hotdogs were the first things to be eaten. Most of our team and a few other people ate the healthy option. But even when the unhealthy options had ended and what was available to be eaten were the healthy chicken sandwiches, many people chose not to eat them. Maybe it was too much: wheat buns plus grilled, not-fried chicken. Perhaps, we should have done hamburgers on wheat buns or chicken on regular buns. Maybe it was too much change at one time. Unfortunately we did not conduct a survey for feedback about the food and what they would have wanted; we honestly did not think of it at the time. But this would be the logical next step to get feedback from community members at community events about their health needs related to cooking and eating healthy eating.

### **Healthy Eating Task Force On Hold: UCVED in Financial Crisis & Dr. Shetty Leaves**

There were a number of ideas we wanted to expand upon with the Healthy Eating Task Force. We wanted to provide classes for Boys & Girls Clubs, churches, and senior centers. We wanted to create a healthy cooking newsletter to be dropped off door-to-door and available at the Mason Square Farmers Markets and Emergency Rooms and

hospitals. The newsletter would provide tips to cooking with better oils, less butter, more fruits and vegetables, and lean meats and fish. A few recipes would be available with shopping lists and ideas for menu planning. The recipes would be culturally relevant by using foods and meals that community members know, yet would have healthier ingredients as during the April, 2012, event. Unfortunately, several issues arose after the Summer 2012 CORI event that have placed the Healthy Eating Taskforce on hold. After the CORI event, we realized we needed to look at our funding in order to better plan for events.

Over the years, I have moved from being an organization member to a leader in the organization. As I became a more central player at UCVED by joining the Executive Board in 2012, I realized that UCVED was in some financial trouble, had lost its 501c3 status, and was missing tax filings for multiple years. After learning of the financial hardship the organization was under, I contacted friends through a Facebook status update and asked for ideas on how to save a struggling grassroots organization. Friends responded with a few different suggestions, including doing house parties, looking at grassroots fundraising books, and meeting with already established gatekeepers. One colleague shared an insightful reference to the need to contact the Springfield Health Department, local church officials, and already established community based organizations (CBOs) to create clear pathways between struggling UCVED and the power players in Springfield. She ended her feedback by saying "As you know, Springfield is VERY political and to grow there without some political, church or established CBO connections is very difficult" (Facebook correspondence 2012).

I brought the feedback about fundraising opportunities to the group. Everyone agreed that fundraising was necessary, but very few people could commit to do the work. And honestly, I knew that, given my work and school schedule, I would not be able to do it alone. We did make some changes to the organizational and membership structure to address the need for funding. I created new membership and informational flyers to be handed out at other community events. We moved from a free membership structure to a sliding membership scale, allowing people to pay in yearly dues or volunteer their time as payment to help keep the organization afloat. Unfortunately, this was not enough. We needed to pay our taxes for previous years and address the money we owed for rent and other utilities. We needed to assess the financial viability of the organization and at minimum we needed a bookkeeper and some member training to get community members with certain basic skills to maximize our collective power. And we needed a steady revenue stream to continue our work after we got out of debt. Another problem that arose for the organization at this time was Dr. Shetty's sudden move from the area. He was offered a new position as Associate Vice President for Global Outreach and Professor of Plant Metabolism and Food Security at North Dakota State University. With him gone, we lost the limited funding we had for the healthy eating and cooking program. With UCVED having funding problems and our one financial resource moving away, we had to place the cooking healthy program on hold.

In truth, there are very few people in the organization that can give the amount of time and effort needed to fix its chronic financial and structural problems. In an attempt to focus our efforts on fundraising, I presented the Board with the idea of suspending the 2013 CORI event. Instead, the Board voted to go ahead with the event even though we

did not have the revenue to eliminate our debt and sustain the organization. One Board member stated that "in order to be a viable organization, we need to be known across Springfield for the work we do and be able to be financially stable" (2013). In reality, we were doing the former, but not the latter. We lost our office in August 2013 due to an inability to pay our rent.

It has been heartbreaking watching the organization slowly self-destruct. I have seen other collaborators slowly disappear from the organization as they move away, change jobs, are over-extended, and more. UCVED was originally supported by Health Care for All and UMASS Public Health faculty. Over time, these collaborations have ended, and the lack of resources has clearly caused UCVED to flounder as an organization. A little stability was provided by Dr. Shetty's support, but, again, when he left, he took his resources with him. What I bring to the table at UCVED is my time and energy and student resources. But funding is something that I have been unable to provide them. Again, it is clear how important it is to have funding agents at the community table, whether it be local agencies, grant funders, or philanthropic support.

Betty is the heart and soul of the organization, and when she stopped being front and center due to her own life circumstances, no one stepped up to take her place and lead the organization. At the time, I did not realize what would happen to UCVED without Betty at the helm. It was not until learning of UCVED's dire financial situation and the passage of time that I now realize the importance of multiple team players in organization and collaboration building. Something Betty once said stands out in this moment, "Springfield needs to be a community-driven city." She has repeatedly said that the city is full of gatekeepers, political and community power players that limit the spread

of necessary information and resources to average community people. Recognizing the need to continue UCVED's work, if only by supporting other important health initiatives being worked on in the city, I decided to attend a community event focused on updating Mason Square community members regarding the work to get a full-service grocery store in the area.

### **Research Story/Vignette 9: Food Justice Grocery Store Meeting**

On March 14, 2013 from 6-8pm, I represented UCVED at a community meeting about the development of a full-service grocery store in Mason Square. While our healthy eating/cooking project was on hold, UCVED wanted to be able to still participate with other healthy initiatives in Springfield. This initiative was particularly important to UCVED as it was focused precisely on providing a neighborhood in Springfield with increased access to healthier food items via a full-service grocery store in Mason Square. The project, undertaken by a coalition of community organizations called the Mason Square Food Justice Initiative, was started a few years ago and has taken a lot of grassroots effort. It started as a dream back in 2006, after Mason Square had been identified as a food desert.

This particular community meeting included a presentation by Develop Springfield to update the community on the architectural needs of the community in order to better design the grocery store. The meeting was held at the Mason Square Branch Library Community Room. There was healthy food, tables and chairs, and pamphlets on healthy eating. About 50 people were in the room, which constituted a decent turnout of community members, Mason Square Health Task Force members, MOCHA Men in Motion, and local healthcare professionals. There were about 40 people of color, of

mixed ages, but mostly adults, and including a few light-skinned people, usually in positions of power, including the engineers, presenters, and some of healthcare professionals. There was also a local youth organization, Gardening Our Communities, represented at the event.

Various architectural engineering sketches by the architectural group Doucet & Associates surrounded the room. One presenter from the architectural group stated early in the presentation that the grocery store was a social justice issue, and highlighted that everyone should have access to healthy low cost food. A community member responded that they want low cost healthy options but that "people in positions of power want liquor stores in our communities instead." I shook my head in agreement with others in the room. From experience we knew this statement to be true for low income neighborhoods in Springfield and other cities. We do have more liquor stores than grocery stores in low income areas and communities of color.

At the end of the presentation, questions were taken from the audience. My favorite question came from Richard\*, a college-educated young Black man who works with a youth organization in Springfield. He asked "if green technology was being used to build the grocery store, given the high rates of environmental toxins and asthma rates in Springfield?" The engineers responded "only if the community wants it." Richard wrinkled his face in disbelief "Wait, are you saying that we have to request green technology, when we know the dangers of the environmental toxins?" The lead presenter quickly stated that "unfortunately, some things will have to be cut out. And we need to hear that this is an area the community DOES NOT want cut."

The Mason Square Food Justice Initiative has been working on getting a full-service grocery store into Mason Square since 2010. They launched the Just Food campaign in 2011 to create greater community awareness of this issue. Grassroots research has been done at different points in this project to ensure that the community wanted to prioritize getting a grocery store in Mason Square. We were told by the presenters that the grocery store is still at least 2-3years out. They discussed potential site locations for the grocery store, including the old Riverview Inn site, which will be taken down because it has asbestos. One member of the Mason Square Food Justice Initiative stated that Mason Square needed some workforce development and training to improve the types of jobs available.

During the meeting, we were given a survey to fill out. Then we had a group discussion and did a click survey as group to discuss the placement of dumpsters, traffic lights, flower boxes, trees, outdoor lighting, trash cans, etc. as important components on the block being looked at for a grocery store. The meeting ended, and many of us were energized to continue our collaboration and see this grocery store happen in the next few years.

### **Collaboration is Not Only About the Fun Stuff: The Death of a Loved One**

The true test of collaboration and trust came at a difficult time. One of the hardest days for me in doing this work came with the death of Betty's (ex)husband. The death of a loved one is hard, painful, and a time for family to come together. The role we played supporting Betty at the time of her husband's death is important to the discussion of collaboration. Betty called on me and my colleague/friend Julie to be part of the family processional, to participate in the funeral mass, and to be present at the cemetery service

and the family lunch afterward. Her children were a little thrown , and we looked a bit out of place. Betty, a strong middle-aged Black woman, asked for two colleagues, the ages of her children, to be her support. In fact, she called us her sisters, and we smiled . Julie and I discussed the comment on our way from the church to the cemetery. We found it interesting that Betty considered us her peers, that our maturity must surpass that of her children, and how much she considered us family. We discussed how the research write-ups never seem to include the building of collaborations and how trust is truly established. To collaborate is to share, ,and at this difficult time in her life, she felt she could share her pain with us. In fact, I gave her literal physical support at the cemetery when Betty could no longer control her grief and almost fell to the ground. Her strength was evident even then, as she was on the verge of collapse, but remained strong in spirit.

The experience helped reaffirm and recognize that to be in a research-community partnership is to be available to assist in community work – wherever needed. Support is crucial, and, given that UCVED is first and foremost Betty’s project, to support Betty is to support UCVED. Betty needed to feel supported; it is her name, her voice, and her energy that drives the organization. And while I did not personally know Betty’s husband, the funeral ritual, mass and family services reminded me of my great grandmother Tata’s passing in Puerto Rico in 2005. I was reminded of how important burial rituals, Catholicism, and family cohesion are for Black and Latino communities, among others. I was honored by Betty’s trust in me at such a difficult time. writes In *Labor and Legality: An Ethnography of a Mexican Immigrant Network* (2011) Ruth Gomberg Munoz describes how she became friends with her research participants and how the book was a truly collaborative ethnography because of it. I had the same

experience with Betty and other community members I have worked with in Springfield. I believe that for true collaboration to happen, personal relationships between researchers and community members must be strong and can enhance the quality of the ethnographic research.

### **Analysis & Next Steps**

The story of Springfield and its residents is complex. There is an obesity problem at the same time as there is social policy to improve it. There are community-level efforts to improve the health of Springfield residents, yet there are Springfield residents who are still oblivious to the new resources available. There are community events to gather community member input on the topic of healthy eating and physical activity, and yet so many of these remain a gathering of the same old faces speaking to the choir. And so the big question of how to get more community members involved in these meetings remains difficult to answer. As the most recent local elections came to a close, I was left with the thought that more door knocking needs to happen. I also feel strongly that community events need to be more accessible to the working class. A few strategies that we might want to try are providing transportation to the event, having childcare available on site, and possibly providing a stipend for participants given their financial necessities. This is an area where the history and strategies of community organizers could really assist research-community partnerships in gaining better participation from average community members.

Researcher-community collaborations take time. I built my relationships with Betty and Dr. Kalidas over time. I attended conferences and other community events representing UCVED. For example, only two months after meeting Betty, I attended the

Health Care for All Conference in Boston. Julie and I drove to Springfield together to catch the UCVED bus. We could have chosen to drive ourselves to the conference, but decided we wanted to be team players and use the bus ride to get to know the other UCVED members. The bus ride was tiresome, but we got a chance to talk and listen to people. Taking the necessary time to be an active and consistent member of a grassroots organization helps to establish rapport and trust. Researchers must take this time to ensure that they can build a mutually beneficial and sustainable collaboration that leads to fruitful research and community projects. While some of the researcher-community partnerships I witnessed and participated in worked well, others fell apart. These constant fluctuations of people can wreak havoc on small organizations like UCVED because when this happens, they lack a consistent membership base to sustain the organization.

Currently, UCVED leadership must take the necessary steps to assess their financial situation, reduce the organizational debt, and find a sustainable revenue stream in order to survive as a non-profit. Occasionally applying for small grants is not enough. UCVED needs to consider partnering more explicitly with some of Springfield's already established community organizations, or face extinction. For example, UCVED should do some networking with local churches and the city health department to garner the financial and social support of these organizations for the work being done at UCVED.

For my part, I plan on holding a short presentation for UCVED community members about the research and community programming currently available in Springfield and the possible areas in which UCVED might be able to contribute. I have also spoken with Betty about the possibility of creating a 10-15 week program for

community members to learn about racial health disparities, social determinants of health, community organizing strategies, and more. Community members from UCVED have been invited to attend my doctoral defense.

Creating greater collaborations across Springfield on healthy eating may also mean establishing a larger taskforce on the issue, or folding ourselves into the already established Mason Square Health Taskforce. Bridging the community divide is necessary to improving the viability of all Springfield residents. The goal is to provide a more equitable dispersal of city resources. Betty made a strong argument for the need for large social service agencies like Springfield Partners for a Healthier Community, who have funding to support smaller grassroots efforts like UCVED by sharing funding and taking them "under their wings." Making a commitment to get more community member and not just community representatives involved is critical to this work.

Re-establishing old partnerships would also be helpful to UCVED's long-term survival. It might be possible and fruitful to contact the University of Massachusetts, Amherst, and Health Care for All to re-establish their support. My advisor, Dr. Forward, also reminded me that the Community Service Learning program at UMASS might also be interested in a community-research partnership that allows UMASS students to make new connections to another grassroots organization in Springfield. My connections to the Service Learning Program at HCC has opened UMASS Service Learning connections since both colleges are working together on service learning assessment. In the meantime, as UCVED attempts to improve its economic and organizational problems, it is important for the organization to continue to support other health projects, like the

Mason Square Health Taskforce's work on Food Justice, allowing UCVED members to be visible, active, and relevant in their community.

In my research on Massachusetts-wide health programs, I located information about a Communities of Practice. The Massachusetts Partnership for Health Promotion and Chronic Disease Prevention created the Healthy Eating Community of Practice, a recent program focused on increasing the fruit and vegetable consumption among Massachusetts youth and adults. They are currently looking for other organizations to collaborate together across the state. Their objectives for 2017 involve "increasing the percentage of Massachusetts youth and adults who report eating five or more servings of fruits and vegetables per day by 1.5%" (<http://www.mass.gov/eohhs/docs/dph/com-health/chronic-disease/cop-fliers-all.pdf>).

Interestingly enough, the Community of Practice model includes multiple health department agencies and some national and state community organizations, but there currently seem to be no grassroots organizations as partners. Maybe by reaching out to the contact people at the Healthy Eating Community of Practice, UCVED could become a partner, bringing a different perspective and different potential skills to this collaboration. UCVED's participation would ensure that the people living in these communities were actually being recruited as equal participants, and were well-represented. I will work to re-establish old UCVED partnerships and create new ones because it is the only way to continue the work and sustain the organization.

## CHAPTER 6

### BUILDING TRUST & MAINTAINING STRONG COMMUNITY-RESEARCH PARTNERSHIPS: TAKING THE INITIATIVE TO THE COMMUNITY

#### **Research Story/Vignette 10 : The (w)hole story**

While writing this chapter, I am struck by a story I remember hearing at a day long workshop training in Boston on November 20, 2010. This training, titled "Racism: The Deadliest Disease in America," was presented by Critical Mass & Center for Community Health Education Research and Services at Northeastern University. As part of an afternoon workshop on Participatory Health Research for Understanding and Eliminating Health Disparities, I heard an allegory highlighting the extreme differences in researcher and community perspectives on social problems and community issues. Researchers and community members see different things. The story goes something like this:

There was once a hole in the ground. Researchers are interested in studying the hole and ask the community for permission to study the hole. The community wants the hole fixed because the hole is not productive for the community. The researchers gather data about the hole's physical makeup (the dimensions of its opening, and its depth) and explain how and why the hole exists. When the researchers are done collecting data, they leave, and the community is left with a hole in the ground, feeling used and unheard.

In this story, the researchers did not connect their study's goals with the desires of the community they were studying. Instead, the researchers wielded academic power by taking from the community with no reciprocal distribution of data, resources and power for the community.

## **The Politics of Researcher-Community Collaborations**

The Community Based Participatory research model, using true collaborative partnership-building with the goal of sustaining community partners, offers a powerful step forward in changing the traditional research narrative. As we have seen throughout this dissertation, community-research partnerships are not easily built and maintained. In fact, collaborations take a lot of work managing time, resources, sincerity, shared power, openness to change, and a flexible research model. Using a community-based health prevention conceptual framework allows for an emphasis on prevention and group/population-based data collection. From its inception, community-based prevention programs were designed as inclusive and comprehensive, involving various members of the lay, research, and medical communities. Prevention programs oriented around community-centered health include the following key characteristics:

- mobilizing communities to actively participate in achieving program goals;
- implementing interventions in multiple community settings, including workplaces, places of worship, health care facilities, and schools;
- using multiple individual level intervention strategies, including contests and competitions, self-help programs, mass media, and screening programs, and
- developing environmental interventions (restaurant menu marketing, supermarket shelf labeling for heart-healthy foods, and policy initiatives) (Merzel & Afflitti 2003: 558).

And yet, research conducted in the last forty years continues to show mixed results for these types of health interventions. The difference in goals and priorities remain a major factor in shaping the continued struggle in effectively conducting community-based research (Horowitz, Robinson & Seifer 2009; Merzel & Affliati 2003). The

challenges to community participation and collaboration remain difficult to overcome, even as we continue to promote the ethics of this type of research.

Critical to the success of any community-based intervention is the participation of the local community, and, according to Bergstrom et al., local community involvement is often limited for three reasons (2012). First, explicitly discriminatory policies (in health, housing, jobs, and other sectors) exist and ensure that marginalized communities have limited say in political and healthcare policies or agendas. Second, even when explicitly discriminatory processes are deemed unfair, traditional public participation has been superficial and has provided limited space for a community members to share stories, knowledge, and ideas, and opportunity to shape agenda in their communities. Lastly, access to government officials and healthcare professionals, let alone trust in them, is low. While I agree with these three reasons, I would add that a focus on basic human needs is another factor that affects community participation. If community members have to work long hours or multiple jobs, they have little to no time to participate in community-research partnerships. Their immediate economic needs may overshadow their community involvement.

In Springfield, policymakers and healthcare professionals continue to struggle to gain the support of marginalized communities. This is evident in community meetings where distrust is marked by the low numbers in attendance, negative verbal comments, and discussions of social structures that hinder community progress. The difficulty of UMASS to gain traction for community-research partnerships in Springfield is another example of this struggle. In fact, only within the last two years have community-research collaborations even begun to be addressed with the creation of a program like Springfield

Bound, a daylong orientation for Five College students who will be working or volunteering in the Springfield area. This type of program is supposed to increase the visibility of university faculty and students in historically marginalized communities providing a bridge for community-engaged research.

In Chapter Five, I wrote about a Food Justice meeting where a community member spoke up regarding the need to use green technology in the construction of the upcoming Mason Square grocery store. This story highlights a level of distrust and disbelief about the work being done at Mason Square, and shows that this is a rational response reflecting the community members' awareness that decisions are being made that are not in their best interest. Without this young community member's comment about green technology, this meeting might have occurred like many others. What often occurs at community discussions or events are the same people, usually representatives of the community, meeting together from different agencies, with the larger "community" often missing from the discussions.

### **Building Rapport & Sustaining Partnerships: Lessons Learned from the Field**

As I was writing this closing dissertation chapter, I struggled to articulate how best to build and sustain community-research partnerships. One of the research articles I came across helped me realize the best way for me to share my conclusions in this research was to expand upon the work compiled by The Examining Community-Institutional Partnerships for Prevention Research Group. In 2006, they published an article titled "Building and Sustaining Community-Institutional Partnerships for Prevention Research: Findings from a National Collaborative" identifying common characteristics of successful community-research collaborations on health prevention.

My dissertation (using two case studies), has explored similar questions, including: What are the factors that contribute to successful community-research partnerships? What are the challenges to creating and sustaining good community-research collaborations? And what recommendations or strategies can build social and cultural capacity for these types of partnerships? This report highlights twelve common characteristics for successful partnerships, which I will now discuss in detail, adding to and expanding upon Seifer's (2006) findings. These characteristics are:

- (1) Building trusting relationships,
- (2) Creating equitable processes and procedures,
- (3) Mobilizing diverse memberships,
- (4) Demonstrating tangible benefits to all partners,
- (5) Balancing partnership process, activities and outcomes,
- (6) [Ensuring] significant community involvement in scientifically sound research,
- (7) Establishing supportive organizational policies and reward structures,
- (8) Maintaining leadership at multiple levels involving multiple people,
- (9) Having culturally competent and appropriately skilled staff and researchers,
- (10) [Creating] collaborative dissemination,
- (11) [Sustaining] ongoing partnership assessment, improvement, and celebration,
- (12) Ensuring a sustainable impact of community research agenda

### **Building Trusting Relationships**

According to Seifer, the first step in building successful community-research partnerships has to do with building rapport, or trust, as collaborators (2006). The traditional experience with community-research partnerships usually begins with researchers trying to establish a partnership with institutional and some financial support to engage community partners in conducting research. Rarely do you find community

organizations seeking out researchers to do health-related community-based research.

This disparity in resources affects the power available to different stakeholders.

Expanding upon Siefer's research, I note that trust is difficult because of the tumultuous past many low income communities and communities of color have with the United States medical system and healthcare professionals. The legacy of medical experimentation on the Black body, and the traditional research model of "taking" from communities, guarantees a level of distrust of researchers by community members, especially those from outside that particular community. It becomes important to be able to invest a lot of time in networking and building relationships. Attending these meetings and talking to people allows the researcher to gain an understanding of what community members believe are their own needs, rather than taking a researcher-driven approach looking first for gaps in the literature and then going into the community with the assumption that they know best.

In another research article "Community Research: Partnership in Black Communities," Hatch and colleagues (1993) argue there are four potential models for collaboration in Black communities like Springfield. The models range "from community members involved as: (1) advice or consent givers; (2) gatekeepers and endorsers of the research; (3) deliverers of researcher or programs (e.g., front line staff); and (4) active participants in the direction and focus of the research" (McKay 2007: 151). Given the history of the Black experience in America, the fourth model is viewed as the preferable collaborative model since it directly involves and empowers the community in the decision-making, implementation, and assessment of the health intervention research. With limited resources and difficulties building trust, researchers must work hard to be

open and honest, be active listeners, and to treat the community as experts in their own health needs. While Seifer's research discusses basic trust building in researcher-community partnerships, she misses the complex negotiation of researcher trust building with historically marginalized communities.

### **Creating Equitable Processes and Procedures & Mobilizing Diverse Memberships**

Part of gaining community trust involves sharing resources, power, and knowledge. This ensures that all partners have a vested interest and a shared understanding of the mutual benefits that can come out of the partnership. Seifer highlights the importance of equity and diversity in building partnerships. Research done by Nancy Gillis and Mariela Nunez-Janes on an ongoing Youth Project expands these critical factors in relationship building. They argue that one of the most difficult challenges in community-based research has to do with miscommunications across research-community partners and the need for transparency in agenda-making and the goals of the varied stakeholders (2013). If partnerships feel inequitable (i.e. having decision making and control be one-sided), there is a greater likelihood of collaboration failure. My experience has shown that this is indeed what happens on-the-ground.

Membership in a community-research taskforce or collaboration board needs to be diverse in terms of race/ethnicity, socio-economic status, skill sets, organizational affiliation, and research interests. This is preferable since it will increase the diversity of ideas and resources available to the intervention. Recognizing the need for varied types of partners, community-researcher collaborations should attempt to include grassroots community leaders, community representatives (i.e. healthcare professionals, community agencies, small business owners, etc.), as well as faculty and students from research

universities and local community colleges. Funding agents should also be contacted as potential partners in health intervention work.

Community colleges are an often untapped research resource, and I have yet to see research community partnerships highlight community colleges as true research partners. Since community college faculty members are primarily devoted to teaching, their potential for research is often underutilized. With a diverse group of students often from the underserved local communities, community colleges can be an invaluable resource to large scale organizing efforts. They can provide on-the-ground support for struggling community organizations. I argue that community college faculty and students are often underestimated and ignored by community members and research universities alike. For example, Holyoke Community College keeps me busy teaching (a five course load a semester is standard), and the college is constantly struggling for financial stability. Yet, because of programs like the Honors Program (of which I am now the new coordinator), the Learning Communities program, and the Service Learning program, there are some resources that would make community college faculty strong partners in community based research.

Situated in the community, with students from the local community, community colleges are a teaching ground for complex and multi-dimensional learning. As I have demonstrated in both case studies, Holyoke Community College students have played a part in Holyoke and Springfield community events through work in a student activism club and while working on Social Action projects for my classes. Events include the CORI Summer event, Get Out the Vote Holyoke, Student Debt Rallies, and Higher Education lobby days.

While there is research on service learning as an applied strategy for student engagement, there is little research on the impact community college students can have as capacity building agents for grassroots organizations. In fact, Holyoke Bound and Springfield Bound are two Saturday training and workshop programs available for 4-year students in the Five-College area who will work in Holyoke and Springfield; yet, the community colleges located in the area are currently not involved in this program. Informal conversations with HCC faculty and staff and Five College Committee for Community Based Learning staff have led me to believe collaboration is possible, but only if the Five Colleges and the community colleges are willing to do some work to make the events accessible to community college students. The community colleges have to be willing to be part of the planning, implementation, and assessment process and the Five Colleges have to be willing to make some programmatic changes to include our students where necessary. This will not be easy, but it is possible. My long-term goals include taking a more active role in both Holyoke Bound and Springfield Bound. A few years ago, I was asked to present on health disparities work and structural barriers to access for Holyoke residents at Holyoke Bound. I hope to be able to do that again as well as provide support for the Springfield Bound program.

Another component to building successful research-community collaborations involves researchers establishing themselves as valuable resources for collaboration. Research credibility is an important, however, often un-discussed, make-or-break factor that can help determine your entry into work with community organizations. A chain of events took place recently provided me research credibility that I previously lacked. Dr. Aline Gubrium, a UMASS Public Health professor was interested in teaching an inter-

institutional course with me. She had contacted the Learning Communities coordinator and asked specifically for me. She was interested in linking her UMASS Public Health and Social Justice Course with my Diversity (Anthropology) 100 level course. Our linked courses would include a service learning component and have students working in the Holyoke community on health-related issues. After we drafted the Learning Community linked course proposal, I received an email from the Program Coordinator for the HCC Foundations of Health program. She was interested in creating a Public Health Taskforce on campus and was selecting people for the team.

Before this linked course proposal, I had minimal interaction with the health faculty on my campus. I attended the first Public Health Taskforce meeting and was connected to an HCC Nutrition faculty member who mentioned a policy council she served in Holyoke. She said that funding was available to do community level interventions. I instantly expressed interest and have started the initial work to become part of this health policy council in Holyoke. I hope to find that Springfield has a similar health policy council. This personal experience showed how collaborations work – it's all about networking and building contacts over time.

The PAR model highlights the relationship between community members and researchers, but I argue that there is a critical component missing from the dialogue, that is, funding agents. Funding agents, I argue, should be considered an integral part of the success of community-research partnerships. The literature rarely discusses funding agents as collaborators; instead, what is discussed is the difficulty of finding sustainable funding for community intervention research (Plumb, Price & Karanaugh-Lynch 2004). I believe that if potential funders are brought to the table as collaborators, the likelihood of

success for community-based research and health interventions increases. A good example of this is the work currently being done by Project Baby/Proyecto Bebe Springfield. This taskforce is connected to the Springfield Health Department and the March of Dimes, two power players in the health industry with financial resources.

The Project Baby/Proyecto Bebe Springfield taskforce spent several years establishing local and state connections on the topic of Safe Sleep without funding. Time and relationships were built *over years* that eventually allowed for a greater disbursement of funding information and grant opportunities. Even as people argue the need for community engagement, funding remains a huge determining factor in what projects are piloted and become sustainable. In a social climate of limited funds along with political attacks on qualitative social science research, a conversation about the power of funding agents to control what projects move forward is necessary. One way to increase your odds of funding is to have funding agencies, health departments, health foundations, and other philanthropic agencies as collaborative partners.

**Demonstrating Tangible Benefits to All Partners, Balancing Partnership Process, Activities and Outcomes, and Ensuring Significant Community Involvement in Scientifically Sound Research**

Collaboration must also be mutually beneficial. All partners must enhance their capacity, stimulate their continued learning, and have a positive impact in the community. In order for collaborations to benefit all partners, partners need to be patient, willing to resolve conflicts honestly and openly, and establish goodwill and sincerity in the work being undertaken. Given their focus on community engagement and allowing for community members to hold some expertise about their experiences and health needs,

successful partnerships conduct sound scientific research and provide innovative solutions to real social issues.

### **Supportive Organizational Policies and Reward Structures**

My work with both the Road to Recovery and UCVED highlighted the need to establish upfront each partner's agenda, their roles, and their expertise. All partners must have a clear understanding of how the collaboration will work, how meetings will run, and how different agendas can come together to create a mutually beneficial collaboration and project. A lot of this work ends up being done as volunteer work since most often it is outside the traditional responsibilities of community members and researchers. How do we justify and compensate people for the amount of work and time this type of non-traditional research takes?

### **Leadership at Multiple Levels & Culturally Competent and Appropriately Skilled Staff and Researchers**

Community interventions are usually created, implemented and evaluated by community-based organizations, regularly staffed by well-meaning individuals that may work to represent the community, but may not actually be part of the community (i.e. live there). My research often led me to redefine the terms community, community representatives, and local experts or leaders. I found that the local experts or leaders were community representatives. Difficulties arose whenever we tried to ensure consistent community participation, even when they were given flexibility about the level of collaboration. Questions that continue to impact the research-community collaboration include: What position must a community member have to be considered a local expert/leader when asked to equitably participate in the research and intervention

work being done? Is expertise about education, life experience, a combination, or even more factors? Can you be an expert if you are any of the following: a health professional working in the community, a homeless person on the street, a home owner, a small business owner, and/or a community organizer who lives outside the local area? What does equitable and shared leadership look like on-the-ground? Are meetings facilitated by the same person, or is meeting facilitation rotated? How can information be adequately shared across group participants – is an email with meeting notes sufficient, or do all members need to be tasked with note-taking and committee responsibilities? Is providing funding support and name recognition enough for partnership? Discussing and finding mutual agreement for these questions are critical to gaining a clear understanding of the complex challenges of building community-research partnerships.

According to Seifer, leadership characteristics of researchers and community partners must include trust and mutual respect, flexibility/adaptability, good negotiation and conflict resolution skills, resourcefulness (i.e. ability to attain financial, social, and person-based resources), some political connections and/or knowledge, and an openness to change and/or adapt to new ideas (Seifer 2006). These qualities are also important for support staff and students, who may be part of the team, yet not as active in the research collaboration. Providing a space for staff and students to provide feedback on the collaboration is also important.

Often collaboration members take on multiple leadership roles in order to ensure that progress is made on the project. For example, in the Road to Recovery case study, I was not only the primary researcher, but also a faculty supervisor for a student interested in doing some research on contingency management. In these roles, I spent a lot of time

meeting with people, presenting project ideas, and discussing strategies for funding support. Being able to adapt to changing situations and the needs of the project is critical. Having community members discussing the research project in their neighborhoods, town meetings, and schools provides a needed level of credibility for the project that would otherwise not exist.

### **Creating Collaborative Dissemination**

Seifer's description of collaborative dissemination focuses on the need to disseminate information across different populations using different formats, and ensuring that all collaborators are given the opportunity to co-author and co-present. Community partners should be involved in the whole process of conducting research, including the evaluation and write-up of the research. She submits that community members, policy makers, and local healthcare professionals are necessary power players in the distribution and consumption of information. However, researchers are not explicitly discussed. Is this because this report was written for an academic audience? Seifer's work highlights mainly academic formats for the dispersal of research information, including public service announcements, professional presentations and peer-reviewed articles, policy reports and handbooks (Seifer 2006). Adding to Seifer's research, I argue that social media networks, mainstream news resources, and alternative news resources should also be utilized to share information gathered from the collaboration. Collaborations should consider having a partnership website with meeting dates and contact information, or at least a list-serve that can be utilized to distribute information throughout the process. Community members and researchers could also create Op-Ed pieces and Letters to the Editor about their research agenda. Conducting

interviews for local media outlets and public station networks will reach a local audience quicker than a peer review article or professional meeting paper.

Another area missing from Seifer's analysis of collaborative dissemination in successful community-research partnerships has to do with the need to strategize how best to communicate your message. What a participant says is as important as how many places it is said. The message must be clear and "catchy" in order to ensure it is effective. Both the Road to Recovery and the Cooking Healthy Eating Initiative lacked "catchy" and clear, concise messages. Another helpful strategy might include creating a Public Service announcement that could run on your program's website, be part of presentations given at community events, and be seen on social media and news sites. Collaborations should also make sure that the language used by the program is similar to those of other local and national health or social messages. For example, the Road to Recovery Project would have been well served to use the behavioral management intervention model language to gain support. One way to do so is to present the project as expanding on the goals of current behavioral management intervention programs. Establishing a partnership between the Healthy Cooking/Eating Initiative to the Just Food campaign and Gardening the Community Springfield would be a critical next step. Also, if the team decides it advantageous to create a "catchy" slogan for this type of health campaign – the message can be changed. Two possible slogans for the Healthy Cooking Program are "Real Simple Healthy Cooking" or "Cook Yourself Healthy." Students would be great resources for tapping into pop culture references that could garner greater community-level interest.

Collaborations should not be discouraged from developing community health interventions due to a lack of funding. Instead, research-community partnerships should assess what can be done without funding, continue building networking relationships, try alternative and grassroots funding strategies, and start small.

### **Sustaining Ongoing Partnership Assessment, Improvement, and Celebration and Sustainable Impact**

Given my personal and professional experience over the last twelve years, I believe that, in the end, successful community-research partnerships must build on the strengths of the community to create a lasting impact in the community. For Springfield, that means bringing "everyone to the table" – establishing allies across organizations, health departments, businesses, community colleges, and more. There is a need to get all community organizations working on the proposed area of interest. Once at the table, it is important to get their verbal and written commitment to the project from the very beginning. With the Road to Recovery project, Jamilah spoke with numerous healthcare professionals who expressed interest in the project verbally, but were unwilling or unable to be real collaborators. Verbal support is minimally helpful, at most. Partnerships that involve all members sharing resources and responsibilities are the most successful. Using K-12 and college events in concert with community events also fosters collaboration. Following a similar format to the UCVED community conversations, this can be used to gain input from community members about what is needed in the community.

Collaborative projects should also utilize and support the loudest community voices as resources and true collaborators. The community must have plenty of

opportunity to provide feedback on the project through different mediums, including, but not limited to, surveys, focus groups, letters, social media, and committee and/or community meetings. Collaborations should hold regular meetings with all partners' perspectives represented.

When partnerships are floundering, team members should bring all partners back to the table and discuss any conflicts. Giving up on partnerships should be strongly resisted. If a partnership must end and be dissolved due to life circumstances or a divergence in agendas/needs, then new partnerships should be sought to sustain the work. For example, the Healthy Cooking/Eating Initiative was most effective when it had UMass resources and held regular meetings with a clear agenda. But Linda Sickler continues to work with other organizations on this, and I am connecting to the Holyoke Health Policy Council to gain some funding to continue this type of work.

In January 2014, I attended a Teaching Community Organizing four-day training for community college faculty. This leadership training was designed for community college faculty interested in increasing their community organizing skills. The purpose of the program was to promote civic engagement, to increase the number of community college students engaged in community work, and to further develop and sustain the growing network of community organizers and teachers. This training was relevant to my work as a community college faculty member, my role as the new Honors Program Coordinator, and my dissertation research. The resource material expanded upon my research on storytelling as an ethnographic methodology and on the importance of networking to create sustainable partnerships. For example, the Public Narrative model, may be used to convey the urgency of a problem by using the "story of self, the story of

us, and the story of now" . This model can be helpful in running a community organizing campaign, in creating a storytelling element in the classroom, and in expanding the work being done by photovoice, digital ethnography, and other visual methods. The model is a valuable tool in community health intervention work. I am interested in developing three workshops on this method for my community collaborators in the upcoming months: one workshop for students, one for community college faculty and staff, and another one for UCVED community members.

The training's focus on developing partnerships among community college faculty and the training staff was also relevant to my doctoral work. Regional and national partnerships were developed through icebreaker activities, small and large group work, outside activities, and out of our core mutual desire to make a difference in our communities. We remain committed to continuing this work on our own campuses with the support of the teams we developed during the training. My research truly benefited from this training.

The sustainability of a community-based project is also directly correlated to the formal and informal resources available to it. Again, a temporary fix to the inadequate support for community member participation is to explicitly link community service learning college projects with community-research partners. This would provide a clear opportunity for community college faculty and students to act as research partners for community based participatory research. This is a level of experiential learning that provides students with civic engagement and the opportunity to act as global citizens. Students learn through action and discussion. Students bring to the table new ideas and the necessary capacity building numbers to support the organization.

As long as community college faculty can provide a certain amount of training for students to do the community work, the partnership could yield productive results for the community partners, research partners, and students. Training should include local population history, socio-economic factors affecting health access and health outcomes, conflict resolution strategies, history of unethical research done on marginalized populations, self-reflection techniques and grant writing/fundraising tools. There is a need for storytelling on all sides of the research-community partnerships. I am interested in learning more about digital and visual methodologies that can be used to establish and sustain research partnerships. Two methodologies I am interested in pursuing in the future are digital ethnography and photo voice to use in my classroom and my community work, potentially as part of the research-community partnerships. A workshop of these methodologies might also provide a low risk environment for community-research partners to discuss mutual interests and differing agendas.

I also recommend training for community members on research and research methods. On December 30, 2013, Michele Munz wrote in the *St. Louis Post-Dispatch* about a 15 week training program where community members are paired with researchers to learn about "minority health and help reduce health disparities in [their] community." Springfield could do something similar to this program, and I have spoken with Betty Agin about the potential for this type of program. Given my background, this would be an opportunity for further curriculum and workshop training development. Next steps include contacting this program for information on their marketing strategies and curriculum agenda. I believe I could get grassroots, service agency and health department support for this type of project given some time and networking resources.

## **Final Thoughts**

In a current edition of *Anthropology News*, Elsa Lechner highlights three challenges that anthropology, as a discipline, faces in doing collaborative research with participants (Lechner 2014). Lechner acknowledges that inherent to the historical research tradition are the issues of asymmetry, reciprocity, and co-authorship. Using the concept of asymmetry, which she defines as "different social groups in the same situation or project" (2014: 12), Lechner discusses the complexity of collaboration given the fact that communities and researchers are coming together without a shared knowledge of the problem or a shared understanding of what collaboration entails. This complicates the issue of reciprocity as it requires a giving and taking that is mutually beneficial to all research and community stakeholders. In fact, research-community partnerships implode "the very structure of 'researcher-researchee' relationship[s]" (Lechner 2014: 13), requiring a renegotiation of power and the potential for transformative work. By including the community partners in all aspects of the research, including co-authorship, the community partners gain credibility in academic circles, researchers gain potentially lucrative public partnership, and historically marginalized communities gain a voice highlighting their own history and forging their own futures.

As a graduate student researcher who allowed her experience in the community to produce and ground her research questions, I have a vested interest in collaborating with community members to generate media attention about newly-established and longer-running community intervention programs around the Springfield area. Research done by Herr and Anderson on local and public knowledge adds to my analysis by requiring

me to think about both the information I can give back to the community and the information that might be useful to a broader set of communities (2005).

I have provided my collaborators with the opportunity to review and provide me feedback for this document before I submit it. This is important to me as I want my ethnographic story of these two case studies to be accurate and informative.

Collaborators and students will also be invited to my doctoral defense, and my presentation will be tailored for community audiences and academics alike. This is important because I have learned that, while funding and community programs may be available, there are gaps in the distribution of information to Springfield residents. Betty Agin would argue that this is once again the work of "the gatekeepers in Springfield limiting what we [the community] know." And so I continue to strategize about how to get Springfield leaders to be more transparent about the work they are doing, provide more avenues for information distribution, and be more receptive to community voices.

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