

Unpacking Early Organizational Development in HIV/AIDS Prevention Organizations Led by Young Members of Key Affected Populations

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ABSTRACT

In early 2011, clinical research revealed innovative methods of HIV prevention that led global health stakeholders to believe that wholescale elimination of HIV and AIDS was achievable. Effective delivery of new HIV prevention methods, however, would require public health stakeholders to collaborate in unprecedented ways. The strategy of 'task shifting' implores that resources be distributed to community-based organizations and community health workers who can effectively provide outreach to populations that are otherwise marginalized by the formal healthcare system. While these types of organizations are playing an increasingly significant role in public health delivery, they experience disproportionately high rates of organizational failure, and little is known about their intra- and inter-organizational dynamics.

Using multiple research methods, this study explores the organizational dynamics of HIV/AIDS service organizations that are designed and managed by young people who are also members of communities that have been deemed 'hard to reach' with HIV prevention and care—people who inject drugs (PWID), men who have sex with men (MSM), sex workers (SW), and people living with HIV (PLHIV). I chose to study these organizations because young sexual minorities account for the highest rates of new HIV infection, and they are also creating new organizations in unprecedented numbers. My goal is to determine how these organizations grow and develop over time, as well as how donor organizations understand and support the growth of these organizations.

After gaining access to donor agencies that provide support to youth-led organizations, I orient my research questions using the life cycle literature, a literature that theorizes organizational change using a framework of 'life cycle stages' and 'motors' that drive organizations from one stage to the next. I undertake a systematic review of the conceptual and empirical literatures on the life cycle model of a range of organizational forms, identifying geographical, methodological, and thematic gaps. Using the results of the review as both a justification for further empirical investigation and as a foundation for data analysis, I embark on three distinct case studies. First, I examine early-stage organizational growth patterns in two organizations that were purposively sampled by donor agencies who deemed them to be 'high-performing.' Drawing on interviews, focus groups, participant and non-participant observations, and archival data, I use an emergent fit analytical method to unpack the organizational trajectories of these organizations over the course of their early years of growth. In my third case study, I focus on the relationship between the organizations and their early-stage donors.

I argue that the strategy of shifting HIV service delivery to organizations led by hard-to-reach youth has been justified by powerful global health actors on both moral and strategic grounds. While I show that these organizations are providing critical services to at-risk youth who have been 'lost to follow up' in the HIV care system, the main focus of my discussion is on the ways in which these organizations have been able to overcome early stage existential threats. After providing an analysis of the fit of organizational case studies to existing life cycle frameworks, I outline thematic areas in which organizations make critical decisions that affect their early-stage growth and vulnerability—leadership, inter-organizational partnerships, strategic drift, and relationships with the state. I then discuss the ways in which the organizations' primary donor understands and influences their growth. I incorporate data from multiple cases to extend existing theory about the organizational life cycle and its application to nongovernmental organizations.

ACKNOWLEDGMENTS

In the summer of 2015, nearly four years into my doctoral research, I took a few days' break to visit a group of friends in South Africa with whom I had originally embarked on work in the HIV/AIDS sector. As I drove through Muchongaville, a district within the largest township in the city of Musina, I weaved nostalgically through a labyrinth of unmarked streets and *spaaza* shops. I eventually landed on the street corner where I had agreed to meet Peggy, a former colleague. After extending her arms for a warm embrace and the habitual Musina greeting, Peggy abruptly let me know that she needed to get something off of her chest. Crossing her arms, shaking her head, and staring nervously at her feet, she muttered "ahhh, Tyler...you've heard about Papas, neh?...He has passed." My heart dropped into my stomach. Papas had been the leader of the HIV prevention program that Peggy and I had helped to start almost a decade earlier, and I had looked forward to reuniting with him on this trip. Peggy explained that he had died of untreated HIV, and that his death was the culmination of a long and slow struggle that he had hidden from most of his friends and family. I was sad for Papas's family…his young son and his wife, both of whom I had come to know over the years. But I was also deeply troubled by the fact that Papas, who had once been a role model for healthy living, had allowed HIV to take him. If the leader of our HIV prevention program had contracted HIV and died of AIDS, was the work we were doing completely futile?

For the past decade, I have juggled the two identities of HIV researcher and HIV prevention practitioner. Before entering graduate school, I spent six years working as a health promoter, first as a volunteer sexual health educator in South Africa and later as the founder and manager of a city-wide HIV prevention program in Washington, DC. I came to Oxford with a commitment to develop a practical skillset in evaluating social interventions, and I originally completed a masters degree in quantitative evaluation methods. I thought I would return home in one year to carry out a randomized trial of the work I was doing in the States. But my experience during my masters degree awakened me to the reality that making a difference was not simply about developing effective interventions and crunching numbers. It was also about effectively leading and managing the people who could make interventions 'go.'

The challenges entwined in organizational management and leadership kept me up at night, and they sparked a passion that has fueled five years of doctoral research. Along the way, I realized—through experiences like the one I had in Musina—that real social change is not about clear-cut, easily measurable solutions, but instead about navigating the messiness that characterizes the politics of development and the powerful social forces that create and perpetuate health inequalities—the forces that coerced Papas into a silent death. As I drove out of Musina a few days after my visit with Peggy, I was more motivated than I had ever been to finish this thesis, and through doing so, to try to help shed light on the complexities of the HIV epidemic. The writing that follows is the result of a five-year journey through libraries, board rooms, foundation offices, and the field, all aimed at trying to contribute to the literature on organizational behavior and to help organizations and their donors be more impactful.

Before embarking on my doctoral research, I had considered myself a quantitative social scientist. But early on in my work, I recognized that trying to answer my research questions with quantitative methods would be like trying to capture the wind in a net. Learning both the foundations and the methodologies of qualitative research was the result of hours spent in courses, in the library, and conversing with mentors, supervisors, and friends. I am grateful for the patience of many people who talked me through the process, and I hope

that this training has ultimately helped me to ‘do justice’ to the thickness of the experiences of my interviewees and their organizations. I am especially grateful to Jenny Hislop and the Health Experiences Research Group, with whom I undertook intensive methods coursework and had many a debate about rigor in qualitative methods. I also could not have completed my work without the enduring support of my supervisors, Ray Fitzpatrick and Sue Dopson, each of whom read countless drafts and helped me to stay focused and persistent throughout the writing process. Finally, my partner Paulina, my family, my friends at Rhodes House, and my fellow DPhil candidates G.J., Willy, and Josh offered both critical feedback and social support when the writing got particularly tough.

I would never have had the opportunity to complete this research had it not been for the willingness of many organizations to participate. I am thankful to John Barnes and Sarah Hamilton at Funders Concerned About AIDS for offering me access to a network of key donor agencies with a stake in HIV treatment and prevention among young people. Similarly, the staff at the donor agencies mentioned in this thesis welcomed me with open arms and very willingly took time away from their desks to ruminate on their day-to-day work, the visions of their foundations, and the challenges faced by their grantees. I am hopeful that my research can lend these stakeholders new insight into the dynamics of organizational growth among youth-led HIV prevention organizations.

Last but not least, I am grateful for the leaders and volunteers of the organizations who are the subjects of my research. They have entrusted me with their stories and opened up their personal and professional lives in order to make this research possible. They have also contributed unfathomable amounts of time, energy, and passion to fighting the HIV/AIDS pandemic. I will not name them here in order to protect their anonymity, but their bravery, compassion, and determination to help others has left an indelible mark on me.

For Papas, Peggy, and the thousands of people around the world who work selflessly and tirelessly to end the AIDS pandemic.

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
ASO	AIDS service organization
BIY	Believe in Youth
BOC	Beacons of Change
CBO	Community-based organization
CDC	Centers for Disease Control and Prevention
CDO	Community Development Organization
CRP	Community Review Panel
CSO	Civil society organization
DFID	Department for International Development
FCAA	Funders Concerned About AIDS
FCO	Foreign & Commonwealth Office
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HTRY	Hard-to-reach youth
LCM	Life Cycle Model
LGBT	Lesbian, gay, bisexual, transgender
MMT	Methadone maintenance treatment
MSM	Men who have sex with men
NGO	Nongovernmental organization
NORAD	Norwegian Agency for Development Cooperation
NPO	Nonprofit organization
ODI	Organizational development intervention
OSOP	One Sheet of Paper (method for thematic analysis of qualitative data)
PEPFAR	President's Emergency Plan for AIDS Relief
PLHIV	People living with HIV

PrEP	Pre-exposure prophylaxis
PSP	Peer Support Person (referring to Believe in Youth's capacity-building program)
PSP	Primary Science Programme (Chapter 2 only)
PWID	People who inject drugs
RCT	Randomized controlled trial
RFP	Request for proposals
SCDI	Supporting Community Development Initiatives
SW	Sex workers
TasP	Treatment as prevention
TB	Tuberculosis
TNS	The North Star
TOR	Terms of Reference
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
UNP+	Utkal Network of People Living with HIV
USAID	United States Agency for International Development
VCSPA	Vietnam Civil Society Partnership Platform on AIDS
VNP Plus	Vietnam Network of People Living with HIV
VUSTA	Vietnam Union of Science and Technology
WHO	World Health Organization

CHAPTER 1: INTRODUCTION

In a cramped basement of the hotel 'Smart Villa' in Gurgaon, a suburb of New Delhi, 21-year-old Mandakini Behara arose timidly from her chair. At the Student Partnerships Worldwide capacity-building workshop in India, it was her turn to introduce herself. Through a testimonial that moved most of the room to tears, she retraced her path from living alone on the streets to where she was today—the leader of a community-based organization that aimed to improve the lives of women living with HIV in India. Years earlier, she had had an arranged marriage with a man she rarely saw. Just weeks after her wedding, her husband left home to take up a manual labor job in a copper mine, returning home just a few months later with a terminal AIDS diagnosis. After his death, Mandakini tested positive for HIV. Her viral load soared, and her immune system slowly weakened. But when she turned to her family for support, they shunned her. Her husband's family kicked her out of her home, and she was forced to live on the streets without food, money, or the critical antiretroviral drugs she needed to keep her HIV infection at bay. "I was not living," Mandakini recounted. "I was walking dead."

After several weeks of despair, Mandakini found her way to a community-based organization that provided HIV treatment, counseling, and temporary shelter. She was so grateful for the support from this organization that, once her immune system and her life had stabilized, she decided to create the Utkal Network of People Living with HIV (UNP+), a grassroots organization that would provide support for HIV-positive women. In India, women living with HIV are significantly less likely than men to receive HIV testing or treatment, and this disparity becomes even greater when disaggregated by age. Women under 30, like Mandakini, suffered in staggering numbers from undetected and untreated HIV (World Bank, 2012).

In a room of peers, Mandakini's story was not unusual. As introductions continued, a young woman named Phyo proudly proclaimed that she was the first transsexual in Myanmar, a country with both strict anti-homophobia laws and exceptionally high rates of HIV and sexually transmitted diseases among gay, bisexual, and transgender youth. Phyo faced death threats and was offered exile in a handful of countries. Instead of fleeing, she decided to stay in Myanmar to create an organization that would fight for improved healthcare for sexual minorities. While the attendees of the Student Partnerships Worldwide workshop came from fourteen countries and all walks of life, they shared a narrative of unfettered determination, resilience, charisma, and a willingness to make sure that others would not face the same challenges that they had faced. Phyo, Mandakini, and nearly 30 other young people from around the world were part of a unique program that offered both funds and residential capacity-building workshops to 'bold' and 'innovative' start-up HIV prevention organizations. These leaders and their organizations were selected for funding because they were forging steadfastly against cultural and political norms in order to advance HIV prevention, treatment, and care.

My experience as an attendee of Student Partnerships Worldwide's workshop in Delhi compelled me at first to want to support these organizations in some way, but later led me to a more critical perspective. I wondered if and how this group of organizations could sustain a real impact against a major global health pandemic. Were these merely inspiring stories from leaders who were making a deep impact on the lives of few, or were they representative of a transformative movement of community-led efforts to combat HIV/AIDS, which for three decades had continued to exact a crippling impact on tens of millions of people? And could capacity-building workshops like the one I had attended help organizations achieve significant public health outcomes, particularly in the face of seemingly intractable adversities?

Two years later, in the first year of my doctoral program, I found myself in the back of a room full of the largest private donor agencies supporting HIV/AIDS treatment and prevention globally. They were convening to discuss sector-wide priorities for supporting the global battle against HIV and AIDS. Groundbreaking biomedical discoveries had caused major international public health actors to stake claims to the achievability of an "AIDS-free generation," and the attendees wanted to discuss how private donors could make the most effective financial contributions. While scientific advances had opened the door to new methods of prevention and treatment, there were still major gaps in people's access to treatment. Of many possible solutions to filling these gaps, one of the most discussed solutions was 'task shifting,' a systemic effort to transfer the responsibilities of HIV treatment and prevention away from clinical settings and into the hands of community-created and community-led organizations. Task-shifting placed the work of people like Mandakini and Phyo in the spotlight, and institutional global HIV/AIDS donors became interested in helping these grassroots leaders to collectively turn the tide against HIV.

I originally pursued doctoral research with the goal of assessing the overall effectiveness of community-led HIV prevention interventions, but through the journey of honing my research question, my interests shifted to *how* organizations like Mandakini's and Phyo's were started and, more importantly, how they were able to overcome organizational threats in order to provide critical HIV/AIDS services to populations previously unreached by top-down health interventions.

In the following thesis, I retrace my steps in selecting, justifying, and embarking on a multi-staged research project aimed at unpacking the complex environments in which organizations like Mandakini's and Phyo's exist, with the particular aim of understanding the ways in which these organizations respond to internal and external pressures. In this chapter, I provide a deeper explanation of the strategy of 'task shifting' and its relevance to

organizations like Mandakini's and Phyo's. I also review the burgeoning industry of capacity-building in the nongovernmental organization (NGO) sector, its key foundations, and its relevance to the efforts of donor agencies to support their grantees in leading community-driven change. In achieving these goals, I weave academic literature from the fields of public health and organizational sociology with evidence from a series of preliminary fieldwork activities in London, Washington DC, and rural Kenya. I finish with a statement of my key research questions, as well as a roadmap for the remaining chapters of the dissertation.

1.1 Overview of the Global HIV/AIDS Pandemic

HIV/AIDS has become one of the world's most serious health and development challenges. Since the first documented cases in 1981, more than 30 million people have died of AIDS. In 2014 (the latest global epidemiological survey), 36.9 million people were living with HIV worldwide, and there were 2 million new infections in 2014 alone (UNAIDS, 2015). Despite advances in research and clinical practice, UNAIDS estimates that more than 6,000 new cases of HIV/AIDS occur each day.

The development consequences of the epidemic are significant, as individuals in their most productive years (15-49 years old) are most commonly infected with HIV (UNFPA, 2010a). In addition to HIV's direct impact on the immune system, the virus has been linked to increased risk of suicide and depression (Sherr et al., 2016) and lower educational attainment (Guo, Li, & Sherr, 2012). At the macro level, HIV/AIDS reduces labor supply and productivity, reduces exports, and increases imports (Dixon, McDonald, & Roberts, 2002). For these reasons and others, HIV/AIDS has continued to be a priority issue area for communities, national health departments, and international NGOs.

1.2 New Prevention Technologies: Treatment as Prevention

Treatment for HIV/AIDS was originally developed in 1994, and it has undoubtedly been one of the most significant advances in the fight against the disease. Antiretroviral therapy (ART) is a cocktail of drugs that, when properly administered, has had a life-changing effect on people living with HIV. Over the 20 years following the first ART clinical trials, the use of these drugs has transformed the perception of HIV from a fatal disease into a chronic condition (Scandlyn, 2000). In countries and communities where the drugs are widely available and where patients adhere to them, deaths from AIDS have dramatically decreased (Granich et al., 2015). Despite the success of treatment programs, however, a number of social, economic, and political barriers have left millions of HIV-positive people without access to care. And while billions of dollars have been invested in scaling up access to ART, the widespread failure of many prevention programs has resulted in an increase in new HIV cases that far outpaces the rate of treatment coverage. In an analysis of HIV statistics, Padian and colleagues (2008) predicted that new infections were outpacing treatment coverage by a ratio of five to two.

In an effort to slow the pace of new HIV infections, a group of clinical researchers hypothesized that the treatment mechanisms that bolster the immune systems of people living with HIV might also be effective in reducing the likelihood that they could pass the disease to other people. ART was previously only administered to people with late-stage HIV infection—people who had substantially weakened immune systems and were susceptible to opportunistic infections such as pneumonia or thrush. In the late 2000s, several trials experimented with providing ART to HIV-positive people who had healthy immune systems, and the goal was to determine whether ART made them less likely to pass the virus on to others. In other studies, ART was given to HIV-negative people who were engaged in risky behaviors (primarily men who have sex with men), and the goal was to determine whether the drugs reduced the likelihood that they would contract HIV. Both groups of trials showed

positive results, with ART reducing the likelihood of HIV infection by as much as 96% (Baeten et al., 2012; Cohen et al., 2011; Das et al., 2010; Thigpen et al., 2012; WHO, 2012). Treatment as prevention, or TasP, was proven to significantly reduce the risks of HIV transmission even in cases of risky behaviors (R. C. Bailey et al., 2007; Grant et al., 2010; Gray et al., 2007; Reynolds et al., 2011), and ART was seen to be more socially and culturally acceptable than condom use (Elst, Mbogua, Operario, Kuo, & Kanungi, 2013).

The policy ramifications of these findings were significant. In the years following the publication of these studies, the World Health Organization (WHO) urged patients to be treated immediately upon diagnosis with HIV; the President's Emergency Plan for AIDS Relief (PEPFAR) created a blueprint to end the epidemic; and one of the largest ART advocate groups published a report simply titled, *The End* (Jared Baeten et al., 2012). These reports and their parallel media campaigns changed the rhetoric of global HIV prevention to focus on full-scale elimination of the disease – the creation of an 'AIDS-free generation' (Clinton, 2012; Pasteur, 2012; UNAIDS, 2011). The United States Secretary of State, who was also responsible for the diplomatic operations of the largest bilateral HIV donor program, declared that the US was committed to ending the epidemic within a generation, and the intergovernmental United Nations program on AIDS reframed its strategy around achieving zero new HIV infections (UNAIDS, 2011). While an 'AIDS-free generation' had been part of the rhetoric of activists and third sector practitioners for decades, 2011 was the first time in the history of the epidemic that policymakers were legitimizing an AIDS-free generation as an achievable development goal. During a plenary session of the annual meeting of Funders Concerned About AIDS, an executive of a major private donor agency summarized the historic 'moment' that was created by TasP:

> This is a pivotal moment. It's [the end of AIDS] a subject I thought I would never really talk about. If you had told me a year ago that anyone would ask me to talk about the end of AIDS, and more importantly that I would accept an opportunity to talk about that topic, I would have said 'no.' It's remarkable to

> sit here and think about what's happened in a year that could allow any of us to be so audacious to think that the end of AIDS is possible in our lifetimes. (FCAA, 2011)

While the plans were exciting, ending AIDS through the distribution of medicines is not simple. For people with HIV to fully benefit from potent antiretroviral therapy, they need to (1) know that they are infected with HIV, (2) be engaged in regular HIV care (e.g. attend follow-up visits with a clinician following diagnosis), and (3) adhere to ART. Following the 2011 biomedical breakthroughs, governments and donor agencies reframed strategies for prevention on maintaining patients in the HIV Continuum of Care. The Continuum of Care is based on the idea that comprehensive HIV prevention strategies should be aimed at testing people for HIV, linking HIV-positive people to a clinical care provider who can provide antiretroviral drugs and monitor the person's response to the drugs, and ensuring that HIV-positive people are adherent to treatment regimens. If 100% of people living with HIV were to be ushered through this continuum, science tells us that the amount of virus in their blood would be so low that new cases of HIV would be virtually implausible. In addition to rolling out ART for people living with HIV, global strategies focused on identifying HIV-negative people who were engaged in high risk behavior, with the goal of prescribing pre-exposure prophylaxis, or PrEP.

While biomedical strategies have the potential to stem the HIV epidemic by suppressing the virus in infectious individuals and reducing infection in high-risk sero-negative individuals, the reality is much messier. At each step along the Continuum of Care, empirical research has shown that people drop out or are pushed out of HIV care for a number of reasons (Young & McDaid, 2014). And for high-risk sero-negative people, both access and proper use of PrEP are major barriers to effective uptake of TasP (Young & McDaid, 2014). Although there has been some success—12.9 million people were receiving ART worldwide at the end of 2013, and AIDS-related deaths have fallen by 35% since

2005—efforts continue to fall short of the growing epidemic. It is estimated that 2.1 million people were newly infected with HIV in 2013, and that of the 35 million people living with HIV (PLHIV) in the world, 22 million were not accessing treatment (Bassett, Wilson, Taaffe, & Freedberg, 2015; UNAIDS, 2014). It is clear from treatment programs and PrEP trials that daily adherence presents challenges to a large proportion of the population.

Several studies have demonstrated correlations between demographic factors and rates of 'dropout' from the HIV Continuum of Care, demonstrating that youth and minority communities experience the greatest gaps in HIV care. Statistically, the demographics least likely to progress through the HIV Continuum of Care are young men who have sex with men (MSM), sex workers (SW), and people who inject drugs (PWID) (Gardner, McLees, Steiner, Del Rio, & Burman, 2011; TGF, 2014; UNAIDS, 2016). These demographic profiles are also responsible for the highest rates of new infections, and thus they are a key target for PrEP and TasP interventions. These demographics have also become key targets for the strategy of delegating HIV care to community-led organizations (e.g. task shifting).

1.3 Practical Imperatives for Future Investments: The Relevance and Challenge of an NGO Response

There is an increasing reliance on grassroots organizations to deliver interventions that link marginalized populations into the HIV Continuum of Care. The Global Fund, for example, includes representation of key populations on its governing board and tracks the participation of key populations in developing grant-making guidelines. The Global Fund also makes direct investments in "service delivery by and for key populations" (TGF, 2014; p. 8). In June 2016, the President's Emergency Plan for AIDS Relief (PEPFAR) announced the largest bilateral investment to "improve the capacity of key populations-led, community-based organizations not only to advocate for changes in policies but also directly implement

services" and to "address critical issues and gaps that exist for key populations in the HIV/AIDS response" (PEPFAR, 2016).

The declarations of these major public health stakeholders have been influenced by human rights advocates justifying the participation of key populations on moral grounds, as well as implementation research which has suggested that the participation of key populations in service delivery can improve public health outcomes. A very strong assumption is being made in global health policy circles about the ability of key populations to not only deliver interventions, but also to manage the administrative tasks of stewarding donor funds, evaluating outcomes, and scaling up their work. I intend to make this assumption a focus of my thesis and to set out to find case studies that will examine the organizational capacities of HIV service delivery organizations led by hard-to-reach populations. As I will discuss, my focus narrows to organizations led by young people who are members of hard-to-reach populations based on the specific promise and challenges of this organizational type.

Pebody (2015) argues that TasP is a "a simple acronym that masks considerable complexity," positing that the medicalization of HIV prevention will require a concurrent investment in interventions that are focused solely on the recruitment and maintenance of patients in the HIV Continuum of Care. The delivery of HIV care, he argues, is as much about behavioral and political change as it is about medicines. Pebody's arguments are echoed in perhaps the most seminal paper on TasP—in 2011, Schwartlander and colleagues used epidemiological modeling to demonstrate that wide-scale TasP would only work alongside 'task shifting.' The model proposed "major efficiency gains through the shifting of service provision techniques to place greater emphasis on community mobilization" (Schwartländer et al., 2011).

The idea of tasking low-skilled workers in delivering HIV care is based on similar strategies in other public health interventions. Luis Huicho and colleagues (2008) provide the most comprehensive study of this topic to date. They compared results across four countries and found that health workers with a shorter duration of training performed at least as well and sometimes substantially better than those with a longer duration of training in assessing, classifying, and managing episodes of routine childhood illness, and in counselling the children's carers. In addition to Huicho's work, there is good evidence and compelling logic to support the allocation of tasks in health-system delivery to the least costly health worker capable of doing that task reliably (Callaghan, Ford, & Schneider, 2010; Hermann et al., 2009; McPake & Mensah, 2008).

In the case of HIV and in the context of low access to healthcare and high rates of HIV among hard-to-reach populations, this thesis focuses on task-shifting the delivery of HIV care to community-led groups that are representative of men who have sex with men, sex workers, and people who inject drugs. There is now a keen interest in investing in small, grassroots organizations in order to facilitate the expansion of ART coverage and to improve retention in care among HTRPs (Grimsrud, Sharp, Kalombo, Bekker, & Myer, 2015). Not only is task-shifting justified by a sweeping activism effort that stakes an ethical imperative to involve affected communities in HIV prevention interventions, but studies—like Huicho's and colleagues'—have also shown that community participation is associated with reductions in loss to follow-up in HIV care by as much as 67% compared with interventions housed in formal clinics (Grimsrud et al., 2015).

In a PEPFAR workshop on advocacy, PEPFAR representatives said these groups were "critical to supporting ethical and effective national responses to HIV and AIDS" and that "people affected by the epidemic offer valuable direct experience that is then translated into better and more responsive programs" (USAID, 2007). PEPFAR sees community-based

organizations as 'technoscientific instruments' that will be critical in instituting new global guidelines for HIV testing and aggressive treatment (Montoya, 2012). Montoya (2012) calls community-led organizations the "most visible and immediate mechanism for extending this [treatment as prevention] apparatus into the population." This recommendation is built on propositions that leaders of marginalized groups will be best equipped to understand the needs of their peers and to influence peer behaviors (UNFPA, 2010a, 2010b). The strengthening of these NGOs has been taken up by international health stakeholders as both "an ethical humanitarian necessity and a technical solution" (Murray, 2005).

1.4 The Challenge of Investing in Grassroots Organizations: The Liability of Newness

While a logical strategy, interviews with donor agencies during my preliminary research evidenced an accelerated rate of failure among organizations that are designed and led by members of hard-to-reach-populations, with one donor reporting that nearly two thirds of its grantees failed to survive during their first year of operations. This anecdotal evidence is bolstered by a breadth of theoretical work by organizational sociologists, as well as by strong empirics. In coining the term "the liability of newness," Stinchcombe (1965) originally argued that new organizations, and particularly new organizational forms, are more susceptible to failure at birth. He hypothesized that their likelihood of failure declines with age. Several decades later, Fichman and Levinthal (1991) added nuance to Stinchcombe's theory by suggesting that organizations experience a "liability of adolescence." In their work, they posit that early excitement (e.g. passion of workers and volunteers, seed capitalization, etc.) about an organization affords it a 'buffer' against nascent threats. They suggest that the risk of failure for organizations is not as linear as Stinchcombe suggests. Instead, organizations have a low rate of failure during a 'honeymoon period,' a higher rate of failure when the resource of 'goodwill' (which I have called organizational 'excitement') runs out, and then a more linear risk of failure for organizations that survive the threat of adolescence.

An increasing mortality rate over time has been empirically observed by a number of researchers (Carroll, 1983; Carroll & Delacroix, 1982; Freeman, Carroll, & Hannan, 1983). Two more recent studies examined the liability of newness from divergent methodological angles, both coming to similar conclusions. In a population of 389 voluntary organizations in Canada, Singh, Tucker, and House (1986) used quantitative methods to confirm the hypotheses of the liability of newness. In addition to showing high failure rates for young organizations, they discovered that failure was more closely correlated to external factors (such as not being registered or not having developed partnerships with powerful external actors) than to internal factors (such as change in leadership, organizational goals, or activities). Singh, Tucker, and House also find that newness is conflated with smallness; new organizations fail because they are small and find it difficult to compete with older and larger organizations. Chambre and Fatt (2002) used a mixture of qualitative and quantitative methods and a sample of HIV/AIDS service organizations to reach the same conclusion.

1.5 Making Sense of Organizational Responses from Preliminary Fieldwork

Adding to the risks of early organizational failure, a UNAIDS report (2012) found that HTRP-led organizations are often characterized by challenging internal and external environments, including high levels of dependence on other organizations and institutions, political hostility toward HTRP and social resistance to support HTRP-led initiatives, and high rates of turnover in leadership.

To address the challenges unique to HTRP-led organizations, donors have made concurrent investments in organizational development interventions, also referred to as ‘capacity-building’ or ‘technical assistance’ programs. Light (2004) writes an extensive account of the boom in these types of interventions in the NGO sector throughout the previous three decades, and Crutchfield and McLeod Grant (2008) argue that organizational development interventions are playing a critical role in determining organizational survival. At

the Funders Concerned About AIDS meeting that I attended during the first year of my research, both donor agencies that were investing in HTRP-led organizations had recently instituted organizational development interventions alongside their grantmaking programs. These interventions entailed residential workshops that imparted didactic and one-on-one assistance to organizations. The workshops were aimed at bolstering the organizations' internal structures as well as their external appearance—their governance, leadership, strategic planning processes, evaluation, and financial health. Organizational development interventions led by both donor agencies were based on a classification of recipient organizations into a given phase of organizational growth, with the goal of these interventions to help organizations progress to the next phase of organizational growth. An internal report from one of the donor agencies suggested that a 'life cycle model' could help the donor agency track the progress of its grantees throughout their capacity-building program. It was assumed that organizations at more advanced stages of the organizational life cycle would be less likely to fail and more likely to achieve their stated public health outcomes.

The core tenet of organizational development interventions is the idea that organizations can achieve legitimacy through forms of professionalization (Hwang, 1983). The pressure to professionalize has been fueled by the rise in number of NGOs and the recent era of accountability, which has dictated that organizations must attain legitimacy through rigorous monitoring and evaluation (Bezjian, Homstrom, & Kipley, 2009; Hwang & Powell, 2009). Empirical research has connected professionalization to various measures of organizational legitimacy (Stewart, 2013), including service quality characteristics (Andersen & Jakobsen, 2010; Bartol, 1979); customer satisfaction (Andersen & Jakobsen, 2010); funding success (Suarez, 2010); and organizational competency and credibility among stakeholders (Tonon, 2007).

1.6 Aims of This Research

While recent public health policy encourages reliance on grassroots organizations as critical providers of HIV/AIDS services, this approach has been challenged by high rates of organizational failure, particularly among organizations that are founded and led by hard-to-reach populations that are most in need of HIV/AIDS services. In order to address organizational risk, donor agencies have invested in parallel capacity-building programs to support their grantees. Despite evidence that HTRP-led organizations experience unique internal and external pressures, however, to date there has been little empirical investigation into the application of organizational theory to HTRP-led organizations.

My research focuses on understanding 'how' community-led organizations navigate the organizational life cycle and respond to the threats of organizational newness. Specifically, it focuses on how community-led, HIV/AIDS-focused NGOs are established and how they evolve, flourish, or fail over time. One implication of this work is to offer insight into how practitioners, academics, and policymakers might design interventions to support these groups. Specifically, my research questions are:

1. How do marginalized youth organizations grow and develop over time?
2. How well do donor organizations understand and support marginalized-led organizations?

1.7 Structure of the Thesis

In this chapter, I have provided an overview of my motivations for the research, its main purposes, and the relevance of these aims to global health strategy and organizational theory. In Chapter 2, I identify gaps in the existing literature by undertaking a systematic review of empirical and theoretical articles about the application of Life Cycle Models to NGOs. The Life Cycle literature has been identified as heavily theoretical (Cameron & Whetten, 1983) and in need of empirical exploration. In Chapter 2, I use systematic review

methods to assemble, critically appraise, and make sense of 13 relevant studies of life cycle theory in the NGO sector. The results of my review demonstrate the lack of high quality empirical research of LCM's application to NGOs, the lack of LCM empirical research on organizations outside of the global north, and the heterogeneity of both conceptual and empirical research. The chapter justifies the need for further exploration into the dynamics of non-Western NGO behavior and the application of LCM to these organizations' trajectories.

In Chapter 3, I describe my iterative methodology for exploring the dynamics of organizational change through case studies of start-up HIV/AIDS NGOs that were founded and led by sexual minority youth. I discuss the ways in which my preliminary efforts at generating research questions and designing my empirical work was influenced by an iterative process of reading and rethinking the research; the practical limitations of what may be possible given challenges to previous research that had been conducted among marginalized groups; as well as my aim to collect and present data that would be both academically relevant as well as strategically useful to global health actors, including organizations, their donors, and capacity-building professionals.

Chapters 4 and 5 are case studies of Women Together and Beacons of Change, two organizations that were winners of substantial grants from Believe in Youth, a global grant-maker to youth-led HIV/AIDS organizations in limited-resource settings. Chapter 4 explores the founding and development of Women Together, an organization in Kyrgyzstan that provides social and clinical services to women who use injection drugs. Women Together began as an advocacy organization, and it was originally funded to conduct a needs assessment for young women who used drugs. In this case study, I trace Women Together's evolution through three distinct phases: formation, development, and stagnation. In explaining the drivers of the organization's evolution, I highlight three main themes: the

challenging political and social context in which Women Together has worked; the transience of its leadership; and the cooptation of the group by well-intentioned mentors and partners.

In Chapter 5, I provide an overview of Beacons of Change, an organization that was formed to provide support services to people living with HIV in Hanoi, Vietnam. Founded by a young woman who had no prior experience in public health or nongovernmental organizational management, I trace the organization's path from formation to development and now consolidation. Like Women Together, Beacons of Change's original leadership changed significantly in the first few years of its existence. However, the case in Vietnam offered insight into 'leadership poaching' and its impact on organizational development. In this case study I link changes in leadership to the organization's response to environmental pressures of competition. Finally, I explain how organizational members' perceptions of the organization's greatest challenges are linked to a larger political context that undermines the efforts of passionate young leaders from creating sustained social change in Vietnam.

Chapter 6 adds a layer to the previous two case studies. It begins by looking broadly at the rationale for offering seed funding to HTRP-led organizations. It then looks specifically at Believe in Youth, a global grantmaker that not only provides seed funding to HTRP-led organizations, but is also a grantmaker which itself is composed of young people representing sexual minority communities. Using interviews conducted over the course of three years in Amsterdam, Washington DC, London, and Mexico City, I build a picture of Believe in Youth's founding charter and its process for selecting and supporting its grantees. I then draw data from my case studies of Beacons of Change and Women Together to analyze the relationship between Believe in Youth and its grantees, specifically unpacking the influence that each has on the other. I argue that these case studies suggest that the external environment has been overlooked in capacity-building initiatives, and that NGOs' relationships with the external environment are critical for determining NGOs' capacity.

Capacity enhancing has traditionally focused on changing internal structures and operations of NGOs, rather than recognizing the importance of the external environment to an organization's success (Hudock, 1995; Moore, Stewart, & Hudock, 1994).

Chapter 7 provides a conclusion to the thesis. The chapter begins with a critical assessment of the key findings of the study, as well as the methods used to reach these findings. After presenting the limitations of the research, I offer areas in which this work lends insight into existing scholarly literature on organizational behavior. I then return to the opening dialogue of the thesis, proposing ways that my work supports and challenges existing strategies that focus on shifting global health strategies into the hands of HTRP 'health workers.' I offer specific ways in which this work can be used by stakeholders in global public health to improve both grantmaking and capacity-building efforts. I finish the thesis by outlining areas of future research that my work promotes.

CHAPTER 2: LIFE CYCLE MODELS AND NONGOVERNMENTAL ORGANIZATIONS: A SYSTEMATIC REVIEW

2.1 Justifying the Need for This Review

With guiding questions about organizational behavior, I chose to orient my empirical work by first reviewing the literature on the life cycle model—a set of broad theories that predict organizational behavior at various points within an organization's 'life.' I chose to review this literature particularly because it was referenced during preliminary research with donor agencies and capacity-building professionals. I also analyzed this literature because it considers organizational behavior over time, and my research was interested in determining how organizations respond to threats throughout their organizational lives. In reviewing the life cycle literature, I chose to focus only on papers that discussed the relevance of the organizational life cycle to nongovernmental organizations (NGOs). While my research questions focused narrowly on HIV/AIDS service organizations led by hard-to-reach youth, narrowing my literature review to these organizations would not have offered a sufficiently solid framework for analyzing my case studies. While HIV/AIDS organizations led by hard-to-reach youth have only risen to prominence in recent years, the literature on these organizations is underdeveloped.

Nongovernmental organizations are playing an increasingly significant role in local, national, and international development. While the number of NGOs has grown in recent years, many NGOs have also experienced organizational failure. Enhanced knowledge about the dynamics of organizational change in NGOs could improve their sustainability and effectiveness. Numerous scholars propose that these dynamics can be understood through life cycle models (LCMs), which, they posit, (1) have clearly definable stages of growth and (2) are universally applicable across all organizational forms. Current LCMs are largely based on theory, and their creators encourage empirical validation. This chapter presents a systematic

synthesis and appraisal of conceptual and empirical research on the application of LCMs in the nongovernmental sector. It examines the characteristics and quality of the extant body of literature, and it discusses emerging themes from the research. It also updates a previous non-systematic synthesis (Hasenfeld & Schmid, 1989) and calls for future empirical research that is systematic, transparent, and reproducible.

2.1.1 The Rise of the Global 'Third Sector'

It is important that I first clarify my definition of nongovernmental organizations. These organizations are defined by what they are *not*, and not what they *are*. In a literal reading, the term 'NGO' could be inclusive of all organizations that are not governed by the state. In the majority of cases, though, the term NGO refers to organizations that fall into the 'third sector,' or organizations that are generated, governed, and 'owned by' the people. For the purpose of this review, NGO encompasses everything from large, global aid organizations to small, community-based, publicly-funded social service organizations and activism groups. While NGOs can be funded by the state or private donations, they cannot be owned by the state or by private individuals or companies.

The NGO sector is burgeoning – the past several decades have seen a significant increase in the number of nongovernmental organizations (NGOs), as well as their share of resources and public legitimacy. In the past ten years alone, the number of new NGOs in the United States outpaced private businesses by a ratio of 25-to-1, and NGOs employed ten percent of the country's domestic workforce (McKeever & Pettijohn, 2014). Similar trends have been observed in both Western and non-Western countries, and international development experts call the emergence of influential NGOs an *association revolution* – an industrial trend that was as important to the late twentieth century as the rise of the nation-state was to the nineteenth (Lewis, 2001).

NGOs are recognized as important actors across a range of development areas—from poverty alleviation and education reform to disaster relief, conflict resolution, and public health. Their legitimacy is often attributed to their flexibility, innovation, and capacity to provide social services to people who are 'hard to reach' because of social, political, or economic exclusion (Smith, 1997). In global HIV/AIDS policy, for example, health officials and intergovernmental organizations have struggled to provide high-risk individuals with HIV testing, treatment, and prevention. In response, a seminal paper (Schwartländer et al., 2011) called for a strategic shift to reduce resource allocation in clinical health settings and increase funding for community-based NGOs, which are believed to have better access to the highest-risk individuals.

Despite marked growth in the past 50 years, scholars warn that environmental pressures and leadership crises have the potential to reverse the proliferation of NGOs. Previous research provides strong empirical support for the notion that NGOs are at a heightened risk of failure in their early years (Bielefeld, 2014; Chambre & Fatt, 2002; Freeman, Carroll, & Hannan, 1983; Hager, Galaskiewicz, Bielefeld, & Pins, 1996; Singh et al., 1986; Stinchcombe, 1965), and donors have become increasingly concerned about the long-term viability of the organizations that they support. This concern manifests in an ancillary industry of contractors and consultants who are paid to help organizations navigate what has been referred to as their 'liability of newness' (Light, 2004; Stinchcombe, 1965). Understanding the dynamics of organizational birth, growth, and death can be instrumental in assisting NGOs to overcome this liability by formulating effective strategies, designing adaptive structures, and developing responsive service delivery systems (Hasenfeld & Schmid, 1989).

2.1.2 Life Cycle Models as a Lens for Understanding Organizational Change

Planned organizational change requires knowledge about the dynamics of organizational behavior. In order to understand the frameworks through which practitioners

and academics examine and intervene on the organizational processes of NGOs, I conducted an online search and found that there had not been a synthesized model of organizational life cycles in more than two decades. I also discovered that existing literature reviews rarely appraised the quality of studies they summarized, a practice that can be useful in determining the overall strength of research findings.

A number of researchers suggest that changes within organizations follow a predictable pattern of developmental stages (Adizes, 1979). These 'life cycle models' propose stages of organizational development that are sequential in nature and involve a broad range of organizational activities and structures (Quinn & Cameron, 1983). The salient feature of the LCM literature is the notion of a predictable, *a priori* sequence of developmental stages (Cameron & Whetten, 1983), and a set of assumptions about the key characteristics and concerns of organizations at each level of the life cycle. Scholars have suggested that the same developmental dynamics occur in all organizations, regardless of organizational purpose or environmental context. More than ten different life cycle models have been put forth by organization theorists (Cameron & Whetten, 1983). Implicit in these models are concepts of organizational routinization, and growth is from small to large (Quinn & Cameron, 1983), from centralized to decentralized (Kelley, 2005; Quinn & Cameron, 1983; Rucht, 1999) and from risk-taking to conservative management (Kimberly, 1979).

The notion that the life cycle model applies universally to all NGOs has been challenged by academics and practitioners, who have argued that neither professionalization nor institutionalization are inevitable stages of organizational growth (D. Brown & Kalegaonkar, 2002; David Brown, Leach, & Covey, 2004). Unfortunately, previous research demonstrates a lack of empirical tests for the fit of LCMs to real-world organizations. As Cameron and Whetten (1983) note, "unlike many of the group stage development models, organizational development models have not been based on systematic empirical investigation. Instead, they

were proposed only on the basis of observations and experiences of the authors themselves" (p. 283-284).

2.1.3 Aim of The Present Review

The purpose of this review is to 'take stock' of conceptual and empirical work on life cycle models in the NGO sector. My aim is to provide a comprehensive, transparent, and reproducible analysis of the use of LCMs in understanding the organizational processes of NGOs. Further examination of the application of life cycle models to nongovernmental organizations is warranted not only by the apparent research gap, but also by an abundance of research which suggests that the early stage of organizational growth in NGOs has a significant bearing on their ultimate survival (Billis, 1991; Marcus, 1988). Enhanced knowledge about whether and how NGOs proceed through stages of the life cycle may be useful to practitioners who are working to ensure the sustainability of these organizations, as well as to academics who are carrying out research on NGOs.

2.1.4 Methodological Approach

Due to the heterogeneity of the literature in organizational studies, as well as the interdisciplinarity of organizational research, systematically reviewing this body of literature using traditional techniques has proven challenging (Tranfield, Denyer, & Smart, 2003). Ad hoc reviews, while useful in ascertaining a basic sense of the direction of previous research, often lack elements of critical appraisal that could more thoroughly assess topical and methodological gaps. I argue, however, that systematic methods (e.g. methods that are explicit, transparent, and reproducible) can and should be adapted and employed to the benefit of current and future organizational research. This type of review of literature is needed so that researchers can understand that a wide range of sources was obtained and that papers were assigned value based on their relevance and methodological rigor. After surveying several approaches to systematic reviews, I decided to employ a systematic review design (Booth,

Papaioannou, & Sutton, 2012; Wilson, Petticrew, Calnan, & Nazareth, 2010). This design allowed for an accounting of different approaches in developing the discourse around a specific phenomena.

It is important to note that my scoping review was *interpretive*, meaning that it sought to broaden the understanding of nongovernmental organization development. This approach stands in contrast to aggregative reviews, which aim to pool the results of studies in order to add 'weight' to a particular hypothesis. The interpretive approach allows for each study to add one or more additional insights and to contribute to the overall picture. My specific methods are discussed in the following section.

2.2 Methods

2.2.1 Search Terms

I built my search strategy using the process of pearl growing (Booth et al., 2012; Schlosser, Wendt, Bhavnani, & Nail-chiwetalu, 2006). This process, which entails iteratively amassing keywords from relevant studies, has been identified as a particularly useful tool for searching multi-disciplinary literatures that might use a wide range of terms to speak of similar or identical phenomena. I identified a known highly relevant article (the pearl) to select terms on which I subsequently structured my search. I chose an article by Hasenfeld and Schmid (1989) as my pearl citation, as it had appeared frequently during my preliminary online searches. It contained a synthesis of the life cycle model literature from the private sector, and it proposed additional life cycle stages for NGOs.

Figure 2.1: Pearl Citation

Hasenfeld, Y., & Schmid, H. (1989). The Life Cycle of Human Service Organizations : *Administration in Social Work*, *13*(3), 243–269.

I used free-text terms from this citation and its abstract to build an initial search in PubMed, which I selected due to its ability to sort articles based on relevance to search terms. I screened the first ten most relevant articles and added both indexed and free-text terms from these articles to my search, and I continued to build the search iteratively until no new relevant terms were found. The full list of terms is displayed below. I adapted the search strategy according to database-specific variances in thesaurus terms, field codes, and truncation rules. I conducted the search on October 13, 2013, using title, abstract, and English language filters (due to time and resource constraints), but I did not impose any restrictions on publication date.

Figure 2.2: Electronic Database Search Terms

Electronic Database Search Template (Web of Science)
Concept 1: Population (Charit* OR NGO* OR NPO* OR "social" NEAR/1 enterprise* OR Organi?ation NEAR/1 ("charitable" OR "civic" OR "civil society" OR "community-based" OR "community-led" OR "human service" OR non?governmental OR non?profit OR "philanthropic" OR "social change" OR "social impact" OR "third sector" OR "voluntary"))
AND
Concept 2: Phenomenon (life?cycle OR "phases of growth" OR "stages of growth" OR Organi?ation* NEAR/1 (behav* OR change* OR develop* OR evol* OR growth*))

2.2.3 Databases Searched

In order to ensure broad coverage of relevant disciplinary approaches to my research question, I searched the following databases: ABI/Inform Global, Web of Science, SCOPUS, and Global Health. Full records of the adapted search terms are included in Appendix A, as

well as the date searched and the results of each search. In order to locate relevant unpublished papers, I also searched ProQuest Dissertations and Theses, an online database of papers produced by university students.

2.2.4 Selection and Appraisal of Documents

I imported all citations from the search processes into Endnote X7. I first screened by title and then by abstract. When it was unclear from the citation's title or abstract whether it met the inclusion criteria, I retrieved the full text of the paper. To be included in this review, papers had to either present or evaluate an explicit life cycle model of NGO organizational change. While it would have been ideal to have an additional researcher with which to triangulate screening decisions and to corroborate analytic interpretation, resource constraints did not allow for this. The following inclusion criteria guided the selection of relevant papers:

Figure 2.3: Screening Guide for Included Studies

Criteria	Yes/No/Unsure
1. The paper contributes novel concepts or empirical evidence about nongovernmental organization growth.	
2. The research references a life cycle model of growth, meaning that it identifies distinct and sequential phases of growth.	

2.2.5 Data Extraction

For each paper that presented a novel conceptual model of the organizational life cycle, I created a table that listed the stage of development on the horizontal axis and the characteristics of each stage on the vertical axis. I then created a single summary table of all

models. For each included empirical study, I recorded the authors, publication year, and journal name; purpose of the study; location of organization or organizations studied; and study characteristics that included design, sampling, methods, and analysis, main findings, and theoretical foundation.

2.2.6 Quality Assessment of Empirical Research

As explained in the introduction, the field of management and organization studies is methodologically eclectic (Tranfield et al., 2003), and so restricting systematic reviews to studies conducted with a single research design—or even privileging one research design over another—is hazardous. Instead, I made an effort to appraise the included empirical studies based on the methodological posture and the corresponding tools espoused by each study's authors. My appraisal was guided by the following overarching questions:

Figure 1.4: Quality Appraisal Checklist

Quality Appraisal Criteria

1. Are the aims and objectives of the research clearly stated?
2. Is the research design clearly specified and appropriate for the aims and objectives of the research?
3. Do the researchers provide a clear account of the process by which their findings were produced?
4. Do the researchers display enough data to support their interpretations and conclusions?
5. Is the method of analysis appropriate and adequately explicated?

2.2.7 Synthesis and Analysis

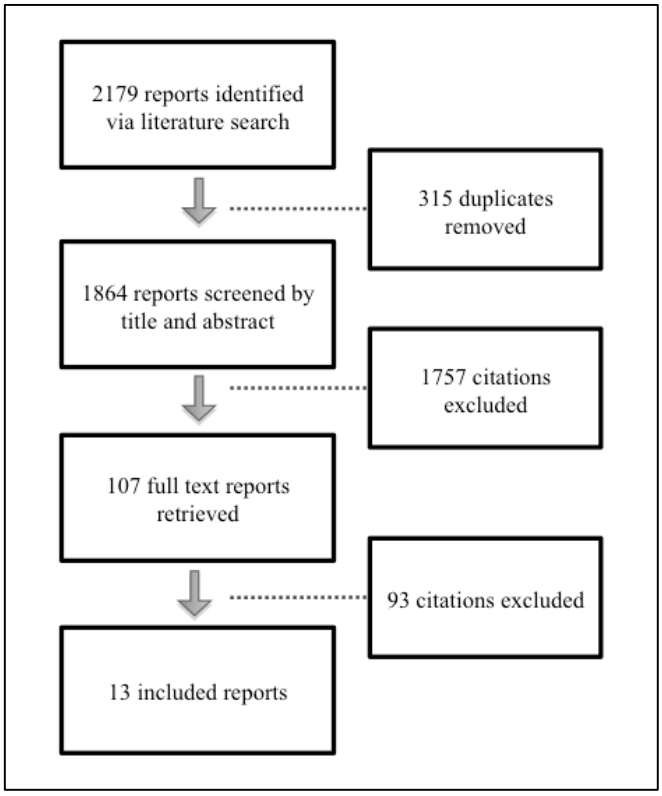
I read included conceptual papers in chronological order, so as to gain a better understanding of how authors built on or contested ideas over time. While I initially hoped to provide a singular integrated model of life cycles, I ultimately decided to abandon this effort in light of the variance in both the content and the comprehensiveness of the models. Instead,

I used a narrative synthesis to highlight both novel and conflicting propositions. For the empirical studies, I followed the three step analysis presented by Petticrew and Roberts (2006)—I organized a description of the included studies into logical categories, analyzed the findings within each category, and synthesized the results across included studies.

2.3 Results

The search strategy resulted in 2,179 potentially relevant citations. Of these, 315 were duplicates. Title and abstract screening removed 1,757 citations, and the full text of 107 articles was retrieved for further screening. After the 107 articles were reviewed, 13 were judged to meet the review's inclusion criteria. Figure 5 illustrates the citation screening process. Of the 13 papers that met the review's inclusion criteria, four were presentations of novel LCMs, and nine were empirical studies that used LCM frameworks to investigate the growth of NGOs.

Figure 2.5: Flow Chart Depicting Search Process



2.3.1 Conceptual Models

The authors of each of the four conceptual models either borrowed theory from research about private sector organizations and adapted it to conform to their implicit or explicit ideas about the unique features of NGOs, or they proposed frameworks based largely on first-hand professional experience with minimal theoretical reference. Barnett's (1988) model was based on a direct translation of the life cycle model from the private sector, suggesting that public and private sector organizations would behave in similar ways; Hasenfeld and Schmid's (1989) model was based on a review of literature; Bailey and Grochau's (1993) model was derived from ethnographic research; and Avina's (1993a) model was based on experience as an international development practitioner. The theoretical stance of all authors was in alignment with sociological functionalism, insomuch as all four life cycle models purported that an ideal equilibrium, or 'fit,' exists between a configuration of organizational parts and the values and styles of organizational members. This 'fit' must be negotiated and renegotiated by organizational members in order to respond to environmental flux.

Despite some theoretical similarities, integrating the four included conceptual models into a single framework proved difficult, and it was apparent that such efforts in the past did not materialize without authors making significant tradeoffs between adequately representing each model and attempting to achieve theoretical convergence (Hasenfeld & Schmid, 1989). Models differed in either the comprehensiveness of the included life cycle stages or in the number of levels of structural analysis. Some authors focused on changes in as few as two structural areas, whereas others presented as many as six layers of change within each life cycle stage. Similarly, some authors only hypothesized about the early stages of the life cycle, whereas others included theory about organizational decline and death.

The conceptual contributions of the included papers can best be organized by looking at three levels of analysis: the proposed phases of organizational development, the

organizational elements included in the models, and the drivers of organizational change predicted by the models.

Life Cycle Stages

According to the results of my search, Barnett's work was the earliest effort to apply the life cycle model to NGO research. Based on a combination of business research (Katz & Kahn, 1966; J. R. Kimberly, 1979; Scott, 1971; Thain, 1969) and the author's intuitive expectations, Barnett's model included the stages of start-up, professionalization, and institutionalization. While he used his model to generate hypotheses about organizational management at various stages of the life cycle, his model did not address the life of an organization beyond institutionalization. Hasenfeld and Schmid's work was the first to extend the life cycle model to account for the process of death. Using Quinn and Cameron's (1983) Integrated Model of Organizational Life Cycles as a foundation, Hasenfeld and Schmid's model added two stages—death and decline—which, the authors argued, arise "out of the hazards of institutionalization and the unstable environments of the human services sector." They also introduced the concept that the order of life cycle stages is not linear—NGOs do not all inevitably die, but instead have the possibility of addressing the hazards of institutionalization and responding to environmental pressures through a process of renewal.

Bailey and Grochau (1993) expanded on Hasenfeld and Schmid's work by explicating the processes through which organizations respond to the hazards of institutionalization and environmental pressures. Their model included a stagnation stage, in which the hazards of institutionalization grow into 'critical issues' that—in order for an organization to survive—must be addressed by an organization's leaders. While Hasenfeld and Schmid simply explained renewal as a transitional process, Bailey and Groachau referred to renewal as a discrete stage within the life cycle, and they suggested that the renewal stage also requires a distinct 'fit' of leadership characteristics.

Avina's (1993a) model is based on the author's first-hand experience as a development practitioner. He presented a model similar in its early stages to the other three models, but added nuance to previous authors' ideas of renewal. In Avina's model, the stage proceeding formalization was 'consolidation,' in which an NGO analyzes its performance and better aligns its operative capacity to its external realities. Avina also introduced the novel concept that 'organizational death,' as described by previous authors, often comes as the result of successful achievement of organizational goals. It is not necessarily a symbol of an organization's failure to respond to its hazards, but instead can be the result of the fulfillment of the organization's mission.

Included Organizational Elements

Hasenfeld and Schmid predicted changes in the greatest number of organizational attributes. Their model included descriptions of external environment, resources, strategy, structure, managerial processes, size, and human resource management. Bailey and Grochau's model included primary organizational tasks, dominant organizational values, the socio-emotional characteristics of leadership, and critical issues. Avina's model included motivations of organizational change as well as the threats and concerns associated with each stage of the life cycle. Finally, Barnett's model included organizational strategy, resources, managerial processes, key skills, and board characteristics.

Drivers of Organizational Change

Understanding the ideal configuration of organizational attributes in each life cycle stage can be useful in designing and measuring interventions to improve organizational capacity. In addition to understanding the dynamics within a stage of life cycle development, it would also be useful to have an understanding about what factors motivate change between life cycle stages. While drivers of organizational change were addressed to varying degrees in

the four included models, it was less clear how change unfolds as these drivers interact. Importantly, both Bailey and Grochau (1993) and Hasenfeld and Schmid (1989) acknowledged that leadership decisions that stabilize an organization in one life cycle stage may eventually become a liability at a later date. Bailey and Grochau called these liabilities 'critical issues,' and they suggested that managers have a choice at each transition point to either maintain the status quo or advance to a different stage of the life cycle.

Hasenfeld and Schmid suggested two areas of the life cycle in which organizations are particularly vulnerable – the transition from formation to development and maturation (in which leaders must enact a process of convergence in order to survive) and the transition from elaboration to decline (in which leaders must enact renewal if they wish to avoid organizational demise). While convergence was a process of professionalization, specialization, and formalization, renewal often involved a range of more radical leadership actions. Bailey and Grochau addressed the gap in predictions about the details of life cycle transitions by stating that the weakness of their model was its artificial, though not arbitrary, exclusion of environmental factors such as an NGO's external legitimacy, competition between NGOs, and the changing demographics of communities in which NGOs work. These drawbacks of current models (based on theory and practitioner experience) call for a more rigorous examination of the application of LCMs to real-world organizations.

2.3.2 Empirical Research

Characteristics of Included Research

Of the nine empirical studies, seven were based in the US and Canada, one in South Africa, and one in Iran. The case study approach was the most common research design. Three studies were single case studies, four were multiple case studies, and two were cross-sectional studies. Five studies tested the fit of life cycle models to NGO organizational growth, one study attempted to test fit but later retracted this aim due to methodological error,

and three studies employed grounded theory techniques. Figure 2.6 summarizes key characteristics of included empirical studies.

Quality of Empirical Research

As discussed in the methods section of this review, a traditional systematic review attempts to give additional weight to studies that are methodologically rigorous, and this weighting is often based upon the privileging of scientific knowledge over more interpretive methods. This sort of weighting was impractical in this review, not only because the search did not return any experimental trials or large volumes of quantitative data, but also because scholars in the field of organization studies have divergent views about what types of knowledge should be privileged over others. Instead of attempting to judge all articles based on a singular hierarchy of evidence, I analyzed the quality of articles based on a set of appraisal questions catered to the respective methodological stance of each author. I deemed the overall quality of the studies to be poor for several reasons. While most studies had explicit and well-justified research aims and methods, more than two thirds did not explain or justify analytical methods. Without understanding how data were managed and analyzed, it was difficult to understand whether and how the findings were logically reached. For some studies, it was clear that the conclusions were not appropriate. For example, Harvey and Peacock (2001) used a single case study design but also suggested, without qualification, that the results were generalizable to other organizations. In another study (Barnett, 1988), the author proposed a novel framework for nongovernmental organization development and proposed to 'test' hypotheses against this model, but he used a convenience sample of organizations with whom he had pre-existing relationships.

The relationship between the researcher and the individuals and organizations being studied has the potential to influence findings. Harvey and Peacock (2001) states that within NGOs, "staff have often invested themselves so personally in their work that it is difficult for

them to be objective" (p. 223). Ironically, he mentions his involvement with the subject of his case study, but he does not address the influence that his personal relationships might have had on his research. While objectivity may be difficult—and I would argue is an impossible aim of interpretive qualitative research—rigorous research requires that the subjectivity of authors be incorporated into the ultimate analysis. Only three of the nine researchers were explicit and reflexive about their relationship to the individuals and organizations they were examining.

Finally, I noted that only six of the nine studies disclosed ethical protocol or requisite institutional ethics approvals. Organizational research presents unique ethical challenges—it has the potential to benefit or harm the individuals involved in the research as well as the collective organizations that they represent. Whereas in most research only the researcher and the individual participant must consent, in the case of organizational research there are three relevant parties – the researcher, the participant, and the organization itself. Some authors also argue that the participation of organizational members in research entails considerably more risk than in many other research settings, due to the hierarchy and power dynamics within organizations (Skarlicki, 2001)

Figure 2.6: Summary of Included Empirical Research

Authors	Study Purpose	Location	Design	Sample	Methods	Analysis	Findings	Theoretical Foundations
Barnett, 1988 Evaluation and Program Planning	presents and tests life cycle model to hypothesize management actions	United States	cross-sectional study	24 out of 199 organizations funded by the Corporate Fund (convenience sample)	standardized interviews with executive director or trustee	unclear	author admitted that process was not rigorous enough to draw conclusions	Thain (1969) and Scott (1971)
Koroloff & Briggs, 1995 Unpublished	provides a 'stages of development' conceptual framework/fit of life cycle to family advocacy orgs	United States	multiple case studies	17 federally funded family advocacy organizations	on-site structured interviews, quarterly reports, and regular telephone contacts, narrative progress reports	unclear	family advocacy orgs went through predictable phases of growth and development; it is possible to know what will challenge an organization's stability at each stage and during each transition	Cameron and Whetton (1983)
Chambre, 1997 Nonprofit and Voluntary Sector Quarterly	tests the application of the organizational life cycle model to new organizations; examines the impact of differential levels of community resources on the founding and evolution of new organizations	United States	multiple case studies	16 nonprofit organizations that were established to fight the HIV/AIDS epidemic	mixed methods	unclear	data failed to support "classic model" of inexorable shift from unpaid to paid labor; demonstrated dependence of most nonprofit orgs on public funds (particularly for orgs that serve low-income clients); indicated interdependency between government and nonprofits	Katz (1970), McCarthy & Zald (1973), Staggenborg (1988)

Figure 2.6: Summary of Included Empirical Research

Harvey & Peacock, 2001 Comparative Education	traces the lifecycle of an organization from initiation to demise	South Africa	single case study	1 organization (Primary Science Programme)	interviews, document review, participant observation	unclear	social and economic environments shaped the organization's development and demise	grounded theory/ecological analogy
Kelley et al, 2005 Nonprofit Management & Leadership	explores the processes of organizational change in an 'underground organization', focusing on the impact of formalization on members and organizational goals	United States	single case study	1 organization (Prevention Point)	interviews (in depth life histories), participant observation, closed-ended quantitative instrument	textual analysis in Ethnograph 5.0, SPSS analysis of quant data	transition undermined much of the basis for volunteer commitment, reinforcing the shift of responsibility from the membership to a new management structure	Weber (1922/1978)
Bess, 2008 Administration in Social Work	tests theoretical assumptions and presents tentative new insights	United States	multiple case studies	6 groups affiliated with a Los Angeles-based incubator agency called Community Partners	content analysis, in-depth interviews, descriptive survey	emergent fit qualitative analysis (Strauss and Corbin)	results were consistent with most first stage assumptions of organization Life Cycle Theory	Quinn & Cameron (1983), Hasenfeld & Schmid (1989), others
Osman, 2009 Unpublished	examines how and why Somali community-based organizations are established and grow, how they manage change, and how they respond to challenges; explores the relationship between managers' education and community culture	United States	multiple case studies	8 community organizations founded between 1992 and 2007	in-depth interviews	translation, transcription, and coding (textual analysis)	community-initiated orgs were more sustainable than orgs initiated by an individual; org growth is horizontal (peer partnerships), not vertical (geographic and service expansion); credentials and community/issue knowledge are important leadership qualifications	grounded theory

Figure 2.6: Summary of Included Empirical Research

Campbell, 2010 Nonprofit Management & Leadership	examines how one organization emerged, evolved, and overcame the liability of newness	United States	single case study	1 organization (Windows of Hope)	founder interviews, review of archival material, participant observation	unclear	organization had high perceived legitimacy; resource acquisition encouraged formalization and contributed to the organization's endurance	Stallings & Quarantelli (1985), Stinchcombe (1965), others
Shahmansouri, 2012 Unpublished	explores the elements and mechanisms of organizational growth of Iranian educational NGOs at their start-up stage	Iran	single case study	5 NGOs from author's network (purposive sampling)	interviews with founders/CEOs	open, axial, and then selective coding (grounded theory)	the main challenging scenarios of growth take place in the interaction of leadership and knowledge engines	grounded theory

Figure 2.7: Quality Appraisal of Included Empirical Studies

Criteria	Barnett, 1988 Evaluation and Program Planning	Koroloff & Briggs, 1995 Unpublished	Chambre, 1997 Nonprofit and Voluntary Sector Quarterly	Harvey & Peacock, 2001 Comparative Education	Kelley et al, 2005 Nonprofit Management & Leadership	Bess, 2008 Administration in Social Work	Osman, 2009 Unpublished	Campbell, 2010 Nonprofit Management & Leadership	Shahmansouri, 2012 Unpublished
Clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Research design appropriate?	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Recruitment strategy appropriate?	No	Yes	Unclear	Unclear	Yes	Unclear	Yes	Yes	Yes
Were the data collected in a way that addressed the research issues?	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Relationship between researcher and participants considered?	No	No	No	No	No	No	Yes	Yes	Yes
Ethical issues considered?	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear	Yes	Unclear	Yes
Data analysis sufficiently rigorous?	Unclear	Unclear	Unclear	Unclear	Unclear	Yes	Yes	Unclear	Yes
Clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Thematic Areas of Empirical LCM Research

While this review did not yield a synthesized framework, the included papers had similar stances on a number of issues related to organizational growth. Not only were the models all built around the perspective of sociological functionalism—meaning that they predicted a set of characteristics that 'fit' an organization at any given configuration of organizational characteristics. In order to succeed in responding to threats, stabilize an organization in a given life cycle stage, or advance an organization to the successive stage, organizational leaders must negotiate alignment of organizational elements outlined in the life cycle models. While there was heterogeneity amongst the number of stages and the elements analyzed within each stage, the models collectively offer useful hypotheses about how NGOs organizations will behave.

The Influence of Founders

The literature had a notable focus on the founders of organizations, and particularly on their qualifications and leadership. Barnett's (1988) model predicts that individual personalities have an unusually strong influence on organizational outcomes during start-up, and Avina (1993) warns that dependence on an individual charismatic leader can incite disaster as an organization grows. The empirical studies elaborated on both of these concepts.

In Bess's (1998) case study of six first-stage nonprofit organizations, interview content analysis demonstrated that founders were inexperienced in the NGO sector generally, and that they also lacked experience in starting a new organization (four of six founders had never started an organization). In Chambre's (1997) multi-case study analysis of HIV prevention organizations in New York, only one of the 36 executive directors had served in an executive position in an organization in the past. The empirical studies also demonstrated that founders of organizations not only lacked experience in executive management, but were also required to quickly learn and succeed in these areas. In Bess's study, there was strong consensus among

founders that raising money was one of the most "challenging, difficult, and frustrating of essential early stage undertakings." While founders reported little experience in raising money, they also disclosed that fund raising was one of the most significant tasks in their daily work.

Although a lack of formal experience seemed to be a common pattern across the empirical studies, some authors suggested that the social capital of founders—measured by their networks of trust and reciprocity—could override their managerial inexperience. In a single case study of the emergence of a disaster relief organization after the September 11th World Trade Center terrorist attack in New York City, Campbell (2010) concluded that the organization's founders succeeded because, as 'insiders,' they were able to mobilize members of the hospitality industry to get involved. While most of the founding members and supporters of the organization did not know each other before the attack, their associational ties from working in the same industry were strong enough to generate solidarity that sustained the organization. Chambre's (1997) work presented a nuanced perspective to the argument that social capital is a critical component of organizational founders. In her study of HIV prevention organizations in the United States, she suggested that while social capital was a critical resource that helped organizations overcome the liabilities of newness in the first stage of the life cycle, minority communities were less likely to benefit from high levels of social networks and resources.

The organization of labor was also frequently included in the analysis of the influence of NGO founders, and the evidence suggested that the first stage of the life cycle is a founder-oriented operation. In Bess's study, the founders were doing most of the work during the early stage of organizational growth, calling selectively upon group members for assistance. Across all of the empirical studies, it was common for organizational staff and volunteers to be people with pre-existing relationships to the founder. While in Campbell's case study these relationships were associational (and not formal friendships), in other examples founders had

recruited their friends and colleagues as volunteers. The founders often shared the burden of the organization's work, and either oligarchic or democratic governance structures were common.

Dependence on the founder to carry out organizational work was shown to be a risk as organizations grew. Chambre (1997) found that the departure of founders often led to organizational crises, and several studies examined the reasons why executives left organizations. The most common reasons were inability to relinquish control as the organization grew, resistance to institutionalization, burnout, and 'brain drain.' In an examination of 17 family advocacy organizations, Koroloff and Brigg's (1995) found that family members of children who suffered emotional disorders were the most common leaders of the NGOs that were studied. The chaotic nature of the children's disorders, the resulting crises in family life, and the lack of supportive services made it difficult for caretaking family members to contribute consistently to their leadership roles. Instead, the work was disorganized, with members playing inconsistent and sometimes unclear roles in programmatic and governance activities. Koroloff and Briggs found that because the organizations' leadership positions were often poorly paid, part-time, or voluntary, family members with the requisite skills dropped out for economic reasons. In a study of NGOs in the northern United States, Barnett (1988) cited burnout as the cause for a key executive director in his sample. Finally, Koroloff and Briggs point out that organizational leaders are often poached by the formal service system and larger NGOs. In their study some leaders established legitimacy by spearheading fledgling NGOs and were quickly offered attractive, well-paid jobs in the public health sector. Chambre (1997) provides an anecdote that highlights many potential risks of a founder-centered NGO, and more particularly of the hazards of founders who are reluctant to lead an organization through change:

> Yolanda Serrano worked as a drug counselor before she became ADAPT's president and then the executive director. Serrano was highly regarded and

> was often described as charismatic, but the organization's early success was due to management assistance and proposal writing provided by two established nonprofits-the Community Service Society and Narcotic and Drug Research Institute-and later help from technical assistance providers assigned by government agencies…Internal documents and interviews with former staff, board members, and contract managers reveal that Serrano was unable or unwilling to develop effective managerial and fiscal systems. Staff and board turnover were considerable, but Serrano was untouchable because she had become a public icon and had enormous influence in the city's AIDS community…Serrano remained the executive director of ADAPT until she died in late 1993, and the organization's reputation, influence, and revenue declined after her death. This anecdote is not unique. (p. 479)

While the evidence shows that founders may struggle to maintain consensus and effective leadership as organizations grow, Koroloff and Briggs's evidence suggests that NGOs that are generated by larger organizations are ultimately less successful than those initiated organically. In their study, all of the four organizations that failed (out of 17) had been originally created, or 'induced' by large organizations, not organically by parents of children with disorders. Three of these were never able to develop strong parent leadership. The fourth organization developed strong parent leadership that was in continual conflict with the sponsoring organization. In one case, the organization was plagued by a schism among the parents that the leadership was not strong enough to handle.

Formalization

Sociologist Max Weber identified the 'hazards of routinization' faced by ideologically minded organizations as they seek to supplant the vision of charismatic leaders with enduring structures and procedures. While his original work has been contested by emerging sociological fields, the LCM literature is predominantly based on the idea that organizations face pressures to formalize and institutionalize as they grow. Most of the papers included in this review assumed that some degree of formalization—also expressed as 'professionalization' or 'institutionalization'—was inevitable. Formalization of an organization occurs when "other organizations recognize their work and legitimate the group's

function" (Stallings & Quarantelli, 1985), and when organizational structure and boundaries become clearly defined. Formalization may be induced by internal efforts to reduce inefficiencies, or it can be imposed by regulations of NGO donors. In Barnett's (1988) research, one organizational leader framed the tension involved with formalization as a decision to let the organization "be run by well-paid, skillful professionals or whether we will cling to the bleeding hearts concept" (p. 17).

Another example in Barnett's research demonstrates a common rationale in enacting organizational professionalization. After a founder resigned because of burnout, the organization's board decided to professionalize the organization.

> The volunteer trustees, seeking to limit their own involvement at the center, voted to double the salary of the executive director and hired a professional manager of non-profits. The trustees turned over all operating affairs to this professional manager, who was familiar with grant writing and fundraising, but was not knowledgeable in early intervention, the organization's core program service area. (p. 16-17).

In Barnett's study, most organizations—with the exception of Alcoholics Anonymous, discussed later—underwent two distinct stages of formalization. During professionalization, organizations focused on mastering a service technology, and during institutionalization they focused on establishing a favorable institutional environment by hiring full-time administrative staff.

While Max Weber's original conceptualization of formalization was based on the notion that this process reduced organizational inefficiency, the included empirical studies demonstrated that formalization does not always correlate with increased organizational effectiveness. In Kelley's (2005) study of the transition of a clandestine needle exchange organization serving drug users, the organization being studied lost the support of many of its volunteers when it formalized. The organization, Prevention Point, was founded with the value of galvanizing a marginalized grassroots constituency. Its founders intentionally chose not to engage with public health institutions. However, as it grew, it eventually became a legally

recognized entity and received grants from the government. Many of the organization's staff and volunteers had hoped that resources from the state would allow them to support greater involvement of the participants and to give them the ability to redirect the work of the organization toward that community's needs. In fact, the opposite change occurred. Volunteers perceived an increased distance between themselves and the organization's beneficiaries, and they began to see the organization as a puppet of the state, as opposed to an oppositional movement, and many of them quit.

While many of the organizations examined in the included studies underwent formalization, the evidence also included disconfirming cases. Alcoholics Anonymous, a case in Barnett's (1988) research, resisted pressures to professionalize or institutionalize.

> Alcoholics Anonymous developed its Twelve Traditions and Twelve Steps early on and has steadfastly and successfully resisted any and all pressures for professionalization or institutionalization, stressing its Eighth and Ninth Tradition, "Alcoholics Anonymous should remain forever nonprofessional" and "A.A., as such, ought never to be organizational" (p. 19).

The leaders of Alcoholics Anonymous believed that it was able to resist professionalization and "organizational drift" through a strong organizational culture and a constant influx of new volunteers and beneficiaries. The trajectory of Alcoholics Anonymous might indicate that an agency can maintain itself in the late start-up stage with perseveration of original objectives, vigor and enthusiasm for decades—or even centuries—through the continued inflow of new members and the adherence to the agency's core objectives.

Legitimacy and Environmental Dependence

The concept of legitimacy was also frequently featured in the literature. External legitimacy is defined as an organization having its actions endorsed by external actors and developing strong relationships with external constituencies (Stinchcombe, 1965). Pfeffer and Salancik (1978) posit that legitimacy is conferred status and, as such, is usually controlled by those outside the organization. Campbell (2010) points out the difficulty of objectively defining

legitimacy, stating that it is ultimately "in the eye of the beholder." Legitimacy may be more ambiguous in the NGO sector as opposed to the private sector, where profit is a clear, easily definable purpose. In the NGO sector, organizations often have more ambiguous goals than private sector organizations, and their progress toward these goals is more difficult to demonstrate (Hasenfeld & English, 1974). As such, their legitimacy is often based on evolving social criteria, such as the satisfaction of external constituencies that may have a diversity of interests. Campbell's (2010) case of the emergence of Windows of Hope following the September 11, 2001, attack indicates that perceived legitimacy enabled its leaders to acquire resources and accomplish key goals. Bess (1998) found that NGO's used symbolic boards of directors in order to improve their legitimacy.

Harvey and Peacock's (2001) case study of the Primary Science Programme (PSP) in South Africa demonstrates the dependence of an organization's survival on acquiring legitimacy. In their case, PSP was able to move through the early stages of the life cycle because of Western interest in investing in NGOs as a method to assist a democratic transition in South Africa. Education was a critical focal point of the anti-apartheid movement in the 1980s and 1990s, and international donor agencies were supporting NGOs as a tool to reform what they saw as an oppressive public education system. After 1994 [and the end of South Africa's oppressive Apartheid regime], 'many donors asked themselves why they should fund NGOs and not the legitimate government's education program.' Large international donors diverted their funding to government-led programs. In the eyes of these donors, the state regained its legitimacy as a provider of education after the fall of Apartheid. Education NGOs, therefore, had to quickly find new sources of funding or new ways to collaborate with the government. For PSP, its founders believed that its participatory management structure rendered it unable to make quick adaptations in the new environment.

There was a preponderance of evidence demonstrating that the negotiation of legitimacy also required NGOs to form relationships of dependency. In Kelley's (2005) study of Prevention Point in San Francisco, interview analysis showed that many organization members believed that the organization became "co-opted" by its funders and supporters. As the organization adapted its forms and practices to accommodate the external pressures that accompanied public support, it was perceived to have reduced its emotional commitment to its constituents, undermining both its participatory management style and its original core ideological stance. Chambre's (1997) evidence corroborated this idea, and it also demonstrated that organizations serving clients in low-income communities are more likely to be co-opted by their public supporters.

2.4 Conclusion

The review of both conceptual and empirical literature supported the idea that the life cycle model is a useful concept for assessing an organization's 'fit' between structural and contingency variables and its institutional environment. However, neither conceptual nor empirical work has clearly explicated the mix and sequence of factors that drive an organization to progress from one life cycle stage to the next. Future research is needed in this area.

This review used systematic search, retrieval, and appraisal methods to assess the body of organizational research on the application of life cycle models to NGOs. It identified and provided thematic synthesis of four conceptual models of life cycle models in the NGO sector, and it appraised nine empirical studies, some of which were tests of fit to life cycle theory and some of which used grounded theory approaches. While systematic approaches to reviewing organizational literature have presented challenges in the past, this review proposed adaptations to traditional systematic reviews that allowed for the inclusion of disciplinary diversity in research and a customized process of appraisal.

A major limitation of the research is its Western bias. The majority of conceptual papers were authored by American academics, and nearly all of the empirical studies examined Western NGOs. Given that the institutional contexts of NGOs may vary significantly from country to country, it is important that future research aim to explore patterns of organizational development in non-Western NGOs. Another limitation of this review was the restriction of language to English. The language limitation may have also contributed to the Western-bias of the results. Future systematic reviews should also employ at least one additional reviewer to corroborate citation screening decisions, research appraisals, and the narrative synthesis of results.

CHAPTER 3: METHODS

3.1 Building on Library Research to Design Field Methods

The opening chapter of my dissertation introduced both the prominence and political salience of organizations led by hard-to-reach populations (men who have sex with men, sex workers, and intravenous drug users), as well as the gaps in knowledge about how nongovernmental organization (NGO) practitioners and public health stakeholders might effectively engage hard-to-reach youth (HTRY) in community-based and community-led HIV prevention initiatives. The second chapter presented a systematic search, synthesis, and analysis of conceptual and empirical research about patterns of growth and change in NGOs, in hopes of generating a framework upon which I could conduct my empirical work. In this chapter I will discuss the methodology and methods that guided my empirical investigation.

3.1.1 What My Research Was and Was Not

Over the course of my fieldwork, I frequently interacted with community workers who were hoping that my research might offer 'proof' that HTRY-led NGOs are effective, or even that it would demonstrate that HTRY-led organizations were *more effective* than other public health interventions. I had to be careful to clarify to them—as I will also clarify here—that my study was not intended to draw direct conclusions about the public health outcomes of HTRY-led organizations. Instead of measuring the effectiveness of HTRY-led organizations, the practical relevance of my research was grounded in the problem of high rates of failure among HTRY-led organizations. It assumed that a 'living' organization would ultimately have a more substantial public health impact than a 'dead' one, and my key research interest was in understanding 'how' some HTRY-led organizations were able to establish and sustain themselves. While organizations that 'are alive' certainly have a greater likelihood of making an impact than those that are not, it cannot be equally assumed that these impacts will be desirable. There are countless examples in the NGO sector of old, large, and financially stable

organizations whose leaders ultimately discover through experimental research that their programs have had unintended harmful outcomes (Becker, Agopian, & Yeh, 1992; Petrosino, 2004; Rogers, 2008; Underhill, Montgomery, & Operario, 2007).

My research purposefully avoided making broad and generalizing statements about 'effectiveness' because in the NGO sector the meaning of this word is constantly under negotiation (Lingán, Cavender, Lloyd, & Gwynne, 2009), and even at any single point in time, its definition varies widely across contexts (Stern et al., 2008). Effectiveness, however defined, is also the result of a confluence of interrelated factors, including but not limited to the services an organization provides, the uptake of these services by its beneficiaries, and the organization's ability to obtain sufficient human and financial capacities to provide these services. For this reason, my research only alludes to evaluation metrics insomuch as organizational stakeholders attributed these outcomes to processes of organizational change.

3.1.2 Navigating the Transition from the Library to the Field

The library-based phase of my research developed a map of the extant concepts and a summary of research that described organizational development in NGOs. My scoping review resulted in several relevant conclusions: (1) that life cycle models for NGOs were diverse and that empirical research was heterogeneous; (2) that the quality of empirical research was generally poor; (3) that there was little research focused on non-Western NGOs; and (4) that despite its weaknesses, the extant literature generated several propositions that warranted further exploration. These discoveries provided fertile territory from which to launch my work.

The results of the systematic review were at first frustrating, as I was hoping to uncover a more robust body of research that would help me to narrow my focus. While the review failed to yield a clear and consistent statement about whether and how NGOs navigate the organizational life cycle, it provided a useful framework upon which I could build my research. The life cycle literature yielded a continuum of constructs from which organizational change

has been analyzed. While these constructs are most often bounded by 'objective truths' (e.g. an organization does or does not possess legal legitimacy), the literature fails to offer a consensus on the interactions of constructs that drive organizational change. Barnett (1988), for example, disclaims that his model leaves out external environmental influences on organizational growth, and it also falls short of explaining the ways in which changes within different organizational constructs interact with other organizational parts. Instead of providing detailed theory through which complex organizational changes can be predicted, explained, and empirically tested, the literature provided a loose patchwork of constructs and isolated empirical tests that serve as a useful starting point for a grounded research approach.

My systematic review offered clear consensus, however, on the idea that the process of organizational change is likely to be determined by a plethora of factors (Dawson, 1996). This idea is the basis of a critical problem in research on organizational change, particularly that which aims to infer causality. Katz and Kahn (1966) and Weick (1979) argue that organizational change research is often overdeterministc, and that causality should be viewed as probablisitic, not deterministic. Markus and Robey (1988) and Mohr (1982) explicate this argument by positing that specified antecedent conditions may be necessary or sufficient for organizational change, but might not be both. From this perspective, any single event or process may fail to have the expected effect due to unrecognized or unmeasured countervailing forces (Huber & Glick, 1993).

The 'overdetermination' of research on organizational change presents inherent methodological challenges that can be approached from two methodological stances. The first approach is idiographic. It emphasizes context-dependent descriptions of the processes of change (Markus & Robey, 1988; Mohr, 1982). The second, nomothetic approach requires that inferences be based on comparatively large samples and statistical criteria rather than detailed observations of a single case. These approaches often employ longitudinal time series and

event-history methods in order to study organizational processes, as opposed to idiographic methods that employ fine-grained qualitative data (Pettigrew, 1992; Van De Ven, 1992).

One option for my research was to assemble a comprehensive population of HTRY-led organizations and to test the fit of these organizations to an existing life cycle model. In the process of conducting preliminary research, I learned that this approach might be prohibitively difficult for several reasons. Firstly, aiming for a generalizable statement about organizational change in HTRY-led NGOs would require a large population of participants, as well as an interview guide or survey instrument that would be valid across a global range of linguistic, political, and cultural contexts. In order to explore the feasibility of such a study, I initiated contact with several stakeholders in the HIV prevention sector. Over the course of several weeks of preliminary fieldwork, I visited the headquarters of a preeminent donor to HTRY HIV/AIDS organizations (which I will henceforth refer to as "Together Against AIDS"). Each week I engaged in both formal and informal conversations with staff members. In return for unrestricted access to the Together Against AIDS data server (e.g. grant applications, progress reports, minutes of board meetings, etc.), I offered to develop a database of key organizational characteristics of its grantees. This process was mutually beneficial – it enabled the staff to view trends in its grantees in new ways, and it enabled me to attain a 'birds-eye view' of the population of HTRY-focused NGOs.

I assembled a database of the Together Against AIDS grantees since the beginning of its grant-making program; the database included organizational services, targeted beneficiaries, location, age, and key characteristics of organizational founders. It included 108 unique grantee organizations in 50 countries on six continents. These organizations were providing peer education, condom distribution, HIV screening, support groups, medical and psychological referrals, advocacy, media campaigns, syringe exchange, capacity-building trainings, and income generation services to hard-to-reach populations.

The leader of the donor agency then introduced me to another donor to HTRY-led organizations (which I will henceforth refer to as "Believe in Youth"), and I compiled a similar database for Believe in Youth's grantees. Believe in Youth had distributed grants to 29 unique organizations in 21 countries on five continents, with one organization having a 'global reach.'

Coincidentally, my visits to Together Against AIDS's headquarters paralleled a donor-commissioned evaluation of its grant-making program. The evaluation included surveys sent to the leaders of its grantees, phone interviews, and a small number of site visits. Through interviews with the lead evaluator, I learned that both the response rate to the survey and the validity of the responses were poor. The evaluator speculated that the poor response rate was probably due to language and educational barriers, as well as a lack of participation incentives. She speculated that the respondents provided answers to survey questions that they believed would be most appealing to their current and prospective donors, regardless of whether or not these answers reflected their own views of the organization's reality. This type of bias is commonly referred to as social desirability bias, and it is well-documented in research on marginalized communities. When the evaluator made site visits to a small sample of the survey respondents' NGOs, she realized that the reality 'on the ground' was significantly different from the image portrayed in the surveys. While I empathized with the evaluator's difficulty in conducting her study, I found the discord between 'report and reality' to be an interesting phenomenon itself.

3.1.3 Refining the Purpose of the Empirical Investigation

My preliminary work with Together Against AIDS and Believe in Youth helped me to refine my research approach. Instead of continuing to collect data on organizational change from the full scope of grantees from both donors and to test one of the life cycle models from my scoping review, I realized that this was not practical. Moreover, the difficulty that Together Against AIDS experienced in avoiding social desirability bias justified a more in-depth, fine-

grained investigation into the dynamics of the donor-NGO relationship. While my understanding of organizational behavior of NGOs was advantaged by my systematic review, I wanted to leave myself open to exploring new avenues. My focus lay equally on analyzing the fit of these models to a small number of organizations, as well as to leaving myself open to developing new theory. Sacrificing breadth in order to gain depth, I focused on the rich details of the processes related to organizational change in a very specific type of NGO. My primary interest was in the antecedent conditions, causes, and consequences of changes across a variety of organizational forms, contexts, and internal processes within HTRY-led HIV/AIDS NGOs.

3.2 Epistemology

I conducted my research within an interpretivist epistemological framework. Interpretive methods are particularly warranted where the task is the description, interpretation, or explanation of a phenomenon (Huberman & Miles, 2002; T. Lee, 1998). Interpretive research does not predefine dependent and independent variables, but instead "focuses on the full complexity of human sense-making as it pertains to the subject being studied" (Myers, 2009, p. 2). Interpretive studies generally attempt to understand phenomena through the meanings that people assign to them, with the assumption that there is no single objective truth, and that 'realities' are social products of people, their interactions, and the institutions to which they belong. The goal is to use methods that provide an interpretation of the social world of research participants by focusing on their "experiences, perspectives, and histories" (Ritchie & Lewis, 2003, p. 3). Here, an interpretive approach is aimed at constructing an understanding of the processes whereby NGOs develop organizational capacities, as well as the context of that growth.

My decision to situate my research in this paradigm was influenced by a short fieldwork trip to Kenya in 2012. I was invited by Together Against AIDS to attend a ten-day workshop for the leaders of 14 NGOs from Europe, Asia, Africa, and South America. I observed

interactions between the workshop's facilitators and its participants, as well as between and among NGO leaders. In addition to my observations, I conducted semi-structured group interviews with two representatives from each organization. While I expected that the responses of interviewees might be biased by their desire to present an appealing image of their organization, I was most surprised that many of my interview questions incited disagreements between leaders of the same organization, even when they were speaking about the same phenomena in their organizations.

Positivist researchers might consider this a problem of 'reliability.' In interpretive research, the lack of reliability is itself a justification for qualitative methods. While some constructs of NGO organizational development can be considered objective (e.g. an organization has a functioning board of directors), the pathways to achieving these characteristics might be explained differently by different members of an organization's network. My observations during my fieldwork trip with Together Against AIDS further justified the interpretivist position that "people, institutions, and interactions are involved in producing the realities in which they live and that these productive efforts are based on processes of meaning-making" (Flicke, 2014).

While positivist research assumes that there is one history to be reported, the interpretive perspective assumes that there might be many histories that are "all valid, all different, and some not discernable until long after the events that are directly observed have occurred" (Seashore, 1983). For this reason, the interpretive approach was well-suited to exploring not only the complex pathways and relationships of organizational change, but also the competing perspectives of various organizational members (Symon & Cassell, 2012). While my research took into account objectively verifiable changes in an organization's financial position, programmatic outputs, etc., it privileged the meanings attached to these objective data by people within the organization's network. After all, some 'hard' results are

best understood analytically and theoretically by reference to the phenomenology of individual members of the organization.

3.3 Research Design

Within an interpretivist framework, I utilized a comparative case study design with present and retrospective analysis of organizational processes. Each case was constructed through the analysis of empirical data from multiple sources to explore the growth of NGOs. In contrast to 'variance' research, which draws on variable analysis of an organization at one or multiple points in its growth, 'process' research sees organizational change as a result of ordered patterns, choices, and activities over time (Langley, 2008). My research focused on the sequence and antecedents of organizational change in NGOs, but it also drew on the concurrent evolution of the relationship between the organizations and their 'seed funders.'

I considered several methodologies before selecting this design. At first, I rejected the possibility of using quantitative research methods. As stated above, quantitative research did not suit my research questions, which emerged to focus on socially constructed understandings about organizational growth. After making the decision to situate my research in an interpretivist paradigm, I struggled with whether to use a comparative case study design or a multi-site ethnography. Ultimately, I chose the comparative case study design because it allowed me to more easily assume dual roles as participant and non-participant, depending on access and appropriateness in engaging with certain organizational activities. Ethnographic research would have required that I aim to 'go native,' ceasing data collection only once I judged to be fully integrated into the organization being studied (Tedlock, 2011).

3.3 Unit of Analysis

The case study design for organizational research involves the collection of empirical data from multiple sources to explore an identified unit of analysis and the characteristics of its context. The unit of analysis can range from a single person (e.g. organization leader) to a

large group (e.g. all NGOs) or an abstract event (e.g. mergers) (Fitzgerald & Dopson, 2011). For this research, the unit of analysis was the process of organizational growth in HTRY-led NGOs.

3.4 Sampling

3.4.1 Case Selection

A defining feature of NGOs is their dependence on public and private donors. For this reason, the originating donors of these groups became a substantial focus of my research, as was the ongoing relationship between NGOs and their donors. Two donor agencies that were known to specifically invest in start-up HTRY-led NGOs were approached in the early stages of my work (Together Against AIDS and Believe in Youth, introduced earlier in this chapter). A series of electronic and face-to-face communication with both donors shaped many of the early decisions about the focus and structure of my study design and methods. As my research proceeded, conversations with these donors led to the development of an entirely separate case study. I interviewed board members of the donor agencies, advisors, grant managers, and executives. I also attended these donors' fundraising events, and I interviewed key stakeholders recommended by these donors. In addition to developing into its own chapter, the case study on HTRY donors also shaped my sampling decisions for my organizational case studies.

Rather than aiming for generalizability across the entire population of NGOs or HTRY-led organizations, the aim of my research was to delve deeply into the dynamics of a small sample of organizations. Instead of sampling for cases that were representative of the population, or for cases that would be considered ideal for testing a theoretical model, I used 'polar types' sampling (Eisenhardt & Graebner, 2007, p. 27) based on data collected from Together Against AIDS and Believe in Youth. This sampling method allowed me to select case studies based on organizations that were known by the donors to have done 'exceedingly well' during their first four years of organizational development, as defined by their donors.

I conducted interviews with key informants at each of the donor agencies (one executive team member and one grant manager from each). The interviews were semi-structured (Appendix 2.2), and they aimed to understand the purpose of the grant-making program, the 'ideal type' of grantee, and the challenges that the donor and had faced in attempting to support its grantees. Following the interviews, I asked each interviewee to identify possible case studies from their database of grantees. I requested that these organizations be selected not based on the foundation's idea of 'the average,' but instead on their perceptions of high-performing grantees.

3.4.2 Within-case Sampling for Interviewees

At the initial meeting, I asked the organizational point of contact to draw a map of the organization's network of stakeholders, including staff, volunteers, local supporters, partners, beneficiaries, donors, community leaders, and governing board members. I used this map as a starting point for recruiting interview participants, with the aim of gaining a diverse set of perspectives on the organization's growth. I invited each member of the initial stakeholder map to interview, and at the culmination of each interview, I asked each interviewee to select additional interviewees who might provide further insight into the organization's growth. I repeated this process until I achieved conceptual saturation (e.g. no new themes or concepts emerged from the data). While previous organizational research suggests that the top manager is most likely to be knowledgeable about a broad variety of important changes both within and outside the organization (Aguilar, 1967; Hambrick, 1980; Mintzberg, 1975; Snow, Hrebiniak, Administrative, Quarterly, & Jun, 2015; Zajac & Shortell, 1989; Zajonc & Wolfe, 1966), there is a wide body of research that calls for multiple informants (Bagozzi & Phillips, 1982; Huber & Glick, 1993).

3.5 Data Collection Timeline

As is often the case in interpretive research, it is difficult to discern the exact moments at which my research began and ended. Repeated iterations of immersing myself in participant observation and interviewing with donors, reflecting, reviewing the literature, and then re-immersing myself in the field were critical to the development of my understanding of the field, as well as to building the requisite trust to gain access to the subjects of my case studies. I commenced conversations with stakeholders in the HIV field (including Together Against AIDS and Believe in Youth), in December 2011 at an international philanthropy conference. These conversations were then ongoing for four years. My research developed in three phases. The first phase included interviews with donors at an international philanthropy conference; follow-up visits to Together Against AIDS's headquarters; a field visit to a workshop for HTRY-led organizations; and the creation of a database of HTRY-led organizations from Together Against AIDS and Believe in Youth. The second phase involved my systematic review; further fieldwork that led to the creation of a case study on HTRY-led donors; and the selection of two NGO case studies. The third and final phase of my research involved two months of fieldwork at the operating sites of two HTRY-led NGOs.

3.6 Data Collection Methods

I used a combination of three data sources: observation (participant and non-participant), interviewing (retrospective, individual), and archival document analysis to construct retrospective event histories (Tuma & Hannan, 1984). I selected these methods because they have complementary strengths and weaknesses (Patton, 2002). From a temporal perspective, participant and non-participant observations are embedded in the present, documents are embedded in the past, and interviews are temporally versatile to the extent that participants might draw on their memories and can link phenomena across time. Using all three

methods of data collection helped to corroborate and sometimes contest understandings of organizational dynamics from multiple perspectives over time.

In terms of content, archival documents were also an important source of data on key event chronologies. Documents emphasized the 'official' truth, but they lacked complexity. Interviews helped me to access the interpretations, attitudes, and beliefs of people engaged with organizational processes, but they are artificial interactions that can be influenced by selective memory, strategic management of impressions, the moods of participants, and the quality of the rapport between the interviewer and the interviewee (Langley, 1999). Finally, observation served to corroborate data from archives and interviews through an analysis of interactions and behaviors of organizational members and stakeholders.

I divided the semi-structured interview guide (Appendix 2.3) into nine sections, and depending on the time constraints of the interviewees, I separated each interview into multiple interview sessions. I developed my interview guide through conversations with Together Against AIDS and Believe in Youth, and I pilot-tested it during my field visit to the capacity-building workshop with 14 NGOs in 2012. At each field site, I worked with organizational leaders as well as my translators to ensure that key words and concepts in my interview questions were appropriately communicated and translated to interviewees. This was an important step, as Blackburn and Cummings (1982) note that organizational members may misunderstand terms that are often used among organizational scientists. In their responses, interviewees were encouraged to describe organizational processes using their own terminology, which Beyer and Trice (1982) recommend as a means to ensure that the development of theory is grounded in the experiences of organizational members.

In order to ensure comfort and convenience during interviews, I conducted all interviews at a site of the interviewee's choosing. Some interviews were conducted in organizational offices, but most interviews were conducted in much more informal settings –

at cafes, clinics, bars, and even on the back of motorbikes. I recorded nearly all of my interviews using a handheld voice recorder and my phone's audio recording application as a back-up. I refrained from recording only when interviewees expressed discomfort with being recorded, which happened only rarely. When it felt as if note-taking would not interfere with the flow of my interviews, I also took short-hand notes during my interviews.

Opportunities arose in which I was invited to participate (through volunteering in the organization's activities) or to observe organizational activities as a non-participant (e.g. board meetings, events, etc.). Both forms of observation gave me the opportunity to corroborate the accounts of interviewees and to pick up on nuances in organizational structures and processes. I also requested referrals to written documents relevant to organizational growth from all of my interviewees (e.g. annual reports, grant applications, brochures, and legal documents).

Translators

The group of NGOs from which Together Against AIDS was suggesting 'ideal types' had a global range, and the majority of the organizations were based in countries where English was not the primary language. I recognized that this could pose challenges to my fieldwork on a number of levels. In Kyrgyzstan, I struggled to locate translators who were both affordable and had the ability to establish requisite rapport with my interviewees. My initial point of contact in Bishkek suggested that I reach out some of her colleagues at the local United Nations office, but she was wary that UN translators would be costly, and she was concerned that they might struggle to establish rapport with my interviewees. Both HIV and intravenous drug use were associated with high levels of stigma in Bishkek (Thorne, Ferencic, Malyuta, Mimica, & Niemiec, 2010), and while my interviews were not focused on risky behaviors, it became obvious to me very early in my research that I needed to be careful in my selection of

translators. The United Nations offices were slow to respond to my request, and I struggled to gain traction in my first couple of days searching for a suitable translator.

On the fourth day of my search, I had no good leads, so I turned to my Facebook account. I used an advanced search filter to locate contact details for citizens of English-speaking countries who were living in Bishkek. I then contacted the most relevant people returned by the search (based on job description and 'mutual friends'), explaining my research and asking to meet for coffee to discuss my project and my search for translators. Within a couple of hours, I had arranged meetings with five people. By that night, I had arranged interviews with two possible translators. I repeated this same method for my case study in Vietnam; however, in Vietnam I conducted social media outreach prior to departing Oxford, and I was able to schedule several interviews before I arrived in Hanoi. In addition to Facebook, in Vietnam I also used an online database of expatriates called InterNations.

My choice of translators involved important tradeoffs. I needed to find translators who could understand the purpose and key concepts of my research, but who could also set interviewees at ease. In both Kyrgyzstan and Hanoi, the richest interviews were ultimately brokered and translated using people who were close in age to interviewees and who had already established a reputation in the field of HIV prevention. While these interviews seemed to be the most detailed, I also had to be vigilant of 'impression management' between interviewees and translators, given that many of my translators also had a clear stake in the organization's work. In one interview, which was conducted in English with a stakeholder in the HTRY-led NGO sector in Central Asia, my interviewee warned me that translators from within the HIV sector might misconstrue interviewees' responses. The respondent recalled an incident a few years prior to my arrival where one translator modified the responses of an organization member in order to make the organization seem more appealing to Western visitors:

> Interviewee: There was a moment when [translator] was volunteering to translate with people from the LGBT (lesbian, gay, bisexual, and transgender) community. Those people were near and dear to me...my fellow LGBT activists. And she was like, she was really adding *so much*…and I'm like, "What!?," like I had to take her outside, and I was like "What the fuck are you doing!?" And she's like, "…it's donors, and I just don't want them to--," and I was like "Yes, I know it's donors, but don't do this." You know? "Don't. Don't." In Russian there is a name "Mi dvizhi usluga," like it's, it's a very Russian thing. "Mi dvizhi usluga," it's when you're like trying to help someone in a way…but then it doesn't help them in the long term…good intentions, bad outcomes.

During the process of selecting translators, my rating of the standard of translations was initially based on my observations of body language during my interviews. When interviewees expressed confusion or intently watched the translator relay messages to me, I took this as a sign that they lacked confidence in the translations or were otherwise comfortable with the translator. It quickly became apparent to me during my interviews whether the interviewee understood the question being asked, and also whether the translator was offering verbatim translations or gross summarizations.

In addition to *in situ* judgments of the quality of translators, I was able to verify translations at the stage of transcription. I used oDesk.com to locate freelance transcriptionists who spoke English as well as Vietnamese, Russian, and Kyrgyz. I asked that, in addition to transcribing my interviews, they provide verbatim translations of the speech of the translator, and also that they re-translate the translated interviewee responses. This allowed me to detect situations in which the translators added their viewpoints on top of the respondents' answers. In other words, it allowed me to 'triangulate' the translation data.

3.7 Addressing Researcher Bias

Under an interpretivst framework, the aim is not to eliminate the influence of the researcher on the results of the research (e.g. to pursue researcher objectivity). Pure interpretivists would see this as a futile goal. Instead, the aim is for the researcher to be cognizant and critical of the ways in which he or she might influence the direction and findings

of the research. Interpretive research asserts that the researcher's perspective is the avenue through which the findings are generated, and so the researcher should be reflexive of his or her influence on the process and interpretation of results (Creswell & Miller, 2000; Krefting, 1991). My access to my research subjects was likely to have been influenced by my identity as a 'peer' to the organizational members that I studied, as well as a stakeholder in the field of HIV prevention. Prior to commencing my research, I had founded a youth HIV prevention organization in Washington, DC. Because of this experience, I was able to relate to some of the experiences of my respondents. Similarly, I had become acquainted with many of the stakeholders that I interviewed prior to my formal research. My credibility as a pre-existing actor in the HIV/AIDS sector may have both allowed me faster and deeper access to many of my interviewees, but it may have also shaped the discourse of my interviews. Throughout my analysis, I have made an effort to transparently reflect on my assumptions and biases.

3.8 Data Analysis

My methods allowed me to generate a historical account of key events, of environmental intrusions, and of phases of change. While this is a critical process in studying organizational change, it is also essential to have some way to impute meaning to such observations. As Van de Ven (1992) notes, process research needs to go beyond surface description to penetrate the logic behind observed temporal progressions—whether simple or complex. Unlike in quantitative hypothesis-testing research, where the analysis often occurs only after data collection is complete, I adopted an analytical strategy that could run concurrent with my fieldwork (Marshall & Rossman, 2011; Schatzman & Strauss, 1973). Analysis occurred as I was in the field and continued upon my return to Oxford. This iterative mode of analysis allowed me to be open to emergent themes (Lofland & Lofland, 2006).

At the culmination of each interview, I wrote my immediate reflections on key themes of the interview, and at the end of each day I reflected on all of the observations and interviews

from the day. I transcribed English interviews on my own, and I used freelance transcribers and translators from oDesk.com to transcribe and provide secondary translations of my interviews. After transcribing my interviews, I read and coded field notes and interview transcripts based on events, themes, and topical markers related to the concepts of organizational capacity outlined by Hasenfeld and Schmid (1989), with flexibility to allow for emergent themes. I undertook a similar coding process for archival documents. I used NVivo software as a tool to manage my data and to assist with visualizing patterns in the data. While not an analysis tool itself, NVivo was useful in allowing me to manage the large volumes of data and then visualize and re-read the data from many different dimensions. Researchers often leap to conclusions based on limited data (Tversky & Kahneman, 1973), are overly influenced by vividness (Nisbett & Ross, 1980) or by more elite respondents (Huberman & Miles, 2002), or sometimes inadvertently drop disconfirming evidence (Nisbett & Ross, 1980). The key to good within-case and cross-case comparisons is to counteract these tendencies by looking at the data in many divergent ways. While NVivo did not perform analysis for me, it allowed me to very quickly search for confirming and disconfirming evidence throughout the process of analysis.

I listened to audio recordings of the data, read my interview notes, and then read and coded the interview transcripts. I used an emergent fit mode of qualitative analysis (Artinian, 1988; Strauss & Corbin, 2008) to construct case narratives, and I used pattern-matching (Trochim, 1989) to explain the processes of organizational growth. I drafted case narratives, and I searched the data a final time for any disaffirming information. Theoretical propositions came from the literature discussed in the scoping review and from interviews with the organizations' 'seed funders.' They were analyzed in reference to the two field sites and their narratives of organizational growth.

3.9 Research Ethics

Ethical approval was granted through the Inter-Divisional Research Ethics Committee at the University of Oxford (Ref No. SSD/CUREC1A/13-045 and Ref No. SSD/CUREC1A/13-225). I consulted both Together Against AIDS and Believe in Youth to ensure that my study information and consent forms were accessible to the communities of the organizations in my case studies, and I further consulted colleagues in both Vietnam and Kyrgyzstan to ensure linguistic and cultural appropriateness. While I maintained compliance with my stated ethical protocol, I adjusted my methods for obtaining individual and organizational consent in order to ensure that the process of obtaining consent could be easily understood by each participant. While I made forms available in both English and local languages, some respondents were illiterate or preferred to have the research explained to them verbally. In these instances, the translator read the consent form aloud.

CHPATER 4: WOMEN TOGETHER: A LIFE CYCLE ANALYSIS OF A GRASSSROOTS HIV/AIDS ORGANIZATION IN KYRGYZSTAN

4.1 Research Setting

Bishkek is the capital and the fastest growing city in Kyrgyzstan, a central Asian republic nestled in the foothills of the Tian Shian mountain range. Not unlike many developing areas undergoing rapid urbanization, political and economic instability in Bishkek have fueled homelessness, unemployment, and drug and alcohol abuse. Krygyzstan has a concentrated HIV epidemic, with around 67% of HIV cases linked to injection drug use. The fall of the Taliban in Afghanistan coincided with a significant increase in opium production. Just as Central Asia was once an integral link in the Silk Road, it is now infamous—facetiously referred to as the "Heroin Highway" by one of my interviewees—for being a narcotics transit route from Afghanistan to Russia. The recent increase in the volume of drug production in Afghanistan led to a substantial fall in prices, making drugs more affordable to the populations of Central Asian countries (Beyrer, Wirtz, Baral, Peryskina, & Sifakis, 2010).

HIV was 'late to reach Kyrgyzstan.' According to sentinel surveillance data, almost 8% of people who inject drugs (PWID) were HIV positive in 2007, increasing to 14.6% in 2010 (Bashmakova, Mamyrov, Sorombaeva, & Imankulova, 2009; Committee, 2012), and in 2011 only half (49.4%) of PWID reported condom use in their last sexual encounter (Committee, 2012). Official data indicates that most people living with HIV are in major cities, where poverty and unemployment, alongside high levels of injection drug use, have been driving forces in the spread of HIV.

As was referenced frequently in interview transcripts and field notes, Kyrgyzstan falls victim to a culture of passivity. Often attributed to the history of Soviet rule, complacency is woven into the fabric of Kyrgyz culture, and it is a particularly potent social expectation for women. One interview respondent expressed her dual frustrations with the social innovation

sector and the way the government was dealing with HIV. "Nothing ever gets done here. Innovation is dead. Having creativity is like having HIV…they [the government] don't pay for that." While many Kyrgyz citizens seem to accept the status quo, in 2011 a small group of progressive young women decided that they were unwilling to sit on the sidelines as drug abuse, police antagonism, HIV, stigma, and discrimination corroded their lives and the lives of their peers. They formed an organization called Women Together, and on my second day in Bishkek, I got the chance to meet them.

In March 2014, I was taken in by a supporter of Women Together, who offered to host me for the weeks that I would spend in Bishkek. The city is organized into a patchwork of 'microdistrict' subdivisions that are connected by a heavily utilized taxi (*marshrutka*) system. On my first day of fieldwork, my host and I took a *marshrutka* through the main commercial areas of Microdistrict 4 into a quieter, more residential zone. We hopped out at a traffic light and made our way through a muddy yard to an unassuming residential building. A male security guard pulled back a corrugated aluminum gate to reveal a group of women smoking cigarettes and having their morning *kofe* and *chay* (coffee and tea). I was led through a corridor and given a proud tour of the building. There was a kitchen, a small office space, a common 'lounge' area, and two tiny rooms that were lined with eight twin-sized beds. Several women sat on the beds whiling away their day, smiling or simply nodding as I passed. At the end of the tour, I was led into the lounge, where three women worked at computers. They were the managers of the shelter. The youngest of the women, Ana, arose immediately and welcomed me.

Ana explained that the shelter was owned and managed by The North Star, an organization that I would later learn was both larger and more established than Women Together. The North Star, in addition to many other activities, provided housing and political advocacy for women who used drugs, many of whom had recently been released from prison.

Ana, a former client of The North Star, was now an employee. But in addition to her work with The North Star, she was also the leader of Women Together, an offshoot of The North Star that aimed to serve the needs of young, mostly teenaged, female drug users in Bishkek.

As we were talking, the women who I had met outside filed into the room and greeted me. These were the volunteer co-leaders of Women Together, as well as several of their clients. During the period of my visit, Women Together was not particularly busy, as they had exhausted their funding and were awaiting a pending grant from Believe in Youth. In the meantime, they came to the shelter almost daily to offer support to the work of The North Star. They worked on a shoestring budget to provide health services to young female drug users, a population with whom they had developed unparalleled trust.

The absence of organizational activity that characterized much of my visit to Women Together was not indicative of their entire history—or even of their recent history—nor was it necessarily a predictor of Women Together's future. In the following analysis I offer a narrative of the organization's early-stage growth, as well as a look into the interpretation of the organization's challenges as described by its key leaders and constituents. I argue that Women Together was experiencing a phase of organizational stagnation. I also argue that its reasons for stagnation can best be understood by analyzing its niche formation, leadership style and attachment to The North Star, and its entrenchment in an unfavorable political environment. I compare the life cycle of Women Together to the hypotheses of the integrated life cycle model (Chapter 3).

4.2 Women Together and the Organizational Life Cycle

4.2.1 Formation

Women Together was officially founded on February 14, 2011, by four women who were recovering from heroin addiction. They shared the common bond of receiving treatment

from The North Star, the only women's shelter for drug users in Bishkek. During their time at the shelter, they grew upset about the disparity of resources available to young women and girls who used injection drugs, and they became impassioned about changing the fate of their peers. They began meeting to brainstorm ways that they could improve the health of their peers.

The real birth of Women Together—at least in terms of formalization and acquisition of resources for the purpose of planned, strategic projects—was marked by a funding opportunity that enabled the women to bring their ideas to life. Youth Power, an international harm reduction organization, recruited the women to facilitate a community-driven needs assessment focused on health issues among young users of injection drugs. The women interviewed their peers and compiled a collection of stories, and they used these stories to advocate for improved policies and services. The project resulted in the production of a video that was presented to government officials from the Ministry of Internal Affairs, the State Service on Drug Control, international donor organizations, and other stakeholders. To this end, the original documented purpose of Women Together was to "develop stronger drug user rights in the region." Women Together aimed to (1) provoke research around the needs of young drug users; (2) assess the impact of drug policy and militia practices on young drug users; (3) mobilize and empower young drug users to act as agents of change in the area of drug policy; (4) and draw the Kyrgyz government's and donors' attention to the gaps in youth-friendly harm reduction services.

Consistent with Hasenfeld and Schmid's (1989) model, the driving force behind the formation of Women Together was the founders' discontent with the status of service provision. While the informal creation of the 'group'[1] was self-initiated, the first major

[1] 'The group' was often distinguished in my interviews from 'the organization,' the term used after the group formalized.

activity was driven by the original donor's (Youth Power's) desire to obtain research on the needs of young female drug users in Kyrgyzstan. Women Together was created because while there were a large number of young women who did not have access to traditional health services, there were few social services that targeted marginalized young women, and there had not been a strong NGO response to this gap in services. Ana and her peers at The North Star expressed the desire to do something to improve their own health as well as the health of their peers.

The initial funding for Women Together was given to The North Star and then sub-granted to the leaders of Women Together. The funding, however, was specific only to the project of conducting research on the needs of young drug users. The grant did not allocate any resources to staff salaries, office space, or any other organizational expenses that might be considered 'overhead' or 'core operating costs.' Most of the administrative duties of the grant were fulfilled by The North Star, and in many ways Women Together functioned as a special project of The North Star. Not only was donor funding filtered through The North Star, but the members of The North Star also provided both formal and informal guidance on the implementation of Women Together's first project. Several staff members at The North Star, however, made it clear in interviews that they wanted to both foster and respect Women Together's autonomy.

Consistent with life cycle theory, Women Together was driven by passionate founders that spent the majority of their time conducting the organization's core programs. None of the original four leaders of Women Together had professional experience in managing NGOs or even in working for similar organizations. But all four women had a keen sense for the needs of women like themselves- young drug users who had very limited access to health services. None of the four founders had any experience in fundraising, though they expressed a

pressing need for additional resources to both continue and expand the organization's services.

The dominant set of values of Women Together in its early stage was rooted in compassion, service, and a desire to 'pay forward' the benefits that the founders had received from The North Star. Women Together had been successful (in the eyes of its founders) because its leaders were conducting outreach to their peers—members of society that stood outside of the margins of government-provided social services. Women Together was doing outreach that either no one had attempted, or that had been attempted by people who struggled to relate to the girls that Women Together were reaching out to. The organization had created a pipeline in which its beneficiaries were encouraged to return the favor to the organization. In line with this core ethos was a desire to maintain a grassroots approach at all levels of the organization – from the 'boots on the ground' all the way up to the organization's management. Many of the women who had been served by Women Together returned to give back.

4.2.2 Development

In 2012, the four co-founders of Women Together applied for funds from Believe in Youth to support the development of additional programs and services, as well as a formalized paid staff and a permanent office space of their own. It was at this point that the organization also solicited support from Galina, a local harm reduction activist and an expert on youth participation and women's issues. Galina did not self-identify as a drug user, and she had completed much more formal education than the average Kyrgyz woman. She had received an undergraduate degree from a Kyrgyz university, studied law in Europe, and was pursuing a teaching and research career through Kyrgyzstan's American University. Galina also had several years of professional experience working with donor agencies. She decided

to volunteer as a consultant to Women Together, offering her expertise and connections in order to support Women Together's leadership.

Galina assisted Women Together in writing the grant application to Believe in Youth, and, after a successful outcome, assisted Women Together's staff with managing the grant. In addition to receiving a grant from Believe in Youth and informal support from Galina, Women Together's leaders were matched with what Believe in Youth called a Peer Support Person, or 'PSP,' who would serve as a local resource to Women Together on behalf of Believe in Youth. Women Together's PSP, Nazia, also had significant NGO experience and had conducted activism to promote women's and gay rights in Bishkek and elsewhere. During this stage of Women Together's growth, both Galina and Nazia met frequently with the organization's leaders to chart out a sustainable plan to scale up the organization's work.

While the initial project of Women Together was to provide insight into the needs of young female drug users in Bishkek, the leaders of the group developed a desire to provide direct services to their peers, many of whom were experiencing struggles similar to those that the founders had encountered before finding The North Star—homelessness, drug addiction, and recidivism. With funding from Believe in Youth, Women Together expanded its organizational aims to include three major 'pillars' – advocacy, education, and health and social services. Education involved the production of booklets and brochures on health issues facing young female drug users (examples included fact sheets on Hepatitis C, HIV, and drug abuse). These materials were kept in the organization's drop-in center, and they were also distributed by volunteers through peer-to-peer street outreach and at community events. Health and social services included support groups, counseling, and a range of medical tests and treatments, and they were provided both on site and through partnerships with clinical agencies. Finally, Women Together engaged in advocacy work whenever opportunities arose.

They organized volunteers to speak at community demonstrations and health-related workshops, meetings, and conferences.

During this phase of organizational growth, Women Together developed a larger base of beneficiaries, and its leaders attributed growth to the acquisition of a physical space that was distinct from The North Star. The organization rented a centrally located office in which young women could drop in throughout the day to receive information and support. Young women could visit Women Together to receive free and confidential HIV testing and condoms, as well as a wide range of individual and group-level psychological support services.

The leaders of Women Together realized that while they had a unique ability to win the trust of other drug users, they did not have the resources or professional training to provide many of the clinical, psychological, and social services that young drug users needed. For this reason, they also brokered local partnerships in order to refer their beneficiaries to clinics, needle exchange sites, and methadone maintenance treatment (MMT) sites. Women Together's staff often physically transported their clients directly to these key health and social services.

The literature shows that partnership-building is a key step in the developmental stage of NGOs. This activity is seen as a venue through which organizations demonstrate their niche (by providing services that supplement or complement the services of other, more established organizations), as well as a venue through which organizations establish legitimacy (by associating themselves with organizations with high levels of external legitimacy).

With the addition of funding from Believe in Youth, as well as paid staff and the establishment of a permanent physical space, the number of clients that the organization served grew. Contrary to the predictions of many second-stage life cycle models, however,

the number of staff had an inverse relationship with the growth in funding and the number of organizational activities. Elina, one of the original leaders of the group, 'aged-out,' meaning that she reached age 30 and by most international definitions was no longer considered a 'young person.' She felt that she could no longer truly represent a youth-led organization, and she eventually lost contact with the organization.

> It is very frustrating. These donors want us to be young but then they want us to have sustainability plan. How can we be sustainable if we must take new leaders each few years? Just because we become older does not mean that we do not know the needs of young people. Especially if we are you know only 30, 31, 32. Maybe we actually know better their needs. (Ana)

Karina, another co-founder, was imprisoned for several years for drug possession. The other leaders of Women Together felt that her punishment was unduly harsh, and they advocated, albeit unsuccessfully, for her release. Finally, Lena, the youngest of the original group leaders, died in a car accident involving the abuse of drugs and alcohol. This left Ana to maintain the leadership of Women Together on her own. The departure of the other three leaders exposes several challenges that may be inherent to an organization like Women Together that is characteristically founded and led by young drug users. Youth-led organizations, by definition, will have transient leadership; and organizations led by drug users, particularly in environments of hostility toward drug users, may face legal struggles or even drug-related deaths. All of these liabilities may impact organizational viability.

As a response to high rates of turnover, Ana immediately began identifying her successors. She invited several women to serve in leadership roles, and she continued to espouse the view that, even with an established leadership structure, the governance of Women Together should done by direct democracy. She maintained that all members would be granted a full vote on organizational matters, and she saw herself as a facilitator of decisions rather than as a dictator of organizational direction.

While Women Together maintained amicable relations with The North Star, they developed noticeable autonomy during this phase of growth. Having a new office space physically separated Women Together from The North Star, but they also began to diverge ideologically on which of their programs should take highest priority. The leaders of The North Star, as well as Galina and Nazia, encouraged Ana and her team to continue their involvement with advocacy. In addition to policy-relevant research being the original purpose of Women Together, The North Star, Galina, and Nazia felt that advocacy was both a more 'fundable' activity as well as a more impactful way to change the entrenched unfavorable circumstances of young women who used drugs. Nonetheless, the only advocacy project that Women Together undertook during this phase of growth—an online outreach platform targeting drug users in Russia and the Ukraine—was seen by all members as largely a failure. While some members believed that the project was fraught with cross-cultural challenges from the outset, others believed that a big reason for its failure was Women Together's apathy for conducting outreach outside of their tightly knit community of Bishkek drug users.

While Women Together's advocacy project did not achieve its desired outcomes, Believe in Youth continued to fund the work of Women Together for two years. Contrary to predictions about organizational revenue during this phase of growth, though, no new donors were acquired. This meant that the organization was not able to establish a reserve of funds to support operations, nor was it able to evade the inherent vulnerability of being dependent on a single donor. Women Together's inability to acquire additional funding was attributed in most interviews to their transition to a period of stagnation.

4.2.3 Stagnation

When I visited Women Together, they were experiencing stagnation. They had been evicted from their office, they had exhausted funds from their two-year grant from Believe in

Youth, and they were awaiting funds from a third donor. There were no available financial resources to support the passion of the organization's leaders or volunteers. As mentioned in my opening vignette, all of the leaders of Women Together had relocated to The North Star. Ana was supported with a part-time job at The North Star, but she still spent some time each week organizing a cadre of volunteers who wanted to continue the work of Women Together. Between three and ten women would show up on any given morning and 'hang out' on the grounds of The North Star. When they were asked, they helped with The North Star's work, and when opportunities arose, they attended workshops and events relevant to drug users' health and rights. They also served as a symbolic anchor for recruiting young clients to The North Star. The constant presence of Ana and her co-leaders at The North Star facilitated a steady flow of young clients to The North Star. The North Star seemed not annoyed by the constant presence of these women, but grateful for it.

While Women Together's growing public visibility during its development stage was in some ways a sign of success for the organization—it also became a liability. The organization's leaders believed that their eviction from their office was the result of the growing traffic of young drug users to their drop-in center. A computer was stolen from the building where Women Together rented their office space, and the building's owner immediately pointed a finger at the women. She evicted them, blaming them for the crime and citing her distrust for drug users. All of the leaders of Women Together maintained that it would have been impossible for one of their members or clients to have committed the crime, and they said that prejudice against them had been rampant as their membership grew. They faced discrimination from several circles of the Bishkek community – from their landlord, to the parents of their clients, to the local police.

In addition to being evicted from their space, a major reason that Women Together's members and leaders were stationed at The North Star was their lack of funds. They had

applied successfully for a third year of funding from Believe in Youth, but they were awaiting the disbursement of these funds. Contrary to predictions of organizational growth, Women Together had failed to increase their revenue during their development stage, and they had failed to bring on support from new donors. At the time, the group was 100% dependent on continued contributions from the Believe in Youth.

Women Together's leadership and its stakeholders attributed the organization's fundraising failures to factors that ranged from a lack of a proactive fundraising strategy to the barrier of not being a legally registered organization in Kyrgyzstan. The dominant tone of the organization and its leadership during this phase was the same as it was throughout Women Together's development—above all else, and in spite of extremely limited resources, Women Together's leaders and members were focused on interpersonal connections with their clients and direct, tangible social services. During the development stage—despite attaining funding from Believe in Youth—the organization did not develop a requisite interest or capacity for administrative tasks or for long-term strategic planning. And even in the face of financial scarcity, the members of the organization spent more time on volunteer outreach than they did on searching and applying for additional funding.

Despite the lack of financial resources, the leaders and members of Women Together espoused a desire, which some interviewees went as far as to call a 'plan,' to establish a holistic live-in shelter that would provide housing, health, and social services to teenage drug users. The dreams of the organization's members were completely misaligned with the realities of their current circumstances. At the time of my interviews, there were no funds to support the operations of the group, and they only conducted activities that could be sustained by volunteers or by small stipends from partnering organizations like The North Star. Yet when asked about how the women imagined the organization in the next couple of years, the vision was grand.

Torbert (1974) refers to the *first* stage of organizations as the "fantasies stage," in recognition of the development of individual visions and fantasies, or as Adizes (1979) explains, founders are dreaming up what they may do. In the human services, this is generally the period in which multiple and diverse ideas are generated on how to respond to an unmet need within the organization's targeted population (e.g. unemployed teens, high school dropouts). Hasenfeld and Schmid (1989) refer to this as a process of building domain consensus with regard to "the population to be served, the services to be rendered, and the technologies to be employed" (p.247). In reference to the organization's strategic planning and its dominant socio-emotional tone, the women of Women Together were still very much fantasizing about the organization's potential.

4.3 Thematic Analysis

4.3.1 The Quest for Organizational Legitimacy

The key to organizational survival, according to Pfeffer and Salancik (1978), is an organization's ability to acquire and maintain resources. Drawing on the biological life cycle metaphor, organizations, like other species, strive for independence and security—food and safety in biological terms—which can be equated with resource maximization and control in NGOs. Hasenfeld and Schmid (1989) observe that groups at the entrepreneurial stage have no "capital or property of their own and must therefore mobilize them from the task environment" (p. 245). Whether the pursuit is for financial resources or social resources (e.g. 'legitimacy'), newly forming groups are attempting to establish a commitment, expertise, and publicly recognized ability to serve a specific population, geographic area, and service technology (Kastelic, 1977). Emerging groups are just beginning to establish an identity that both aligns and distinguishes it from other providers, and which enables it to begin to appeal to various interests for support.

With Women Together, there seemed to be two critical elements to niche formation. The first, which the organization established well, was its ability to service a need identified by the community (or at least *a* community). A review of the city-level and national-level data on HIV prevalence among female drug users and a mapping of the resources available to young drug users showed that there was a clear gap in services for Women Together's target population, and they could easily demonstrate that they were able to provide young female drug users with access to vital health information, psychological support, and clinical care. Women Together occupied a niche in that they were the only organization in Bishkek that solely and specifically advocated for and conducted outreach to young female drug users. They had also aligned themselves with key health service providers, which was consistent with international comprehensive HIV strategies for drug users.

The second aspect of niche formation, however, requires organizations to establish legitimacy amongst external groups that possess power and resources. These groups are critical to the survival of small, early-stage organizations like Women Together. While Women Together had established high levels of international legitimacy, within the Bishkek donor community they were not very well known. The most obvious sign of legitimacy amongst international stakeholders was Women Together's start-up funding sources—Youth Power, a global organization supporting young drug users, and Believe in Youth, a global organization that supported youth leadership in the movement to end AIDS.

Women Together's successful applications to these foundations not only resulted in financial support, but it also put them in a network in which they were recognized by other international bodies. Just a few weeks before my arrival in Bishkek, for example, Ana had been flown to Geneva by the United Nations for the organization's semi-annual interagency meeting on HIV/AIDS. Ironically, though, several of the top donors to NGOs in Bishkek were unaware of both Ana and the work of Women Together. In an interview with a high-

ranking official who was in charge of helping the Kyrgyz government to distribute international aid to projects in key target cities (including Bishkek), my interviewee mentioned that she had never heard of Women Together nor of their leaders, and she was impressed to learn that the organization had represented Bishkek at the United Nations meeting in Geneva.

There are several possible explanations for why Women Together failed to establish legitimacy among local donors. Firstly, interviews, archival documents, and my observations corroborated the notion that neither leaders nor members of Women Together spent much time or money promoting their work outside of a very small circle of potential clients. They did not effectively reach out to potential donors or to high-ranking government officials to communicate their many achievements.

> Women Together tends to underestimate their own achievements. For example what they have done for two years for a young organization and for a youth-led organization is a lot, but they don't have this growth, they don't have education. Sometimes they write grammatically incorrectly, or they might have problems counting big numbers, but they still, despite that…they still achieve a lot. Their problems are that they don't, like, speak about their achievements as much as The North Star does, for example. They don't advertise themselves, but I am inspired by the great achievements they have accomplished in only 2 years. (Tania)

> Women Together does a lot of things, but they don't know how to report them or how to document them…their work goes invisible…they do a lot of things, but…they just think that "oh, we're doing it like regularly da, da, da." But if you as an outsider look at it, you get impressed. (Galina)

While both Youth Power and Believe in Youth had promoted the work of Women Together among the international donor community, Women Together was doing very little to promote their work amongst the local government agencies and donor communities who might have been able to provide more sustainable support for their work. They had not developed a 'resource niche' within their local and national donor environments.

Another explanation for Women Together's relatively low levels of external legitimacy was their conscious resistance to formalization. While Women Together's

international donors were more lenient about the pace at which the organization formalized—or whether the organization ought to formalize at all—a multitude of interviews illuminated the reality that nearly no local or national donors, particularly government donors, would recognize or support Women Together in the absence of formal registration and standard operating procedures. These policies and procedures were critical, it seemed, to the ability for small organizations to receive local legitimacy in post-Soviet Kyrgyzstan.

Finally, the lack of external legitimacy may have been borne out of Ana's perceived fear that if people in powerful positions knew about the work of Women Together, they might try to either take them over or to shut them down. The relevance of both of these issues will be discussed in the following two sections.

4.3.2 Leadership

There were several poignant factors and circumstances that lent insight into the leadership crises experienced by Women Together. These ranged from the instability of Women Together's leaders and volunteers—young women who were either currently using drugs or who had previously used drugs; to the organization's desire to maintain a flat decision-making structure; to Ana's and her colleagues' resistance to pursue organizational activities that were recommended to them by their donors and advisors. There were four original founders: Kalina, Lena, Elina, and Ana. Lena was the youngest at 16, and she died in a drug-related car accident a year after Women Together was founded. Kalina was imprisoned for drug use early in the organization's history, and she was still in prison during my time with Women Together. Elina 'aged-out' of the organization when she turned 30. This left Ana as the only remaining leader, and the loss of her co-leaders all occurred within the first two years of the organization's existence. Ana was also left to manage the organization's transient volunteer base. While many of Women Together's volunteers

believed in the organization's mission, many also struggled with drug addiction, and periodic relapses hampered their reliability.

> The drug users, because they are not very stable, you know, one day they, they say "Yes we are committed, we're going to do that. We're going to help you guys. We're really interested. Yes, these are our lives we want to do that" but then next day they're like "Oh no I just, I don't know. I, like, I found out about this really cool new drug…" or something like that...and they just like move…move on with other things. (Volunteer, Vice President of Women Together)

I spent a lot of time discussing Ana's leadership style with Ana, herself, as well as with her colleagues and representatives of Women Together's community partners. I also went back to the literature on organizational leadership during the early stages of organizational development. The literature was rich, and it is outlined in detail in Chapter 3. Ana displayed core qualities of entrepreneurial leadership—she was a risk taker, and she dogmatically pursued the development of her organization's programs. Above all, she was willing to put her beneficiaries ahead of her own needs, often offering them funds from her meager personal savings and responding to late-night phone calls from girls who were in trouble.

Ana did not, however, possess a key characteristic of early stage organizational entrepreneurs—she had neither passion nor confidence to address two of the organization's most pressing needs: securing new sources of funding and promoting the organization's work to prospective local and national donors. Several of the organizational stakeholders were frustrated with her team's apathy about developing a long-term strategic plan and an actionable fundraising plan.

> Strategy? There is no, like, real kind of step-by-step strategy…it's more like, you know, kind of bizarre…whenever they hear something or see some [grant] announcement. [Strategy] is all on the level of [ad hoc] discussions. (Advisor to Women Together)

> Although they are super enthusiastic about their work, it is very hard to move forward just based on this kind of naked enthusiasm. They need to start to learn how to fundraise and how to deal with paperwork—with administrative

> duties—because local donors and international organizations have very harsh requirements. And they also tend to work with the same organizations for like 16 years. (Staff Member at The North Star)

Chief among the strategies that its advisors recommended to Women Together was to get more involved in advocacy, both locally and internationally. Their advisors at The North Star, at Believe in Youth, and among the Bishkek community had all believed that the young women's stories were their most powerful assets, and stakeholders also felt that it would be hard to enact sustainable change to the root causes of the women's disadvantage without high-level policy reform.

The tension between the two groups, while often downplayed during interviews as if by courtesy (e.g. the desire not to stir up trouble or to appear conflicted), was palpable. It also spoke to an additional challenge of Women Together's leadership during the organization's stagnation stage. While in the formation stage the group had been in many ways incubated and supported by The North Star, during the development stage they developed their own identity and had much less frequent contact with The North Star. During stagnation, they moved back to The North Star's shelter, and Women Together's advisors strongly encouraged them to follow in the footsteps of The North Star. Galina and Nazia met with them to try to help them plan for broad-scale advocacy for young female drug users, offering free workshops and even *pro bono* help with the writing of an advocacy-specific grant. As Ana recalled the external pressure to broaden Women Together's scope of services, she remembered her response, which was not favorably received by her mentors:

> I said, "maybe we shouldn't really." Right now we should kind of keep low so that we can still at least provide services to the communities…because they really need our current services.

Nazia felt like she ultimately failed to mobilize the group.

> We wanted them to try and feel this transformative power and then be moved by it. And then, then once they feel it, they can go and move others.

In addition to the pressure to revert to activism over direct services, Galina and the staff at The North Star insisted that Ana and her team learn how to be better administrators. In some instances, they supplied Women Together with either real or projected images of bureaucratic structures. One of the organization's supporters met several times with donors during site visits and portrayed Women Together as a much more structured organization than they really were. Another advisor believed that the organization was being co-opted by The North Star, and that bureaucratization would steal the core identity from Women Together. She referred to a Russian term, *mi dvizhi usluga* which translates literally to a "a bear's service."

> This is also, in Russian there is a phrase "*mi dvizhi usluga*." Like it's, it's a very Russian thing, "*mi dvizhi usluga*", it's when…you're like trying to help someone in a way…but then it doesn't help them in the long term. I don't believe that they need to become professional. Being professional means becoming bureaucratic. They [The North Star] sterilized their office. It is very post-Soviet. You have one leader and you do what they say. You don't challenge the funding that comes through. (Nazia)

The phrase *mi dvizhi usluga* comes from a tale in which a bear, in good intention, tries to swat a bee from a cub's head and ends up killing the cub. In this quote, the interviewee was concerned that the pro-bono grant-writing, glorification of Women Together during donor visits, and attempts at bureaucratizing Women Together's governance were all efforts that—no matter how well-intentioned—exacted a negative impact on the organization's growth.

4.3.3 The Organization Environment

The final and most frequently referenced theme in my interviews was the series of challenges posed by the political and social environments that hampered the growth of Women Together. Six of sixteen key informants identified legal organizational registration among the most critical concerns for Women Together. Prevailing academic research on NGOs treats these types of organizations collectively as a 'third sector,' distinct from profit-seeking businesses and from the state. In Kyrgyzstan, the reality was that the state had

significant control over the third sector through a bureaucratic and seemingly opaque process for registering new official NGOs. The fact that Women Together was working with clients who were engaged in illegal activity—and that Women Together's members were often working with drug users while keeping the police in the shadows—meant that a formal application for charity registration would be difficult if not impossible. One archival resource cited that registering a standard charity in Kyrgyzstan might take up to several years.

Among the public, there was also a general view that NGOs were not making good use of donor funding, or that they were simply puppets of the Kyrgyz government or the West.

> There is this view that NGO's [nongovernmental organizations] are 'grant eaters.' There is even a word in Russian, "*granta jede*," and literally it means eaters of grants…just to say that all these organizations who receive funding from foreign agencies are…like they're not doing the work that they're supposed to be doing. But they're just like getting money from donors and not doing any work at all. And that's the view of the general public. Yesterday I was talking to this taxi driver about NGO's, and he was like "Oh yeah, NGO's…whatever…they just like get grants, and they don't really do anything. They don't really solve any problems. They just, you know, get the grants…you know…make money. They're like businesses but even worse." That's the attitude toward NGO's (nongovernmental organizations). Yes, there are organizations who *are* grant eaters but because of them the image of others suffer, who really work. So, yeah that's kind of like the environment…it's tough. (Galina)

Finally, in addition to an unfavorable environment for the start-up of politically controversial NGOs, Women Together faced numerous existential threats from police.

> There are always policemen at the points where they [Women Together's clients] go to test [for HIV]…they take [the young people] to a jail, or they demand some money from them. (Ana)

Women Together was unique in its ability to build rapport with clients by offering many of their services 'under the table.' They allowed their clients to register themselves as beneficiaries of Women Together's services using only their first name, a nickname, or even no name at all. As Ana explained, "they can use any name, number, or symbol of their choice." This made it more difficult for them to be targeted by police harassment, arrests, or

bribes. Nonetheless, there were several instances in which Women Together's members felt that the organization might have to shut down for concerns over safety.

> We have had some events where our young girls are taken by police. They call Gulnara…they call her at any time in the night. Recently they called her at 4 o'clock in the morning. Gulnara goes over there [to the police station] to help them. The police have no right. Two weeks ago we had an occasion where two girls were arrested and the police stole the girls' documents and money.

This issue diminished the view among young women that Women Together was a safe space for women to receive support, and Women Together's response was to pay the police bribes in order to have the young girls released. The problem became such a financial and emotional drain on the organization that they requested (unsuccessfully) funds from Believe in Youth to support the payment of police bribes. This incident highlighted several themes that were relevant to Women Together's growth. First, it was obvious that the political environment was unfavorable for conducting meaningful programming for many of the current and potential clients. Second, the women's response to the situation reflected their organizational ethos of doing whatever it took to help women most in need. Instead of spending their resources on structural level policy change that might have attempted to address the problem of police bribery, they asked Believe in Youth for funds to continue to pay bribes in order to ensure the immediate safety of their clients. Ultimately, this strategy was at odds with the mission of Women Together's chief donor, Believe in Youth, which was more inclined to fund interventions that would change the systemic forces that put young female drug users at risk.

CHAPTER 5: "THEY CAME LIKE MUSHROOMS AFTER RAIN": EXAMINING THE LIFE CYCLE OF A YOUTH-LED HIV/AIDS AND HEPATITIS ORGANIZATION IN HANOI, VIETNAM

Less than 48 hours after landing in Hanoi, I found myself in a battle with jetlag, rolling back heavy eyelids to pull myself out of bed a few hours before dawn. I was scheduled for a 5:00 a.m. departure to my first site visit of Beacons of Change (BOC), an 'ideal type' grantee of Believe in Youth. BOC was a youth-led organization that implemented a range of online and in-person outreach programs for young people living with HIV. I clung tightly to Thet, the sprightly 21-year old leader of BOC, as we angled through Hanoi's streets on a motorbike. We soon arrived at the organization's headquarters—an unassuming office space tucked between two alleys that BOC shared with another fledging community-based organization. Greeted by a handful of young volunteers, I helped load crates of *chả lụa* (Vietnamese chilled pork rolls), rambutan fruits, and Coca Cola onto a bus, and then we were off on a three-hour journey into rural Vietnam.

Believe in Youth's grant managers had told me that BOC was an organization focused on preventing and treating HIV and Hepatitis co-infection, and that they had primarily worked in urban Hanoi with young drug users, sex workers, and men who have sex with men. So as palm trees began to outnumber electrical wires and cooking fires became more abundant than traffic lights, I was puzzled. What I had expected (urban street outreach) was far from what I found myself taking part in (a field trip to a rural village).

A few hours later, I found myself surrounded by small children at a primary school in the rural Ha Dong district. I participated as BOC's volunteers facilitated games that taught lessons about HIV. During lunch, a volunteer awarded prizes to children who could correctly reiterate messages from the games, and at the end of the day, BOC volunteers distributed bags of food and clothes to parents who had attended the event with their children. My immediate assessment was that the activities had positively impacted the children in the

short-term by filling their bellies and giving them a laugh, but also by imparting HIV prevention and anti-stigma messages.

But the image of BOC that I had fashioned from conversations with Believe in Youth stood in stark contrast to my day in Ha Dong. At the core of Believe in Youth's ethos was the desire to cultivate transformational leadership and to address some of the most difficult cultural and political structures that inhibited the health of marginalized communities. Believe in Youth's staff members would likely have classified BOC's Ha Dong event as 'charitable' (e.g. supporting the daily life of those in need) moreso than 'transformational' (e.g. attempting to change the structures that create and maintain the disadvantage of people living with HIV).

While my trip to Ha Dong with Thet and BOC was far from what I had expected, in the coming weeks I would come to understand the dynamic ways in which BOC navigated multiple organizational identities. In the following analysis, I unpack these identities, chronicle BOC's developmental stages, and argue that the organization was experiencing consolidation at the time of my fieldwork. Similar to Women Together in Kyrgyzstan, BOC struggled to sustain organizational growth due to leadership issues, the changing priorities of its volunteers, and, ultimately, its struggles to achieve legitimacy in a difficult political context. After introducing BOC's contextual backdrop and situating the organization's narrative in terms of the life cycle framework, I will illuminate each of these points in the following analysis.

5.1 Research Setting

Hanoi, home of Beacons of Change, is Vietnam's capital and its second largest city. The political and economic hub of North Vietnam before Vietnam's communist reunification in 1976, it is now one of the most rapidly growing urban areas in the world (Vandemoortele

& Bird, 2011). In 1986, the Vietnamese government initiated a series of reforms aimed at transitioning to a market economy—a transition often referred to as *Doi moi* (Witter, 1996). Economic deregulation of non-state enterprises led to the creation of more than 50,000 new businesses in Hanoi alone, and rapid growth meant constantly changing demographics in the city. Most markedly, the population of expats and tourists boomed, as well as transient groups of migrant laborers coming from Vietnam's bordering countries.

While the economic opening of Vietnam led to many changes that have been described as positive—such as an increase in GDP and improved educational attainment—the Vietnamese government often attributes the beginning of its HIV/AIDS epidemic to the influx of foreigners. Vietnam's public health care system, which was a pillar of the government's legitimacy throughout the country's tumultuous history, has consistently been underfunded and underdeveloped. In 2013, only 3% of the GDP was spent on the healthcare system, and the literature is rife with reports of underpaid doctors, unaffordable care for the poor, and corruption (Hoang, 2013). Several of my interviewees described the Vietnamese public healthcare system as inadequate, and one (a medical trainee at Hanoi's largest hospital) joked that "the only way to be seen [by a doctor] is to come with cash [to bribe hospital administrators] in your hand."

With a marginal budget for healthcare spending, the Vietnamese government has turned to foreign aid and NGOs to bolster the public system. Huynh, my translator, described the growth of small community-based organizations as, "like mushrooms after rain." BOC was born at a time that favored the creation of new groups, but its journey in its first half-decade sheds light on the challenges faced by new organizations in Hanoi.

5.2 Beacons of Change and the Organizational Life Cycle

5.2.1 Formation

Beacons of Change was established in 2008 by Linh, a 28-year old native of Hanoi. After serving for several years in the Vietnamese army, Linh learned that she was HIV-positive, a diagnosis that resulted in her immediate discharge from the military. Unemployed and in a "dark place," she decided to spend her idle time searching for and befriending other HIV-positive women. Linh originally established BOC as a support group where she and a cadre of peers could discuss their struggles. According to Linh, in its early stage "BOC was an informal support group for parents [mostly women] living with HIV." The organization's primary activities were "to console each other to make life easier, and we also provided nutritious food for young children living with HIV" (Linh). According to the organization's written documents, BOC's main aim was "to provide self-help, referrals, and educational services to young men and women living with HIV."

In agreement with the extant literature on nonprofit startups, Linh's motivation for starting BOC sprang from a passion to solve a societal problem. But Linh's case was more nuanced. In addition to being frustrated and impassioned by the lack of services available to HIV-positive women, she created BOC because she was also desperate to help *herself*. She was not only able to empathize and sympathize with her HIV-infected peers, but she was also eager to find hope for her own condition. "I call the reason I created this group as the 'turning point' in my life…I never thought I would take part in this field [HIV/AIDS], but it was ultimately my change." While Linh's personal narrative and charisma seemed to be the keys for initiating BOC, she had no relevant professional experience in the NGO sector. She had never raised money, and she had no previous experience with designing psychosocial support interventions for people living with HIV.

Similar to Bess's (1998) study of first-stage organizations, Linh's original group was an outgrowth of friends, new and old. Linh played the role of "prime mover" (Adizes, 1979;

Mintzberg, Waters, & Wiley, 1985; Quinn & Cameron, 1983; Torbert, 1974) of BOC. She filed the organization's records, conducted outreach to recruit its first cohort of HIV-positive beneficiaries, and organized the agendas of group meetings.

Bess (1998) described the focus of early stage organizations as "beginning to establish an identity that both aligns and distinguishes it from other providers, and which enables it to begin to appeal to various interests for support." BOC, unlike Bess's proposition, was much more focused internally than it was on its external environment. Linh and her founding members spent most of their time recruiting and implementing effective support group meetings, and they intentionally spent very little time self-actualizing about the organization's identity in the broader environment.

In congruence with both the Women Together case study and with the literature on new and nascent organizations, the core socio-emotional tone of the organization in its early stage was one of compassion and caretaking. Very early in my conversations with Linh, she insisted that "the community" was her motive for starting BOC. "Many organizations only care about their public image…the position and size of their logos. I want to help the community" (Linh). Throughout several interviews with Linh, she referenced her prioritization of the community as both a strength of the organization and as a source of weakness.

In its early years, BOC lacked a long-term strategy, and instead only pursued opportunities that were of immediate relevance to its members. The organization was supported with a patchwork of small grants and contributions from its members. BOC's first grant was for $4,000 from a support network called National Technical Assistance Plus (ATN+), and it was earmarked for projects for HIV-positive parents and their kids. Linh proactively sought opportunities to gain resources—both financial and social—that would support the group, but she was also willing to run the organization on a shoestring budget.

She said she was also not strategic about managing donors or promoting the work of BOC. "When we worked, we just worked. We didn't take photos or videos or anything like that" (Linh).

While Linh and BOC did not spend much effort promoting their outcomes, they had many successes in their first two years. Most notably, they formed a critical partnership with the leader of Hanoi's governmental effort to promote public health. Linh developed a close working relationship with the Chief Executive of the Bureau of HIV Prevention, such that he would frequently request that BOC and its members attend various government meetings and events. In partnership with the Bureau of HIV prevention, BOC added additional services. Through one program, the organization provided eligible members of BOC with free legal services. In another, BOC worked with the Bureau of HIV Prevention and a large international donor organization to develop and promote anti-stigma policies in schools that taught HIV-positive students. The funding for these projects was supported wholly through the Vietnamese government and its partners.

5.2.2 Development

While Linh remembered the early stage of BOC as a time of excitement, at the end of BOC's first two years, she felt "very tired," and that "the organization was still standing at a starting point" in terms of its operational capacity. Despite the growth in programs, Linh implemented the majority of BOC's work alone, with minimal help from members of her support group meetings. She recognized the need for help with managing BOC, so she sought and received capacity-building grants from two regional donor agencies. Unlike previous grants that had funded core organizational activities, funding from these donors was restricted solely to supporting the organization's infrastructure, or as Linh described, "organizational policies and management structures."

Through workshops sponsored by these donors, Linh established a formal board of directors for her organization, as well as several processes to select and groom new organizational leaders. Perhaps the most noticeable change in BOC, though, was its change in strategy. Many of the beneficiaries of BOC's programs were not only HIV-positive, but were also infected with hepatitis C (HCV), a chronic liver condition that affects more than 50% of HIV-positive drug users in Vietnam. With help from capacity-building consultants, Linh added the aim of HIV/HCV co-infection treatment advocacy to the organization's mission.

She worked with members of BOC and consultants to craft a proposal to a highly competitive social innovation competition hosted by the World Bank and the Vietnamese Ministry of Health. Through the competition, BOC proposed to improve the competence of doctors and patients in addressing HIV and HCV co-infection. They would create a set of guidelines based on a needs assessment combined with international best practices, and the main outcome would be a document that would serve as an educational tool for co-infected patients and as a training tool for clinical professionals. The project was selected for funding, and Linh called this honor the "second turning point" for both herself and for BOC (the journeys of which often seemed one in the same). "When BOC won the prize, I was very happy. I was just proud and excited because we beat more than a hundred other applications" (Linh).

The launch of the document online and offline helped to solidify the credibility of BOC as a leading organization in the HIV/HCV co-infection space in Hanoi. As Huynh recounted:

> It was not just like an online document or online manual going around…it's not like people never know who's gonna read it or something. Copies were distributed among SCDI [Supporting Community Development Initiatives] and other networks. The report was published right before the National VCSPA [Vietnam Civil Society Partnership Platform on AIDS] meeting. They [BOC members] were invited to present the basic introduction and treatment about co-infection issues to the National Network of People Living with HIV.

> It was quite a huge thing to Beacons of Change. It was their first acknowledgement and recognition at the national level.

The document was taken up with so much interest that the government partnered with Linh and BOC to improve access to HIV and hepatitis medical and social services. As predicted by the literature, BOC was beginning to establish a more clear 'niche' by addressing a very specific, unmet challenge.

Toward the end of this stage of BOC's growth, a convergence of factors—including fatigue, the desire to enable youth leadership, funding opportunities, and job offers from other organizations—led Linh to step down as leader of BOC. She transitioned from a staff member to the leader of the board of directors, and she initiated a succession process aimed at developing the leadership capacity of BOC's young volunteers.

Linh believed that younger leadership could enable BOC to more effectively reach one of the most underserved populations in Hanoi—youth who were at risk of HIV/HCV co-infection. In the third stage of BOC's growth, she wanted the organization to specifically serve youth *and* to be led by youth. She felt that social change in Vietnam would be brought by young members of key affected populations—drug users, sex workers, and MSM, yet she felt that she had become too old to relate to youth. Thumbing over her old mobile phone, she laughed as she mentioned that she was a generation older than BOC's youngest volunteers. "They were all using Facebook and Twitter, and they knew how to use social media for outreach."

Linh, BOC's board members, and BOC's volunteers began looking for her successor. They groomed Bao, a student at the Vietnamese National University, as an interim director of BOC. Bao was part of a transition in which Linh and the other members of BOC wanted to see a greater impact of their work on young people who were co-infected with HIV and HCV. The narrowing of the focus of BOC qualified the organization to compete for the largest grant in its history – a project-based grant of $15,000 from Believe in Youth. Linh

worked with Huynh and Bao to submit a multiple-year project that would expand BOC's co-infection work. The project aimed to (1) promote the implementation of the HIV and hepatitis co-infection handbook that was created through BOC's previous work; (2) create a 'treatment action group' that would engage youth as activists in demanding better care for both HIV and hepatitis; and (3) foster youth-led research and analysis of the outcomes of new guidelines for HIV/HCV treatment.

As a condition of funding from Believe in Youth, BOC's staff was offered mentorship from a Peer Support Person, who helped to assess the organization's goals and to strengthen organizational systems. Members of BOC's staff also attended a week-long residential training focused on strengthening its leadership. Bao was graduating from university, and after a very short stint as the head of BOC, he was interested in training a younger university student to take his role.

5.2.3 Consolidation

This brings me back to my point of my entry into Vietnam and my first night ride on the back of Thet's motorbike. After BOC's residential training with Believe in Youth, more than 20 organizational stakeholders elected Thet as the new leader. Under Thet's leadership, the organization began administering a slew of new services related to both HIV and hepatitis. They conducted educational outreach to young people ranging from children to university students, and they also provided information and charitable support to parents living with HIV or raising an HIV-positive child.

Consistent with the hypothesis that an expansion of services would be correlated with increased staffing, BOC's volunteer base tripled in size. They had between 10 and 30 university students manning their events and conducting BOC outreach. The boom in volunteers was attributed to Thet's election, as he was able to recruit friends and fellow students from his university as volunteers. Thet divided the group into subcommittees, each

of which was responsible for a very specific domain of organizational activities. As he said, "recently I've just divided the group into small teams in charge of logistics, decoration, taking care of children" (Thet). The purpose of this division was that "all the teams can perform their tasks more efficiently without overlap." (Thet). With a larger and more delegated volunteer structure came a change in the socio-emotional tone of the organization. Whereas conversations about BOC during its first two growth stages were very much about the leader of the organization, under Thet's leadership the members spoke more often about their own work and the work of their teams. "We have solidarity and delegation" (Thet).

Even with a more decentralized and organized volunteer structure, Thet complained that volunteers were transient, and he attributed this to their youth. "There is a high turnover of volunteers because they are mostly students, undergraduates…and yea they might have enthusiasm and fresh energy, but then they are inexperienced and this is a disadvantage. It's hard to control or manage them properly" (Thet).

And while the number of volunteers increased, the volunteers felt less interested in and capable of continuing the co-infection work of the organization. They did not feel as personally compelled to work as activists and to take up the cause of changing clinical practice. As Thet noted, "what we are doing about the Hep-C co-infection is not an easy project, so it's difficult sometimes to get things done as planned [through our Believe in Youth proposal]." While the co-infection work came with the largest grant that BOC had ever received, the organization struggled to implement the project under its new structure and leadership.

Despite these negatives, several interviewees noted that BOC improved its public visibility by engaging volunteers to document its day-to-day work and its community events, primarily through the use of social media.

> Now people know Beacons of Change and what they have been doing thanks to all the internet savvy young people, those who are in charge of like online

> and social media communications. We [former leaders] are not really familiar with internet and stuff, and we couldn't have done it [promoted the organization online] in the past. (Linh)

Thet was also effective at brokering new partnerships with two other youth-led public health organizations in Hanoi. Both of these organizations were of similar size to BOC, and the partnerships were primarily programmatic. When BOC hosted outreach events, they invited representatives and volunteers from its new partners, and vice versa.

While Thet was arguably the most effective at managing BOC's 'horizontal' relationships (e.g. bringing more young people and young organizations into the work of BOC), he struggled to maintain the 'vertical' relationships that Linh had created with government stakeholders who could provide BOC with power and resources. Because of this, BOC no longer received support through government-sanctioned programs. Thet believed that under his leadership the organization lost some legitimacy in the eyes of local government institutions and international donors – "We've written many proposals to such organizations. They seem to appreciate our ideas but they don't support much eventually. They don't take us seriously."

Thet, as well as Linh, Huynh, and several volunteers, expressed frustration with BOC's struggles to become a registered nongovernmental organization in Vietnam. With registration, they believed that they would be more competitive for grants and donations. However, a number of legal requirements (which will be further discussed in my analysis below) made it nearly impossible for BOC to be officially recognized as a nongovernmental organization. "The group is still a self-help group. It hasn't had a legal status, despite the fact that we were the first group working on these issues [HIV and hepatitis co-infection]...BOC hasn't got support from donor agencies because we are just a self-help group" (Thet).

Despite its challenges, BOC was still implementing regular activities, and their reliance on member donations was keeping the organization strong enough to resist imminent

failure. Toward the very end of my time in Vietnam, though, several interviewees expressed reservations about the viability of BOC in the long term. These reservations were the manifestations of the impending changes in humanitarian donor relationships to the Vietnamese government and NGO sector, as it had recently been upgraded from a low-income country to a middle-income country by the World Bank. "Vietnam has escaped poverty, so issues related to HIV are no longer a priority. We are wondering what we are going to do when these kinds of projects end" (Thet).

5.3 Thematic Analysis

5.3.1 Leadership Transience

When I begun to write this chapter, I often found myself using Linh's name in place of 'Beacons of Change.' This was because BOC and Linh were one in the same during the nascent years of the organization's growth. As the founder and prime mover, Linh was involved in every single organization activity and meeting. It was not until BOC started adding programs, toward the end of its formation stage, that Linh began to delegate tasks to BOC's members.

While Linh stressed that she was not savvy in organizational management—professing that BOC was focused on the community and not on the interests of donors and other stakeholders—she was very effective at building key relationships with government personnel. Huynh attributed BOC's early organizational successes to Linh's capacity to establish partnerships within the HIV stakeholder community of Hanoi. "Linh has a lot of connections in terms of the local NGOs [nongovernmental organizations], CDOs [community development organizations], PLHIV-AIDS [people living with HIV/AIDS]. That has been very helpful."

Academics studying social capital within organizations describe relationships as possessing either 'bonding capital' or 'bridging capital' (Putnam, 2000). Bonding capital refers to an organization's ties within its peer community, while 'bridging capital' refers to the value of relationships that an organization develops with non-peer stakeholders. In BOC's case, examples of non-peer stakeholders included Hanoi's governmental public health agencies and donor agencies, among others. While Linh did not spend much of her energy developing relationships with donor agencies, her relationship with the leader of Hanoi's Bureau of HIV Prevention ultimately served as a proxy for drumming up financial support.

Scholars of the Vietnamese NGO sector note that relationships to state agencies have been critical to organizational survival since the 1986 reforms. In some cases, founders of organizations had pre-existing relationships. In a study conducted in Vietnam and China, interviewees emphasized the importance of personal ties with government representatives. "Some interviewees confirmed that their success was due to personal relationships with people in government. Some even stated that "without relationships, you cannot do anything in Vietnam" (Lux & Straussman, 2004). In some cases, former state officers were themselves the founders of NGOs. This was the case for 19 or the 30 organizations studies in Lux and Straussman's work.

Linh shouldered the programmatic workload of BOC and secured its key partnerships. Her departure from BOC, the process of which began in the organization's development stage, had a significant impact on BOC's identity. The organization took a markedly different path under the leadership of Thet. Thet, like Linh when she founded BOC, had very little management experience when he took the helm of BOC. He had, however, volunteered with the organization for several months. He had demonstrated sufficient competence and charisma to be voted Linh's successor.

Thet was charged with leading BOC through its most recent change—to narrow the organization's focus on young people who were HIV/HCV co-infected or at risk of co-infection. While Thet was effective in mobilizing his peers to donate their time and skills to BOC's work, he struggled to build 'bridging' relationships with government institutions.

> And Thet was not…he *has* not been a really talkative or active person in terms of, like, online communication or email and stuff so...he has been quite passive in a way. Sometimes I'm thinking he's hesitant or like he-he's intimidated to talk to me directly. (Huynh)

Huynh even expressed concern that Thet's lack of interest and skills in extra-organizational communication might be a threat to BOC's financial security. Believe in Youth was BOC's largest donor during its consolidation stage, but Thet struggled to maintain communication with Believe in Youth's grant management team.

> Believe in Youth really needed their mid-term report submission and stuff, and it was slow…it [the relationship between Thet and Believe in Youth] was quite dull and a bit, like, low. (Huynh)

This case study illuminates an interesting phenomenon for youth-led organizations—one which was subtle in the Women Together case study but which is much more obtuse with BOC. While I would not diagnose BOC as being a failure—in fact, far from it—there was a significant and undeniable change in the organization's identity following the departure of Linh. Her transition to BOC's board of directors was itself a dynamic event. It can be analyzed from several angles, all of which may be 'true' to an extent, but none of which can singularly explain the change.

Linh's rapport with Hanoi's HIV prevention bureau afforded BOC a number of organizational opportunities, but it also attributed professional mobility opportunities for Linh. She recounted in my first interview, "I never saw myself in this space [HIV prevention]." Yet in less than two years she had transformed from an unemployed, HIV-positive former military servant into a leading advocate for some of Hanoi's most marginalized groups. Not only was she the founder and leader of BOC, but she also became

the unofficial "right hand woman" of the director of Hanoi's HIV prevention bureau, and she had been asked to serve on multiple advisory boards for other international and local organizations. While a review of multiple interviews corroborated that Linh's decision to vacate her position at BOC was about more than just a selfish pursuit of professional opportunity, the 'poaching' of Linh by organizations in Hanoi and elsewhere is similar to what Ana faced in Kyrgyzstan. This scenario begs the question: if the seed-funders of youth-led organizations aim to develop the leadership skills of charismatic young leaders, then how do they intend to ensure, if at all, that these leaders do not flee their organizations in search of new, more lucrative opportunities?

It was clear that one of Linh's primary reasons for leaving BOC was that she believed in the power of young people to make change. As she mentioned in my conversation, BOC had been "the turning point" in her life. Not only did it inspire her to have hope for her own health and prosperity, but it equipped her with both hard and soft skills that enabled her to be a leader. She wanted to establish a system of leadership succession whereby BOC could continue to foster the development of younger leaders.

Finally, Linh showed signs of what Adizes (1979) calls "prime mover fatigue." While her passion for her work continued to grow in tandem with BOC, she also complained of exhaustion. While she was serving as leader of the organization, she failed to set up a system of task delegation that would eliminate some of her own workload. She took a paternalistic approach to the organization's direction, as she did not want to burden members with responsibilities that they might not want to do or be capable of doing.

In the end, it was a dynamic interaction of these three factors that led to Linh's departure—perhaps the most influential event in the organization's history. It was not merely founder burnout, but instead the dual desires to take on greater positions of leadership in larger organizations and to foster the leadership growth of BOC's young volunteers. Youth-

led organizations may experience multiple pressures to leadership transition that might not exist in other organizational forms.

5.3.2 Competition and the Liability of Newness

Vietnam existed under a regime of central planning and a subsidized economic system for more than 30 years, with almost no legal space for non-state actors. After the political environment became more favorable for NGO growth in 1986, there was a "virtual explosion" in both the total numbers and the absolute size of individual organizations that describe themselves as NGOs or exhibit similar characteristics. Development aid to Vietnam also increased 1,000% from 2000 to 2008 (Martinez, 2008). Vietnam was selected as one of the recipients of the original funding round for the President's Emergency Plan for AIDS Relief (KHN, 2003), and it became a partner of other major global health agencies like the Global Fund. This created an unprecedented opportunity for NGOs—not only because the state had created a space for growth, but also because international donors often required the participation of NGOs in the implementation of bilateral funding agreements.

While some argue that there are no credible data enumerating exactly how many NGOs exist in the country today (Lux & Straussman, 2004), other reports show a rapid increase in the number of registered and non-registered NGOs in the years following economic reform (Kerkvliet, Nguyen, & Bach, 2008; Norlund, 2007). According to the Vietnam Union of Science and Technology's (VUSTA) study, the number of registered organizations increased from 15 in 1983 to 156 in 2004, and then to more than 500 by 2011 (VUSTA, 2011). VUSTA estimates that the number of NGOs had climbed to more than 10,000 by 2015.

In one of my first conversations with Huynh, he mentioned that the growth of the NGO sector "came like mushrooms after rain." Unlike in Kyrgyzstan, it was evident—through statistics on the size of the NGO population, through policy analysis, and through

conversations with key informants—that NGOs were gaining acceptance as a legitimate sector by the Vietnamese government. While the change in political and economic circumstances favored the creation of new NGOs at an unprecedented pace, the growth of the sector was not without competition, organizational redundancies, and inefficiencies. As my method for sampling interviewees involved asking each interviewee to suggest other people in Hanoi who might be able to speak to my issues of interest, I ended up interviewing many of BOC's partners and its competitors. One interviewee complained that the small network of organizations working on youth sexual health issues was characterized moreso by competition than by collaboration. One of the former members of BOC was accused of forming new groups to constantly out-compete existing organizations in Hanoi. While competition is often theorized to strengthen the overall impact of the human service sector, in the case of Hanoi it seemed to create a series of personal, political, and professional battles that gave the involved organizations a bad reputation. "He founded that group [another sexual health organization] just to compete with mine. Then when he got kicked out of the group he founded, he founded another one just to compete with his old group," recounted one interviewee outside of BOC's network. In another instance of competition, Huynh recounted that one of BOC's community partners had originally refused to work with them.

> It's endless competition among them [youth-led organizations]. At the beginning there was some drama in politics and tension between BOC and VNP Plus (Vietnam National Network of People Living with HIV) because VNP Plus wanted to take on that issue [HIV/HCV co-infection], and they had also submitted a proposal. But then BOC got funded right away by Believe in Youth. VNP Plus…at first the-the coordinator, he refused to support anything of BOC's on the issue of promoting or educating or training on co-infection...he thought that BOC just stole his idea on purpose and then did what he had wanted to do.

5.3.3 The Organizational Environment

The HIV epidemic has substantially influenced the formation of NGOs in Vietnam. It was not until the emergence and rise of HIV that the development of groups representing the

most disadvantaged and vulnerable people, such as people infected and affected by HIV, drug users and sex workers, was observed in the country (Montoya, 2012). In response to the epidemic and with important technical and financial support from international and Vietnamese agencies, hundreds of self-help groups have been established, and networks linking these groups have been formed nationwide (USAID, 2009). In addition to the open market for NGOs to establish themselves and seek resources, the growth of the NGO sector was bolstered by earmarks that many donor agencies placed on government aid. In many cases, international donor groups required their bilateral grant recipient governments to include the participation of non-state actors (Lux & Straussman, 2004).

NGOs in Vietnam have assumed different levels of autonomy with regard to their relationship with the state. Many organizational leaders stated that their work functioned as a supplement to the state's efforts to meet the needs of communities. Interviewees expressed the idea that providing direct services to clients was often welcomed and promoted by the state. "We were working with people that were not going to clinics. We were doing things that the government was not able to do" (Linh). But advocating for changes in the state's public health policies was another story, as nearly every interviewee corroborated statements about the political difficulty of implementing BOC's advocacy agenda. A previous study of NGOs in Vietnam supported this issue, stating that NGOs' power to advocate on "issues like health insurance, drug quality, drug prices, and illness-prevention activities remained weak" (Wells-Dang & Wells-Dang, 2011).

While BOC began with providing direct services to clients, it picked up an advocacy agenda that saw Linh and her team developing anti-stigma policies and advocating for improved treatment literacy for HIV/HCV co-infected patients. Linh attested that the government supported the work in its early stages, but Thet and Huynh both discussed the difficulty of pushing the work forward as BOC grew. Some of these challenges were

attributed to internal organizational issues, but many were blamed on a government that was not interested in NGO-friendly policy change. The literature suggests that in adverse policy environments, achieving policy impact was especially difficult (Spicer et al., 2011).

Data from the population of NGOs in Vietnam substantiates interviewee's claims that NGOs also face harsh formal regulatory obstacles from the state. After 1986, the state became more open to the existence of NGOs, but it has continued to exert control over organizations through a prolonged and challenging approval procedure for registration and formal establishment (Sidel, 2010). Current legislation has placed age and educational requirements on leaders of self-help groups and NGOs. In order to register as an NGO, founders must hold a university degree. Neither the founder nor any of the leaders of BOC had received an undergraduate degree, and thus it was impossible for them to register as an NGO. Not only did the group's lack of registration reduce their local legitimacy, but it also disqualified them from the majority of available international grants. "Because we don't have a legal status, sponsors and donors don't trust us," remarked Thet. Linh also complained of the organization's lack of registration: "the biggest challenge is how to get the legal status. This challenge prevents us from being sponsored or raising funds." And finally, the Peer Support Person assigned to BOC elucidated the organization's greatest challenges: "It's just the frustration being unregistered—the unregistered status of the group has been a pity on a lot of opportunities and resources. Most of the time, the donors don't trust them." Many self-help groups working on HIV remain unregistered. A recent review showed that among the self-help groups working on HIV in Hanoi, 13 groups have registered as companies and cooperatives, while more than 200 groups remained unregistered (UNDP, 2011).

According to international good practice, coverage of needles and syringes to IDUs needs to reach 80% to have a real impact on the HIV epidemic. Vietnam is currently well short of this target. Despite substantial support and moderate progress from its scale up in

2005, Vietnam's national HIV response is still far from achieving its original goals. Current coverage of anti-retroviral therapy (ART), at around 26-30%, is still far from the 70% government target set for 2010.

A national-level HIV response that has been subsidized by several major international HIV/AIDS donor agencies has afforded an important political opportunity to boost the work of NGOs and their relationship with state agencies over the past several decades. While national endorsement of NGOs since 1986 has led to the creation of many new organizations, the HIV/AIDS epidemic still persists among certain populations. And while both the Vietnamese government and international donors have supported HIV prevention and treatment organizations that are designed and led by members of hard-to-reach groups, these groups have encountered significant political and infrastructural barriers. In order for the government to fully endorse the work of these groups, it must allow them to institutionalize by reducing Vietnam's strict NGO regulations (particularly those relevant to education and age of organizational leaders). Further, BOC highlights the risks that an organization faces during leadership transitions. Start-up donors might improve organizational viability by offering counseling and incentives for leadership succession planning in the early stages of an organization's growth.

CHAPTER 6: FUNDING THE UNFUNDABLE

In the opening chapter of this thesis, I offered an overview of the growing prevalence of HTRY-led organizations and their rise in importance in achieving an end to the global HIV/AIDS pandemic. Despite the significant role that these organizations might play in stemming the epidemic, donor agencies have reported high rates of organizational deaths among HTRY-led organizations. In the second chapter, I explored the literature on organizational life cycles of NGOs. I identified ways in which existing theory predicts organizational challenges at various stages of growth and across multiple dimensions. I also identified geographical and methodological gaps in the research, setting the stage for further empirical work. In my two case studies of HTRY-led organizations, I chronicled the ways in which organizations enacted change and reacted to changing internal and external dynamics.

My case studies identified the inability of grantee organizations to acquire legitimacy from the state as a common organizational challenge. In Kyrgyzstan, the leaders of Women Together purposefully avoided legal organizational registration because they feared it might put their group and its members in physical danger. They were a primarily clandestine operation by choice, and they believed that becoming a formally registered group would expose their members and their activities to a particularly oppressive government. They were also concerned that government recognition or endorsement of the group might result in a loss of credibility or trust among current and potential clients. In Vietnam, the law prohibited Beacons of Change from registering as an NGO without having at least one member with a university degree and over the age of 24. While the group included students, none had graduated from university, so the organization was unable to become a state-legitimized NGO.

The immense challenge of acquiring external legitimacy in both contexts is analytically important because previous research predicts that organizational failure is

inversely correlated with external legitimacy—organizations that are unable to obtain and sustain approval from external sources are more likely to succumb to the liability of newness (Chambre & Fatt, 2002; Singh et al., 1986). While both Women Together and Beacons of Change struggled to obtain and maintain legitimacy from actors in their external environments, Believe in Youth afforded them legitimacy—financially and symbolically—during their organizational nascence. Given that existing scholarship suggests that external environments are of vital importance to organizations in their nascent stages, presenting the case studies of Women Together and Beacons of Change without providing a deeper look into Believe in Youth, their primary donor, would omit a significant perspective.

I collected data on HIV/AIDS donor agencies from October 2011 until 2016, enriching and narrowing the focus of data collection iteratively before, during, and after my organizational field visits. In this chapter, I aim (1) to bring this data together in order to highlight the relevance of donor agencies to contemporary HIV prevention strategies; (2) to discuss the evolution of Believe in Youth, the major donor of Women Together and Beacons of Change; and (3) to demonstrate the ways in which Believe in Youth has influenced the growth of Women Together and Beacons of Change. Looking at the donor environment as a separate case study sheds light on how and why HTRY-led organizations acquire legitimacy, as well as how the relationship with their early donors influences their future direction and their long-term sustainability.

6.1 Setting the Stage: Research Context of Donors Focused on HIV/AIDS

My research on donor agencies began during the first year of my DPhil with a panoramic view of the sector. In December 2011, I was invited to attend the annual summit of Funders Concerned About AIDS (FCAA), a leading global organization that "mobilizes the leadership, ideas, and resources of funders to eradicate the global HIV/AIDS pandemic and to address its social and economic dimensions" (FCAA Website). The purpose of FCAA's annual

summit was to convene leaders of philanthropic organizations to discuss the latest research on HIV treatment and prevention. Most of the discussion at the meeting was framed by two key documents—a research report by the Kaiser Family Foundation on trends in government aid and private philanthropy to fight HIV/AIDS, and the *Lancet*'s Strategic Investment Framework for scaling up treatment-as-prevention to end the epidemic.

The Kaiser Family Foundation report focused on global declines in HIV funding, both from governments and private foundations. In 2010, the Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated that it would cost between $22 billion and $24 billion annually to fully address the impacts of HIV (including providing funding for the full continuum of HIV care). In the same year, UNAIDS also reported that the actual total contributions—including domestic public and private spending, donor government bilateral assistance, multilateral organizations and private philanthropic aid disbursements—totaled $18.9 billion (Kates, Wexler, & Lief, 2013). Not only was there a significant gap between funds needed to fight HIV/AIDS and the available funding from donors, but research showed that both public and private funding for HIV/AIDS was declining.

In the first decade of the 21st century—the third decade of the global fight against HIV/AIDS—both public and private aid declined. Lee and colleagues (2013) measured a decline of 30% in private philanthropy from 2007 to 2010. Kates and colleagues documented a flattening of government aid from 2008 to 2011, and then a decline in government aid in 2012 (Kates et al., 2013). These declines have been attributed to both the global financial crisis that began in 2007, as well as "AIDS fatigue," a phenomenon in which donors became tired of funding a single disease in favor of addressing other social problems (Moszynski, 2010).

While the financial outlook for HIV funding was grim, one panelist at the FCAA meeting suggested that "if the battle against AIDS were a business, this would be the best

time to invest in it." He referred to mathematical models of the rollout of treatment-as-prevention (TasP) that had demonstrated that financial contributions to the fight against HIV/AIDS could exact a greater, more cost-effective impact on the epidemic than ever before (FCAA, 2011). He then discussed the results of a study referred to as "HPTN052," one of the landmark randomized controlled trials that had spurred the dawn of TasP and the wide-scale shift in HIV prevention strategies.

> As HIV/AIDS funders, we find ourselves at a very momentous crossroads. It's punctuated by extreme urgency on the one hand, and unprecedented opportunities for meaningful collaboration on the other. We ride on the tails of recent positive news…scientists are talking about the possibility of ending AIDS. However, all of this promise comes at a time of great financial challenge. Today is our time to figure out the 'so what' and to develop the call to action to determine what these breakthroughs mean to us as funders. Hopefully that means deriving meaningful impact out of limited resources.

FCAA's leadership concluded that while it was unlikely that investments in HIV would significantly increase, it was possible to make smarter investments in order to maximize impact, particularly given the recent breakthroughs from TasP studies. As subsequent introductory speakers echoed this sentiment, I thumbed through a folder that I had been given at the registration table earlier that morning. I was looking for a paper that had already been verbally referenced several times – The Strategic Investment Framework. It was a document written by a team of health scientists, economists, and practitioners and published in the *Lancet*. The Strategic Investment Framework emphasized that TasP was a potentially transformational tool in the global fight against HIV/AIDS, but that it could only be successful alongside healthcare reform.

Discussed in the paper and reinforced in a speech from a representative of one of the largest HIV/AIDS NGOs in the United States, the majority of people who were at high risk of contracting HIV or spreading HIV were not being reached by top-down health interventions. While there were not sufficient funds to provide full coverage of HIV services to all who needed them, the reality was that even in areas with high levels of resources, social and

structural barriers limited access to care. In the United States, a high-income country with a comparatively aggressive national HIV prevention strategy, nearly 75 percent of HIV-positive residents were not receiving the care they needed to stay healthy (Skarbinski et al., 2015). The NGO representative at the meeting commented that "stigma is still a huge issue in the US and globally, and people still need education and awareness about how to navigate the continuum of HIV care."

As introduced earlier in this thesis, the *Lancet* paper emphasized 'task shifting' as a cost-effective solution for narrowing the existing HIV care gap with limited resources. This strategy is often grouped with a general trend in public health that follows evidence showing that community members can be trained to effectively carry out basic health services at a much lower cost than traditional professionals. The Strategic Investment Framework suggested that community-designed and community-led organizations could achieve better HIV care by improving both the accessibility and acceptability of HIV testing and treatment.

With the agenda for task-shifting set by FCAA's meeting organizers, the remainder of the day was spent debating and strategizing about the ways in which donors could support task-shifting for key interest groups through grantmaking. FCAA assembled attendees into focus groups to discuss ways in which their agencies' grantmaking programs could accommodate the Strategic Investment Framework's recommendations. I chose to observe the focus group on achieving universal access for young people. Globally, this age group not only accounted for roughly 40% of new infections, but it was also the demographic that was the most sexually active, the least likely to be sero-aware (to know their HIV status), and the least likely to utilize medical services. The focus group was facilitated by the leader of Believe in Youth, which at the time was recognized as the sole global grantmaking organization that was not only specifically funding youth-led organizations, but was also designed, managed, and led by youth representing key affected populations. Given that youth

are listed as a priority in the Strategic Investment Framework, but that youth ranked fifth overall in terms of amount of targeted HIV funding (Lee et al., 2013), the work of Believe in Youth seemed like an ideal entry point for exploring the viability of task-shifting HIV care to marginalized young people.

6.2 Believe in Youth

Believe in Youth (BIY) was formed in 2009 at the Oslo Young Leaders Summit, a special meeting organized by UNAIDS. Nearly 30 years into the HIV/AIDS epidemic, the goal of the meeting was to convene young leaders from around the world to develop long-term solutions to issues faced by youth in the HIV response. As one of my interviewees put it, BIY's purpose was "to bring together young leaders from the HIV response who had already had experience in either local, regional, or international HIV work."

During the Oslo summit, participants identified funding to be insufficient—both in structure and in amount—for grooming a new generation of HIV activists. A group of attendees generated an idea to create a funding mechanism that was youth-led, and that was transparent and accountable to young members of hard-to-reach populations. They wanted to create a funding agency that would be designed and managed by hard-to-reach youth.

> We recognize that there are young key affected population groups who will not receive funding from anywhere else if we don't give them funding, either because they are criminalized or because they are so marginalized that they don't have access to funding mechanisms, or they cannot form organizations legally. So those aspects make it difficult for them to access any other kind of resources to be able to address the needs at the community level, which is where Believe in Youth steps in. (Staff member of Believe in Youth)

Another founding member of Believe in Youth suggested that young people had the best ideas and social networks to provide solutions to the HIV epidemic that had not been tried by larger and "non-local" institutions.

> There's a lot of stuff that nobody has the answers to, so it's easy to sit by the desk in Amsterdam, or the Hague, or D.C., and just say, "You know, you can't do that…it doesn't make sense, it's not efficient, it's not effective," but a lot of

> the times we *don't know*…because if we did know, we wouldn't be facing the fact that there are a large number of people living with HIV who don't know their status or use condoms or get treatment. That's one of the problems...so we try to change that. (Founding member of Believe in Youth)

In Believe in Youth's first public press release, the World AIDS Campaign's Youth Campaign Coordinator endorsed the organization by saying that "Peer-based programming is highly effective yet chronically underfunded, and youth-led programs often lack support for core resources." Believe in Youth wanted to utilize a community-led funding model to engage young members of hard-to-reach populations in setting funding priorities and making funding decisions.

Believe in Youth's overarching goal, which was not explicitly stated in any materials I received but which was repeated through several interviews, was to "institutionalize young key affected populations in all aspects of the HIV response." One of the founding steering committee members of Believe in Youth elucidated the rationale for this goal—it was assumed, he said, that global agencies would not take risks on the community-led groups that needed organizational services and support.

> Steering Committee Member: One of the reasons that Believe in Youth came about was that the – was the push of the donor community to… to move beyond the lip service of community involvement to say, "Yes, communities need to be involved. Yes, young people need to have a procedure to be taken seriously." But the global institutions…United Nations institutions…bilateral donors…are not equipped to support grassroots youth organizations…DFID (Department for International Development), USAID (United States Agency for International Development)…they do not have the processes in place to support real grassroots organizations…because there's so much risk involved.
>
> Me: What are the risks? What is the greatest risk?
>
> Steering Committee Member: Well, if you want to support a movement of young female sex workers who use drugs in Malawi…and you see as a global institution, or a USAID or whatever…you see the opportunity to create a powerful voice and a powerful movement that can really make a difference, that can help you as a global institution to address some of the reasons why that community is not accessing services, is not accessing testing, is not getting the support they need in order to… fulfill the goals that we all agreed to …*then you need to figure out a way to support that*. But because they are young female sex workers, they don't have access to a lot of the

> organizational services that they need in order to get funding from them [large institutions]…so that is the bottom line of why Believe in Youth adds value…why it has a reason to be there.

Believe in Youth received its initial funding in 2009 from the Norwegian Government (NORAD). A global survey conducted in several languages informed the design of Believe in Youth's structure and grantmaking priorities, and the International Treatment Preparedness Coalition played a critical role in advising Believe in Youth on its programs. Believe in Youth set up a steering committee to help decide the early structure and governance of the organization. Its staff, which originally consisted of only one full-time director (and later an additional full-time position of 'grants director') was called the Secretariat, and it was responsible for the administration of Believe in Youth's grant program. The global governing board was called the Steering Committee, and it included 12 members from 11 different countries representing different affected communities. At the time of my research, nearly one third of the Steering Committee was living with HIV, and Believe in Youth was committed to ensuring that at least a third of its funding was dedicated to providing services to young people living with HIV.

> We specifically focus on supporting work that is unfunded or underfunded by existing funding mechanisms, including core funding for youth-led organizations. Believe in Youth funds initiatives led by and serving young people who are excluded from and marginalized within existing programs. This includes young sex workers, young men who have sex with men, young people who use drugs, and young people living with HIV. (BIY, 2011)

6.3 How Believe in Youth Gives

Believe in Youth's Steering Committee selects a committee of community members to serve on a 'Community Review Panel' (CRP) that makes the final decision on successful grant applications. The CRP is made up of young people who are recruited by Believe in Youth because they have had significant leadership experience in youth HIV issues. Through the CRP, Believe in Youth engages young people to make decisions about which youth-led

initiatives in their region can best meet the needs of young people affected by HIV. While the geographic and demographic focus areas of Believe in Youth's grantmaking program have changed significantly since its founding in 2009, it has kept its core eligibility requirements, which are listed in Figure 6.1:

Figure 6.1: Believe in Youth's Grant Applicant Eligibility Requirements

Eligibility:

The work must be youth-led. Youth-led means your organization or project is coordinated and governed by young people aged 30 years or younger. Youth-led organizations and youth-led projects (this can be within a larger organization or a new initiative) are eligible for funding. Proposals which clearly demonstrate that a team of young people share decision-making responsibilities and leadership will be prioritized.

Registered and non-registered organizations may apply.

We highly encourage applications from groups that are by and for young people most affected by HIV. This includes young people living with HIV, sex workers, people who use drugs, men who have sex with men, transgender people, and women.

Ineligibility:

The following groups are not eligible for funding: individuals, for-profit organizations, government institutions, bi-lateral and multi-lateral institutions. Youth-led organizations that have an operating budget of over $100,000 are ineligible. Non-youth-led organizations which have youth-led projects applying and whose annual organization budget exceeds $250,000 are ineligible. In addition, you cannot serve on Believe in Youth's Community Review Panel and also apply for funding as the leader of a project or organization.

The size of grants that Believe in Youth distributes range from $5,000 to $20,000 per year, and to-date the organization has distributed more than half a million dollars in grants. Believe in Youth funds organizations for up to three years, and its aim is that organizations will be self-sustaining beyond Believe in Youth's funding. While all grants are originally made for a single-year period, Believe in Youth considers renewal applications from organizations at the end of their first year. The decision to fund organizations for additional years is contingent on the grantee meeting the eligibility criteria, but is also contingent upon good

progress toward their organizational goals and reliable communication with Believe in Youth's staff during the previous year of funding. While these are common criteria for multi-year grantmaking (Orfield, Lipson, & Hoag, 2015), Believe in Youth also subjectively considers an organization's likelihood of receiving additional funding. If a grantee organization is deemed able to receive additional funding, Believe in Youth is less likely to offer it a renewal grant. Believe in Youth limits renewal grants to a maximum of three years.

Believe in Youth requires all of its successful grantees to report on both the progress of their programs and on the expenditure of their grant funding. Reports must be submitted to BIY at the mid-point of the grant year and at the end of the year. They are guided by a BIY-provided template in which grantees are asked to give a detailed narrative of the activities they have conducted, their progress on key organizational objectives, their measurable results, and challenges and lessons learned by the grantee.

In 2010, Believe in Youth initiated a global call for grant proposals, receiving more than 2,700 grant proposals. The Community Review Panel then narrowed the pool of applicants to 23 organizations in developing countries across the globe. After the global grant cycle, Believe in Youth's Steering Committee decided to focus its grantmaking strategy by taking a regional approach in 2011. Believe in Youth's leadership expected that concentrating its subsequent rounds of new grants in specific regions would allow it to better support its grantees. The Steering Committee decided to select three regions with what they deemed to be the highest need. Southeast Asia and the Pacific would be the focus of grantmaking in 2011; Eastern Europe and Central Asia would be the focus in 2012; and West and Central Africa would be the regional focus for Believe in Youth's 2013 grant cycle. In addition to allowing for more targeted funding and a more robust technical support program, the regional grantmaking strategy enabled Believe in Youth to increase access to their grants by making grant applications available in local languages.

While its grantees in Southeast Asia and the Pacific represented multiple constituencies of HTRY (including organizations that represented people who use drugs, sex workers, men who have sex with men, and young people living with HIV), in the 2012 grant cycle to organizations in Eastern Europe and Central Asia, the Steering Committee decided to focus the grants specifically on young women who use drugs, citing a disease burden of 40% among female drug users and a lack of resources focused on this demographic.

Believe in Youth selected Women Together (a 2012 multi-year grantee) and Beacons of Change (a 2011 multi-year grantee) in response to my solicitation for ideal-type grantees. While I had the practical restriction of only including organizations that were conducting activities in a country that was 'safe' according to the United Kingdom's Foreign and Commonwealth Office classification, there were few other pre-conceived directives.

6.4 Analysis of Believe in Youth's Funding Program

Revisiting my notes from the Funders Concerned About AIDS convening in 2011, I recalled a speech and ensuing debate about how task-shifting might occur in practice, particularly among HTRY. While HTRY-led organizations existed prior to 2011, the call-to-action of the FCAA meeting was that these organizations should become vital to task-shifting efforts. In other words, FCAA members should fund HTRY-led organizations to assist with the delivery of TasP to hard-to-reach clients. And while many HTRY-led organizations were already providing HIV treatment, many were providing other services, such as counseling, clean needle exchange, advocacy, and peer-based education. One representative of a donor agency highlighted the challenge of pivoting donor priorities toward the new area of TasP. "If they [HTRY-led organizations] historically have had less access to funds anyway, how can we now ask them to not only survive financially, but to also be on top of science and pivot in the face of new biomedical breakthroughs?" Another speaker added that "hard-to-reach

communities need support to access funding, as well as to navigate leadership transitions and overall organizational management."

Believe in Youth's grantees exemplified the thoughts of the FCAA speakers. With the majority of its grantees encountering significant struggles during the first year of their grant-funded projects, the organization launched a parallel capacity-building program. Its aim was to provide group-level training to help its grantees improve their leadership and management skills, and, in turn, to improve their organizations' programs and sustainability.

> I mean the [Believe in Youth grantees'] initiatives are so young and so in the very early stage that they need a lot of support. And it's not just the grant support, but really… how to make sure that…now that most of our grantees are in the last year of the grant renewal cycle, that we're not going to support them anymore, and we really see the challenge. Okay…probably this initiative is not going to make it because they are not going to have enough support, and we are not going to be able to do it. So yeah, I think – yeah. That would be also like… a challenge but an opportunity for capacity building. (Staff member of Believe in Youth)

At the outset of the funding period for each grant cycle, Believe in Youth assessed each grantee's needs in the areas of financial management, monitoring and evaluation, networking, fundraising, technical knowledge, and advocacy (Believe in Youth website). They created a local mentorship program, the 'Peer Support Program,' in which they connected grantee organizations with people in their region who had experience in initiating and growing organizations. PSPs were required to speak the same language as grantees and to have backgrounds in youth HIV issues, enabling them to advise on technical challenges that grantees might face (Believe in Youth website). And lastly, Believe in Youth provided a fully-funded three-day residential workshop for its grantees. According to Believe in Youth, "an in-person training is critical to ensure they [grantee organizations] will develop skills in project implementation and grant reporting. (Believe in Youth website)."

While capacity-building support to grassroots organizations has become a widely accepted 'good practice' in the field, not all interventions produce intended outcomes. Many

of these initiatives were built on Western notions of organizational professionalization, which was assumed to improve performance, efficiency, and accountability. Several authors have noted, however, that expected outcomes of capacity-building processes are not always perceived as desirable to recipient organizations (Aveling, 2010; Bondy & Bedford, 2008).

Women Together's leadership complained of "too many workshops," often speaking of donors' capacity-building requirements in a tongue-in-cheek manner. When I was scheduling interviews for my research, Ana admitted with frustration that it would be difficult to schedule my interviews efficiently, as there were three workshops that the women were required to attend during just the first three weeks of my visit to Bishkek. My observation was that while organizations valued at least some of the content of workshops, they found many of them to be burdensome and irrelevant. They did, however, feel obligated to attend workshops, either at request of their donors or in order to appear more legitimate to external stakeholders.

> We would do our programs better if we did not spend so much time in workshops. When we were starting, it was fun to travel to new places and to meet others who were providing social programs. But now it is a hassle. Sometimes it's our donors that require it. Sometimes it's our partners. (Ana)

While she and several of her colleagues acknowledged that workshops in Kyrgyzstan were plentiful and to varying degrees helpful, they complained that workshop facilitators often misunderstood—and sometimes made no efforts to understand—the realities organizations faced.

> Well, from… yeah, I think from a very personal point of view, I think it would be that … the lack of capacity is really… like bigger than we thought. I think we thought that it works like, "Okay, we're going to support the initiatives and that's how they are going to strengthen themselves, and then they are going to have the capacity to grow up as an organization," and we thought that was going to be the natural response. But to be honest, that's not true. (Staff member of Believe in Youth)

Interestingly, organizations also recognized—and sometimes exploited—the symbolic value of workshop attendance and the content from workshop modules. Particularly in the case of Women Together (who had attended many more workshops than Beacons of Change), there

was evidence that the organization's leaders had learned what language to use with donors and how to craft a useful external appearance when needed, even if this external appearance did not align with what was happening in reality. Both organizations, to some degree, were guilty of 'projecting' an image of themselves that, whether it aligned with reality, might afford them a positive external image. In Women Together's case, their grant applications and reports did not align with many of the core values and the core implementation activities that were happening on the ground.

6.5 Believe in Youth as an Intermediary Donor

While the industry of NGO capacity building may be built at least partially on the desire to see organizations make a greater and more efficient impact on their beneficiaries, it has indisputably become institutionalized within the NGO sector. In addition to improving the outcomes of NGOs, organizational development interventions are designed to improve organizational accountability. Accountability, as described by Ebrahim (2010), "centers on the relationships among various actors, with some giving accounts of their behavior and others receiving and judging those accounts." In my research I noted with interest that the dynamics of accountability were more layered than I originally expected, and this shaped my understanding of the roles of Believe in Youth and its grantees.

When I originally encountered Believe in Youth at the Funders Concerned About AIDS Summit, I was not aware of the financial circumstances and restrictions that Believe in Youth faced as a donor agency. While many of the agencies at the FCAA meeting were making grants from large endowments or from substantial geographically or issued-based donor-advised funds, Believe in Youth was itself a grant-funded organization. Like its grantees, Believe in Youth was also dependent on external funding, and therefore accountable to the requirements of those donors. The demands of Believe in Youth's donors

inevitably shaped the organization's infrastructure, and, perhaps more importantly, they shaped the way that Believe in Youth structured its own relationships with its grantees.

NGOs are expected to be accountable to multiple actors: upwards to their funders or patrons, downwards to clients, and internally to their missions (Edwards and Hulme, 1996; Kearns, 1996; Lindenberg and Bryant, 2001; Najam, 1996). Ebrahim argues that accountability is a major driver of organizational behavior in the NGO sector, and particularly that accountability is systemically maligned to benefit those with power and money as opposed to those who receive services from NGOs. In other words, a power dynamic exists in which NGOs must please donors first and beneficiaries second, and there is a clear hierarchy in terms of the downward flow of funds and the upward flow of accountability for use of that funding.

These dynamics played out in several ways in my case studies. In Kyrgyzstan, Women Together's leaders spent hours amassing metrics to send to Believe in Youth and their other partners, and, perhaps more significantly, they strategically created a grander image of their organization than was the case on the ground.

In Vietnam, Huynh had mixed feelings about the ways in which the organization had changed over time. He applauded the outcomes of the capacity-building that Believe in Youth provided to Beacons of Change—chiefly, that Beacons of Change had developed a strategic plan and a more organized governance structure as a result of Believe in Youth's residential capacity-building workshop. However, he also felt that Beacons of Change had made some critical growth decisions in order to better align with Believe in Youth's grantmaking priorities. "After the workshop…they tried to reconstruct the whole group to fit into Believe in Youth," he said.

Importantly, Believe in Youth's grantees were not alone in feeling the pressure to navigate 'upward accountability' to their donors. As Believe in Youth began to distribute

more grants and gain new funders of its own, several of its donors began to question the value added of Believe in Youth. Since it had been initiated with a very flexible approach to funding, it had not originally required all of its grantees to submit extensive metrics. But when its own donors decided to enforce new accountability measures, Believe in Youth found itself in a conundrum. "If we were a foundation, we wouldn't have to deal with those pressures," remarked one of its former leaders in a phone interview.

> Yeah. I think it's really one of the… one of the challenges that we've tried to address… that we now have to measure everything. Everything has to be measureable, and I understand the reasons behind it…but you know we're now forced in a lot of cases to make things measurable that aren't really measurable. (Staff member of Believe in Youth)

Believe in Youth felt the pressure to continually restructure its grantmaking program in order to please its current donors and to appeal to new donors. While Believe in Youth's organizational ethos celebrated flexibility, innovation, and risk-taking in its grantmaking, it was hard for them to exercise these values in the context of donor dependency. While community participation is a key tenet of task-shifting and is valued on a moral basis by scores of philanthropic donors, in practice communities are often not given the liberty to fully own and lead their own interventions. Accountability to those who afford power and resources ultimately appears to impose limitations on the degree to which participation can fully be exercised by community groups—and in the case of Believe in Youth, by the intermediary donor agencies that support them. This sort of participation has been criticized by some observers as being a feel-good exercise in which "the sham of participation translates into the sham of accountability" because "unlike donors, communities cannot withdraw their funding; unlike governments, they cannot impose conditionalities" (Najam, 1996; p. 346-347).

6.6 Institutionalizing Youth Leadership in the HIV Response

The discussion of accountability not only elucidates the challenges at both the donor and the organizational level, but it also highlights a fundamental challenge for Believe in Youth's long-term vision. My interviewees from Believe in Youth's Steering Committee, Community Review Panel, Peer Support Persons, and staff showed me that, above all, Believe in Youth wished to institutionalize youth leadership in the fight against HIV/AIDS. One Steering Committee member commented:

> I don't see Believe in Youth as a donor. I see Believe in Youth as something that catalyzes the leadership and then steps out of there so that they can get mainstream donors to sustain their work, and they can work with the partnerships that exist in the region and sustain them. (Staff member of Believe in Youth)

This goal was legitimized by one of the closing speakers of the FCAA meeting: "We must fund programs that will foster leadership development, not only at an organizational level but also at the institutional level."

While pressures to be accountable to NORAD and its other donors led Believe in Youth to begin reporting outcomes from its grantees, many of these were short-term metrics such as numbers of people screened and counseled for HIV. Research shows that institutional changes often have less clear outputs and outcomes, and they often take much longer to achieve than outcomes such as HIV testing and treatment. A former director of Believe in Youth remarked that "most donors are not patient for the outcomes that matter. If we believe in fostering real leadership, it will take time for that to show."

Perhaps a greater challenge for Believe in Youth, though, is balancing the desire to foster leadership with the desire to build a sustainable youth-led HIV response among HTRYs. This challenge was clear in both cases—with Women Together, Ana had been hired by The North Star, and in Vietnam, Linh was 'poached' by one of Beacons of Change's partners. The loss of Linh in particular had a significant impact on the organizational trajectory of Beacons of Change. The challenge, then, is whether to consider the hiring of young HTRYs as a

successful outcome of Believe in Youth's investments in the organizations in Vietnam and Kyrgyzstan. Had Believe in Youth not seed-funded the organizations and provided training to their leaders, the counterfactual is that the organizational leaders might not have had appealing candidacies to the jobs that hired them off. In both Ana's and Linh's case, their paid jobs were also in the HIV sector, and they were at organizations operating at a larger scale than Women Together and Beacons of Change. Does the potential impact of Ana and Linh in their new positions outweigh the effects of their absences on their respective organizations? The answers to these questions are not definitive, but the questions themselves pose a quandary for Believe in Youth. Finally, Believe in Youth struggled with the dangers of promoting and celebrating leadership among marginalized groups

> We've had one grantee in Mexico who got killed because he was… openly living with HIV, and he got… I mean it was – yeah, we lost a friend but it also meant… on the one side you want to mobilize the community because you need that voice to be heard, and at the same time you don't want to put them in danger. (Staff member of Believe in Youth)

6.7 Conclusions

While the long-term goal of Believe in Youth is to foster youth leadership in the global HIV response and to institutionalize youth-led organizations in global funding priorities, its functional goal is to ensure that youth-led organizations thrive. A founding member of the group summarized that "a successful scenario would be an organization that did not exist that now has some impact in their community where that's recognized by their community as being a relevant actor in making services more accessible" (Staff member interview, Believe in Youth, 2013). Despite providing organizational capacity-building support to its grantees, Believe in Youth grantees have generally experienced high rates of failure, with many of its grantees ceasing to exist during their first three years. While Beacons of Change and Women Together were selected as 'ideal type' grantees, they were far from invincible to organizational threats.

CHAPTER 7: DISCUSSION AND CONCLUSIONS

In the opening to this dissertation, I told the stories of Mandakini, a young woman living with HIV in India, and Phyo, a transsexual fighting to improve sexual health among Myanmar's LGBT community. I embarked on the work of this dissertation with an interest in shining light on the challenges that young people like Mandakini and Phyo face in providing impactful and scalable HIV services to their peers. Marginalized youth experience the highest rates of HIV infection globally, and they are the least likely to seek HIV care. Mandakini and Phyo were social entrepreneurs whose organizations were providing HIV prevention and treatment to populations that had previously been unreached. Unfortunately, while their organizations provided unprecedented healthcare access to hard-to-reach communities, they constantly struggled to overcome internal and external organizational threats. This dissertation used a systematic review and a series of three case studies to explore the processes underlying organizational start-up, growth, and change in HTRY-led HIV service organizations like Mandakini's and Phyo's. In this final chapter, my task is to lend insight into what my findings contribute to the organizational sociology literature, to provide critical reflection on my methodology, and to discuss implications for policy, practice, and future research.

7.1 Main Findings

I began by outlining the policy relevance for funding HTRY-led HIV prevention organizations. I discussed recent clinical trials that demonstrated the efficacy of antiretroviral therapy as a form of HIV prevention, or "treatment as prevention" (TasP). I presented the connection between this research and global "test and treat" strategies, which aim to encourage HIV testing and treatment coverage globally, and particularly among the high-risk groups of men who have sex with men, sex workers, and people who inject drugs. Gaps in access to basic HIV services have prevented some of the hardest-to-reach groups from benefiting from the promise of TasP. I then discussed how the desire to bring TasP to scale gave birth to the salience

of implementation science, an emerging research field whose focus is to develop strategies to effectively deliver public health interventions. I introduced task-shifting, a healthcare delivery approach that was the subject of a landmark public health paper published by Schwartlander and colleagues (2011). Task shifting involves a strategic effort to relocate healthcare delivery duties from clinical settings into the hands of community-based organizations. Task-shifting has been motivated by the idea that the cost and reach of some basic healthcare services has been both more effective and less costly when delivered through community organizations that possess an acute understanding of local people.

My review of research and policy set up my discussion of the current landscape of HIV prevention organizations led by hard-to-reach youth (HTRY). Given that HTRY have the highest incidence of HIV and the lowest utilization of medical services, shifting the responsibility of HIV prevention and care activities to community-based organizations for these demographics has been seen as both a morally and strategically justified public health approach. Morally, putting HTRY at the center of organizations that serve other HTRY provides an important opportunity for participation. Scientifically, organizations that are driven by representatives of 'affected communities' have often resulted in more effective delivery of public health interventions (Huicho et al., 2008). Through my case studies, I showed how HTRY-led organizations have linked marginalized demographics to much-needed HIV treatment and care. Despite declarations of the moral and strategic imperative to incorporate marginalized youth into the design and implementation of HIV prevention interventions, however, community-based organizations within these demographics have experienced significant operational challenges. Over the past decade, several donor agencies have established funding mechanisms that specifically provide resources to HTRY in order to foster the development of services for HTRY. I discussed how donor agencies in this sector have

shifted to ‘funding plus’ grantmaking, offering community-based organizations financial support accompanied by some form of capacity-building technical assistance.

My introduction led to unanswered questions about the theoretical foundations of capacity-building interventions for NGOs, and particularly about the Life Cycle Model of organizations. Toward the end of my first chapter, I discussed the evolution of my empirical work, drawing on preliminary research in which two donor agencies expressed concerns over high rates of organizational decline among HTRY-led organizations. Both donor agencies had established capacity-building interventions that aimed to buffer HTRY-led organizations against the threats they faced during the early stages of organizational growth. Through interviews and document analysis, I developed a focus on the Life Cycle Model of organizational change, a framework used by both donor agencies to classify and measure the progress of their grantee organizations. The Life Cycle Model literature was predominantly theoretical, and most empirical studies had only tested the model’s fit to for-profit organizations. This discovery set up an opportunity to conduct a systematic review of literature that focused on the application of Life Cycle Models to nongovernmental organizations (NGOs). Several organizational sociologists proposed that NGO life cycles would differ from for-profit organizational life cycles in fundamental ways. While the Life Cycle Model lacked rigorous empirical validation, in my preliminary research it was evident that this model was considered to have significant practical relevance. Given the practical utility of Life Cycle Models but an apparent dearth of data supporting them, attaining both a broad and deep view of the NGO life cycle literature could be useful in setting up further empirical research.

In my second chapter, I adapted systematic review methods from Booth and colleagues (2012) to search and appraise the conceptual and empirical literature relevant to Life Cycle Models of NGO growth. The review described four conceptual life cycle models and then discussed the findings of nine quantitative and qualitative empirical studies. These studies

utilized a range of research methods, but the overall quality of evidence supporting the models was poor. In addition to poor evidence, the heterogeneity of life cycle components, research methods, and units of analysis made a synthesis of life cycle models impractical. Instead of attempting to conduct a meta-analysis or distill the research into a singular framework, I discussed several hypotheses that the literature proposed. I also highlighted key areas in which the literature opened up questions for further research. Specifically, the review identified competing propositions about the inevitability of NGO formalization, the influence of resource-dependence on organizational growth, and the influence of founders in the long-term trajectories of organizations.

The systematic review of life cycle models justified further empirical research, and it provided a loose framework for structuring data collection and analysis. My research proceeded with an in-depth investigation into the life cycles of HTRY-led HIV service organizations. These organizations were becoming both more prevalent and more prominent in global HIV prevention strategy, but they were experiencing high rates of failure, and donor agencies struggled to understand and react to the threats that these organizations faced in their early years.

I designed a multi-case study investigation that examined the early-stage growth of two organizations through an analysis of interviews, observations, and organizational documents. The organizations were selected through a series of interviews with grant managers from their first major donor. After asking grant managers to discuss their perceptions of organizational performance and the intended outcomes of their grantmaking program, grant managers from the donor agency were asked to select organizations that they believed were doing exceedingly well. The first case study took place within an organization serving an urban population of young female drug users in Kyrgyzstan, a Central Asian republic with a severe HIV epidemic among heroin users. The second case study focused on an organization serving men who have

sex with men, drug users, and people who were concurrently infected with HIV and Hepatitis C. The organization focused its work on promoting education, social care, and treatment adherence for these populations. Both case studies took place over a ten-week period, with follow-up interviews conducted over the course of the following year.

With each case study, I presented organizational growth by parsing out key stages of the organization's history. Both organizations from my case studies encountered an early period of success in which the founders mobilized peers to provide HIV prevention services to HTRY. With Women Together in Kyrgyzstan, this period was followed by the loss of three of the four original co-founders—one to a fatal car accident involving drug and alcohol abuse, another to imprisonment, and the third to 'aging out.' Women Together's remaining leader remained passionate and determined to continue providing services to the organization's target population, but she resisted pressures from external advisors and capacity-building consultants to devote more of her time to administrative activities such as fundraising and strategic planning. At the end of my research period, the organization was experiencing consolidation and stagnation. The members had failed to mobilize financial resources; they had been evicted from their office space as a result of stigma; and they had reduced their organizational activities to occasional outreach events in which they provided health and social service referrals to a larger, older, and more financially stable NGO.

In Vietnam, Beacons of Change had experienced a similar fate, though for different reasons and under a different set of circumstances. The organization was founded by a charismatic young woman who was living with both HIV and Hepatitis C. Beacons of Change was originally created to provide group-based social support for people living with HIV in Hanoi. As it grew, it strategically broadened its program activities to include charitable outreach to very young children living with HIV in rural areas, educational outreach to young men who have sex with men in Hanoi, and a large-scale project involving the development and

dissemination of treatment guidelines for clinicians serving HIV and Hepatitis C co-infected patients. The founder of Beacons of Change, Linh, purposefully expanded the organization's services in order to appeal to a broader range of donors as well as to attract additional volunteers. Linh, who had characteristically been responsible for the majority of the organization's programmatic and administrative activities, was eventually 'poached' by a larger organization that could pay her a salary, and she left Beacons of Change's direction in the hands of a young Vietnamese university student. At the end of my research period, Beacons of Change was struggling to fulfill its numerous and wide-ranging project goals, and its volunteers were more interested in carrying out its charitable activities for young children who were perinatally infected with HIV. Because Beacons of Change had failed to acquire new funding sources, the organization could only carry out activities that could be facilitated by volunteers and with minimal cost.

Despite being identified by Believe in Youth as exceedingly successful grantees, neither Women Together nor Beacons of Change had been able to develop long-term financial sustainability. Due to the importance of Believe in Youth in providing legitimacy to these organizations, as well as both organizations' dependence on Believe in Youth for resources, I decided to devote a third case study to an examination of the aims of Believe in Youth and its interactions with Women Together and Beacons of Change. My third case study utilized data about Believe in Youth and similar donor agencies collected over the course of four years. Data collection began with a series of Skype and in-person interviews at two international conferences in 2011. Between 2011 and 2015, I also conducted online and in-person interviews with the founding members of Believe in Youth. Believe in Youth granted me access to its archival grantee data and information about its board meetings and strategic planning activities, and this data helped me to put together a narrative of Believe in Youth's evolution as a donor agency. My donor case study showed that donors saw investments in HTRY-led organizations

as risky. They saw themselves as pioneer funders, and they hoped that their grant program would inspire other donors to make funding available to organizations that were designed and led by HTRY. Believe in Youth's staff accepted that not all of their grantees would thrive in their first few years. However, they had developed a capacity-building program and network of peer mentors (Peer Support Persons) that they hoped would help protect their grantees from succumbing to existential threats. They also prided themselves on a flexible grantmaking program that aimed to avoid imposing restrictive reporting requirements on grantees.

While Believe in Youth had roots in unconventional, high-risk investments in young organizations that they believed might not otherwise be funded, they were ultimately unable to be as unconventional in their grantmaking as they had hoped. In one of my meetings with Believe in Youth's Executive Director, he expressed worry about the external pressure to deliver compelling results to the agency's donors. He was concerned that Believe in Youth was not collecting enough data to justify their presence to large Western donors, so he was going to propose that one of their donors offer them a special grant solely for the purpose of evaluating Believe in Youth's impact. In addition to seeking their own resources to support evaluation activities, Believe in Youth began requiring grantees to provide an increasing amount of objectively verifiable data. The Executive Director was also concerned with how Believe in Youth might go about collecting the type of data that large donors wanted to see. "These guys [BIY grantees] have so many other worries. They need to address big social and political barriers just to implement programs…they even sometimes face threats of violence. It will be hard to ask them to do some RCTs or something," he remarked.

Overall, the landscape for HTRY-led organizations was fragile. My case studies revealed organizations that experience internal threats but which also face structural resistance from environments which have controlled or actively resisted the development of NGO participation from marginalized communities. While Believe in Youth emerged as an

unconventional donor focused on making risky investments in youth-led organizations, they, themselves, suffered from institutional threats.

7.2 Contributions to the Literature

In their *The Organizational Life Cycle: Issues in the Creation, Transformation and Decline of Organizations*, Kimberly and Miles (1980) provided a thorough exploration of organizational life cycle models. Kimberly and Miles aimed to demonstrate that the life-cycle metaphor is not simply an editorial device, but that it is a solid framework on which future longitudinal organizational research should be built. Rowan (1984) critiqued the work of Kimberly and Miles, arguing that the life cycle metaphor is little more than an editorial device.

> Although the main authors repeatedly assert that this collection of papers is an exploration of the life-cycle metaphor, competing models of organizational dynamics that emerge over the course of the book are nowhere integrated with or compared with the life-cycle metaphor that organizes the book. (Rowan, 1984; p. 978)

After finishing the laborious process of sifting through 2,179 citations and reviewing more than 100 papers in my systematic review, I was left with a stack of 14 papers that either proposed or empirically tested the application of life cycle models for NGOs. I began my systematic review with the hope of being able to synthesize existing NGO life cycle models into a single comprehensive framework, but my thoughts after reading these papers were disappointingly similar to Rowan's. Perhaps the biological metaphor of organizational life cycles, while a useful tool for practitioners who want to classify the growth of organizations, was not much more than that. The models that I found were neither compatible with each other in structure nor in their overall explanations of organizational growth.

I had hoped that I could be the first academic in several decades (since Hasenfeld and Schmid in 1989) to propose an integrated and contemporary model of NGO life cycles. Instead, I concluded that an integrated model would not make sense given the heterogeneous nature of the existing models. I had also originally wanted to embark on my empirical

research with the goal of testing the 'fit' of a newly integrated life cycle model to the trajectories of HTRY-led organizations. While this approach ended up not being productive, I was able to use the review to narrow the focus of my empirical research.

My empirical research was ultimately guided by the emergent fit analytical method. Emergent fit distinguishes itself from grounded theory in that it favors the extension of existing theory as opposed to the generation of new, isolated theories (Wuest, 2000). The task of emergent fit research is "to develop an emergent fit between the data and a pre-existent category that might work." (Glaser, 1978, p. 148). Glaser stresses that an extant theory must be carefully fitted as data emerges to be sure it works. To this end, I want to discuss the ways in which my analysis has made the life cycle theory particular.

Leadership

Barnett (1988), Avina (1993), Bess (1998), and Chambre (1997) all agreed that founders played a significant role in influencing both the early identity of organizations and their long-term trajectories. In both of my case studies, there was a high rate of leadership turnover. In Kyrgyzstan, only one of four original founders remained after Women Together's first year. In Vietnam, there were three leaders within just the first several years of Beacons of Change's existence. While my case studies supported the notion that founders were critical to establishing an organization's identity and carrying it through nascence, data from both case studies presented nuanced information about the drivers of organizational leadership transience. Both BOC and Women Together were seed-funded by a donor who mandated that the organizations be led by people under the age of 30. 'Aging out' was a process in which founders had to voluntarily leave an organization before they became too old. In Kyrgyzstan, one of the four founders exited the organization due to age. In Vietnam, Linh sought a new leader because, among other reasons, she felt that she was becoming too old to relate to the youth that the organization served. When comparing Linh and the

founders of Women Together to the examples of founders that were presented in the systematic review, the notion of a regulated restriction on the age of leaders' resulted in important leadership transitions very early in the organizations' histories.

In addition to the inherent leadership transience caused by the age restrictions on HTRY-led work, Women Together revealed threats that might be both common and particular to HTRY-led organizations. Women Together lost one of its co-founders to a car crash in which drug and alcohol abuse were involved, and the organization lost another co-founder to a drug-related prison sentence. The loss of these two leaders is important because they both left the organization due to threats that were tied to their identities as members of hard-to-reach youth. Women Together's members and stakeholders attributed much of the organization's success to their ability to connect with and change the behavior of young female drug users. Unfortunately, the fact that the organizations' leaders identified as part of this population meant that they, too, were vulnerable to the risks of socializing in a peer group of people who used drugs.

Formalization

While not all of the life cycle papers agreed on whether organizational professionalization and formalization increased organizational efficiency, all authors of life cycle models agreed that some level of professionalization was inevitable. My systematic reviewed showed that professionalization could be driven by several possible factors, including internal desires to delineate clear roles and responsibilities of members (Avina, 1993), an organization's governors' desire to avoid vulnerability during leadership transitions (Barnett, 1988), or external stakeholders' mandates to hold organizations accountable (Chambre, 1997).

While Women Together and Beacons of Change both actively resisted professionalization, in both cases it was clear that the pressure to professionalize was coming

from *external actors*, and this commonality makes these cases stand out from existing examples in the literature. With Women Together, Believe in Youth's appointed Peer Support Person persistently encouraged Ana to design a long-term strategy for the organization to acquire resources and expand its programming. When I was in Kyrgyzstan, Women Together was also physically housed by The North Star, which was seen as an emblematic bureaucratic Kyrgyz NGO. Nazia complained that The North Star had been 'sterilizing' the office of Women Together—she was concerned that while The North Star had good intentions, they would pressure Women Together to become a typical 'post-Soviet' NGO. Women Together was borne out of a shared value of collective participation and it had a flat organizational structure, and Nazia was worried that The North Star would influence Women Together to professionalize to the point that it would lose its core identity—that its members would begin to "follow a leader and not question what that leader says."

In Vietnam, Beacons of Change maintained a flat organizational structure, even as it added new programs and services. Huynh, the Peer Support Person that Believe in Youth assigned to Beacons of Change, expressed concern that the organization was too disorganized, and Huynh had suggested that Thet create structures to ensure that Beacons of Change could fulfill its organizational objectives and could properly report its progress to its donors. While the sample size for these case studies was too small to generalize the results to all HTRY-led HIV organizations, it was of note that professionalization was a process imposed by external stakeholders and which was actively resisted by both groups.

The Influence of Organizational Environments

Life cycle theory posits that organizations undergo growth in a staged pattern and that each stage of growth carries a distinct and predictable set of organizational characteristics and concerns. While institutional environments are discussed in the life cycle literature, Life Cycle Models have assumed that external environments are relatively stable and amendable

to organizational growth. Both Women Together and Beacons of Change faced significant threats as a result of prevailing political agendas. In Kyrgyzstan, Women Together intentionally avoided becoming a legally registered entity. Ana was sure that the Kyrgyz government would not permit the organization to be legally registered, and she feared that an attempt at registration would expose the organization in a way that could endanger its beneficiaries. Her fears were not unfounded, as several of Women Together's clients had been harassed by the police in the organization's short history. Beacons of Change faced a legal barrier to registration as well. Its members did not meet the age or educational requirements to obtain NGO status. While the Life Cycle Model posits that a mix of internal dynamics will lead to critical organizational crises, the most critical and most intractable organizational crises for both of my case studies originated at the structural level.

Early Organizational Liability

Given that my research was also situated in a context of high rates of organizational demise, I also want to revisit the literature on organizational vulnerability that I discussed in my introduction chapter. Stinchecombe's (1965) work argued that new organizations are susceptible to failure, and it purported that the likelihood of failure declines with time. Stinchecombe's work formed the foundation for research on organizational mortality that continues today, and many researchers have confirmed his hypothesis. Fichman and Levinthal (1991) modified Stinchecombe's hypothesis in coining the term 'liability of adolescence.' They argued that while an organization's chances of demise generally decrease over time, there is a brief period at the beginning of an organization's life in which the likelihood of death is slim. This 'honeymoon period' is the result of a stock of assets which can take a variety of forms, including favorable prior beliefs, trust, goodwill, financial resources, or psychological commitment. Fichman and Levinthal hypothesize that these

assets reduce the risk that key relationships will dissolve even if the initial outcomes of these relationships are not favorable.

My findings were consistent with Fichman and Levinthal's hypothesis. Believe in Youth's grant served as a prime financial resource to buffer Women Together and Beacons of Change organizations against early failure, and the charisma of the organizations' founders attracted a base of followers that helped to foster each organizations' growth. Interestingly, Fichman and Levinthal stress that an organization's honeymoon period allows it to receive resources even in the absence of successful outcomes. As discussed early in this dissertation, 'success' in the NGO sector is a loaded term that assumes different meanings depending on the audience and on the time (e.g. definitions of success are constantly changing). While I avoid defining the overall work of the organizations as successful or not, in both case studies there was a lack of compliance with donor expectations. Women Together was able to resist the pressure to provide advocacy in favor of the leaders' desires to provide direct services to their clients. Even though Women Together's donor-commissioned adviser ("Peer Support Person") was frustrated by the women's resistance to her advice, Believe in Youth continued to provide support to the group. In Vietnam, Huynh complained that Beacons of Change had failed to submit required reports to Believe in Youth, but they continued to receive funding nonetheless.

Data from my Believe in Youth case study showed that the donors saw both organizations' administrative failures (e.g. rejecting consultants' advice and failing to comply with donor requirements) as 'normal' for small and relatively new organizations. The charter of Believe in Youth, though, was to provide temporary funds to organizations that were 'unfundable.' And when the organizations had spent the resources from Believe in Youth, the prospects of finding future funding were grim. Women Together had significantly reduced their operations, and Beacons of Change was running a very small individual donor campaign

that funded outreach activities for youth. Though in my case studies I highlighted different organizational trajectories for Women Together and Beacons of Change, the end of the Believe in Youth grant marked the culmination of the honeymoon period for both organizations.

As the stock of early organizational assets waned, the most important survival task for Women Together and Beacons of Change was to mobilize resources from new donors. Despite significant leadership changes in their first few years, both organizations were able to maintain a fairly stable base of volunteers. The threat to their existence was primarily financial, as there was limited money available to support programmatic and administrative costs.

7.3 Strengths and Limitations of this Study

My research included two distinct components. The first was a systematic review of the application of Life Cycle Models to NGO organizational behavior, and the second was a multiple-case study empirical investigation into the dynamics of early-stage organizational growth among HTRY-led organizations. It is difficult to distinctly identify where the research began and where it ended. In my introduction, for example, I discuss the evolution of my research question and approach. The purposive shift from my early desire to do evaluative research to what later became an exploratory qualitative study was the result of conversations I had with stakeholders in the HIV prevention space, observations at HIV conferences, and ongoing library research on HIV prevention policy and clinical research. These readings, conversations, and observations immensely shaped my approach to the major components of my research, and they also helped me to better understand what sorts of research questions would be most useful to the field and most achievable within the bounds of a DPhil. In the end, though, data from the early stages of my research were incorporated into the analysis of my case studies—particularly my case study on Believe in Youth. The overall findings of this study

come from both components—the systematic review and the case studies—and thus I will discuss the methodologies and limitations of each set of findings separately.

Systematic Review

For my systematic review, I was ambitious in wanting to provide a rigorous—systematic, transparent, and reproducible—review of the extant literature on the application of Life Cycle Models to NGO research. I was frustrated that previous literature reviews rarely reported or appraised the quality of the research through which important findings were reached. I was also concerned that I could have been biased in my selection of background reading, so I wanted to conduct a search that was sensitive enough to identify papers that I might not have come across in my more informal searching. I designed my review methods based on two seminal works in systematic reviewing—Booth's (2012) book on systematic review typologies and Petticrew and Robert's (2006) guidelines for conducting systematic reviews in the social sciences. Systematic reviews originally gained popularity in the medical sciences, and they asked very specific questions about the efficacy of biomedical interventions. Systematic review methods enable researchers to amass and meta-analyze the results of many studies, providing clinicians with evidence-based advice about which interventions would be best for their patients.

My review, in contrast to most biomedical systematic reviews, was much more open-ended. I intentionally selected broad inclusion criteria because I wanted to consider both theoretical and empirical research on the application of life cycle models to NGOs. Several sociologists suggested that the unique conditions of NGOs warranted life cycle theory that was different than for-profit businesses, and Cameron and Whetten (1983) pointed out that life cycle models had not been thoroughly empirically tested with NGOs. After conducting my search and narrowing down the results to a handful of relevant papers, I came to the conclusion that a meta-analysis of my data was impractical. The included empirical studies were too

heterogeneous in terms of research aims, methods, and data analysis. Instead, I resorted to a narrative description of the findings, and I identified several areas for future research.

While my systematic review did not yield a synthesis process that was easy or 'clean,' I believe that this finding alone provides a useful statement about the challenges of interdisciplinary organizational research. Systematic reviews were originally designed to serve healthcare decision-making, but they have recently been popularized for assessing the efficacy of social and behavioral interventions as well. Establishing more systematic methods for reviews of organizational literatures can benefit practitioners and academics by offering a more robust and critical depiction of existing research. Further, systematic reviews, by definition, provide reproducible methods—the same search can be re-run periodically in order to assess the ways that new research might have changed the previous overall findings of a review.

My goal of producing a systematic review was ambitious. Many reviews are undertaken by large research teams, are costly, and can take years to complete. The fact that I conducted this review alone may have biased my findings in a number of ways. Perhaps the largest flaw in my review was the lack of a co-reviewer. My original search returned 2,179 citations, and I spent almost three weeks screening citations, abstracts, and full papers to decide whether they met the review's inclusion criteria. Because my inclusion criteria were relatively broad, I had to spend quite a bit of time carefully reading articles in order to determine whether they fit the review's aims. Using a co-reviewer is a best practice for systematic reviews because it not only limits human error, but it also allows multiple interpretations of a study to be considered in the decision to include it or not. If I could repeat this review, I would commission at least one other co-reviewer to assist in screening papers and analyzing data. If I were able to re-run the review, I would also add professional outreach to the search strategy. As stated in the introduction and again in this conclusion, the very beginnings of my research involved conversations with two donor agencies that had used life cycle models to help classify the development of their

grantees. A thorough process of professional outreach might have yielded additional gray literature about NGO life cycle models that could have enriched my overall findings. Finally, I would have broadened the language constraints of my search to include papers that were not published in English. My review found that seven of nine empirical studies were conducted either in Western English-speaking countries or within Western English-speaking NGOs that were operating in non-Western countries. It is possible that this finding was the result of the fact that my search only detected papers that were published in English.

Case Studies

This thesis applied a case study approach to investigate the early-stage growth of HTRY-led HIV organizations. The case study approach afforded me the time and the tools to gain adequate access and trust of my research participants. The fact that I was not evaluating the effectiveness or efficiency of the organizations allowed me to empower my research participants with the ability to make the research about *their* story. Instead of seeing me as an outsider with a prescribed task, I loosely structured my interviews around the organizational processes of Beacons of Change and Women Together, and I reassured interviewees that the most valuable data was their honest opinions and perceptions of each organization's history. My research was conducted under the idea that there might be many different and competing truths about organizational events, that all of these truths were valid and important, and that together they could form a robust picture of organizational change.

My position as a researcher and my existing relationships within HIV prevention and research communities likely influenced my data. Before embarking on my DPhil, I had volunteered as a program manager of a South African HIV prevention organization, I had founded a youth-led HIV NGO in Washington, DC, I had served as a 'focal point' to a global online community of youth working on HIV prevention and treatment, and I had spent a year

as a research student conducting HIV prevention systematic reviews. These experiences connected me to donor agencies and to other young people working in the sector, and they afforded me the credibility to pursue the type of research that I undertook. In the early stages of my research, Believe in Youth and Together Against AIDS both granted me full access to all of their board meeting minutes and to all historical documents pertaining to their grantees (e.g. proposals, reports, etc.). Had I not already known the agency and its staff prior to my DPhil research, it would have been unlikely for me to have been able to negotiate such access.

There were countless cultural, educational, and other socio-demographic differences between myself and my research participants. While I was always careful about how I approached my interviews, I felt that many of my interviewees trusted me because I had also had the experience of founding and building an NGO. While my organization had operated in a context very different from the contexts of Women Together and Beacons of Change, I felt that I was able to relate to my interviewees in a way that would not have been possible if I were perceived solely as an academic researcher.

Nonetheless, as with all research, my case study research certainly had limitations. Chief among its limitations was the very small number of cases. Both of my HTRY-led organizational case studies were sampled purposively to represent organizations that the donors thought were performing exceedingly well (with 'performing well' defined by the donors themselves). This meant that the cases, by definition, were not expected to be representative of the entire population of HTRY-led organizations. It is possible that other HTRY-led organizations behave in ways that are fundamentally different from Women Together and Believe in Youth. Given that some of the findings from my case study seemed to be entirely dependent on local contexts (e.g. the challenges that the organizations faced with legal registration), even other HTRY-led organizations that donors might have selected as high-performing could face a unique set of context-dependent challenges.

I took many intentional efforts to solicit 'thick descriptions' from my interviewees (ensuring comfort with translators, offering to conduct interviews wherever interviewees felt most comfortable, and spending time simply building rapport with both organizations). I also collected multiple forms of data in order to corroborate developing organizational storylines. Finally, I 'double-translated' all interviews to see how translators might have altered questions and responses during interviews en vivo. I believe these efforts allowed me to observe and reflect on possible biases. Still, there remains a possibility that I misinterpreted some of data or that interviewees intentionally misconstrued organizational events that might have been seen as 'unfavorable.' Given these limitations, I believe that my research offers several contributions to the literature.

7.4 Prospects for Future Research

While this thesis revealed threats that were shared by two HTRY-led NGOs that were operating in very different contexts, I am not able to generalize these findings to the entire population of HTRY-led HIV NGOs, and certainly not to all NGOs at large. However, in the opening two chapters of this dissertation, I discussed the limited organizational research on HTRY-led NGOs and on the life cycles of NGOs as a whole. Given the increasing number of HTRY-led HIV NGOs and the important role that they might play in stemming HIV infection rates, additional case-study research on HTRY-led organizations could help to determine whether the cases of Women Together and Beacons of Change are representative of the sector. Given the limited number of studies and the overall poor quality of empirical work on the NGO life cycle model, I would also recommend that organizational researchers create new studies that follow a longitudinal trajectory of organizational changes.

This research also presented the challenging organizational contexts in which Women Together and Beacons of Change operated. HIV stigma is a heavily researched topic, but stigma's impact on organizational trajectories is under-researched. Goffman (1963) wrote the

landmark work on the social psychology of stigma, calling it a "form of spoiled image." He also extended his scholarship to stigma at the organizational level, arguing that "core stigma" is an institutional negative evaluation of an organization because of its core attribute or attributes. Women Together faced stigma when they had a public office space, and they responded by relocating to a more discreet site, removing signage, and 'hiding.' Beacons of Change was unable to legally register as an NGO because the government stigmatized the youth and the uneducated. They responded by diversifying their programmatic offerings in order to become more appealing to local audiences (e.g. doing outreach to young children in addition to drug users). Core stigma seemed to be an existential threat to both organizations, and interviews with Believe in Youth showed that this challenge might be pervasive among other HTRY-led organizations. For this reason, future research might examine the impact of core stigma on organizational development and the strategies that HTRY-led organizations employ to overcome it.

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APPENDIX A: SYSTEMATIC REVIEW SEARCH STRATEGY

Database: ABI/Inform Global
Searched On: 12 November 2013
Citations Returned: 722

SU.EXACT((“Community organizations” OR “Nongovernmental organizations—NGOs” OR “Nonprofit organizations” OR “Charities” OR “Tax exempt organizations” OR “Nonprofit management” OR “Public enterprise”) AND (“Organizational change” OR “Organization development”)) **OR** (AB,TI((charit* OR (“charitable” P/1 organi?ation*) OR (“civic” P/1 organi?ation*) OR (“civil society” P/1 organi?ation*) OR (“community-based” P/1 organi?ation*) OR (“community-led” P/1 organi?ation*) OR (“human service” P/1 organi?ation*) OR NGO* OR (“nongovernmental” P/1 organi?ation*) OR NPO* OR (“nonprofit” P/1 organi?ation*) OR (“non-profit” P/1 organi?ation*) OR (“philanthropic” P/1 organi?ation*) OR (“social change” P/1 organi?ation*) OR (“social impact” P/1 organi?ation*) OR (“social” P/1 enterprise*) OR (“third sector” P/1 organi?ation*) OR (“voluntary” P/1 organi?ation*)) **AND** (life?cycle OR “phases of growth” OR “stages of growth” OR (Organi?ation* P/1 behav*) OR (Organi?ation* P/1 change*) OR (Organi?ation* P/1 develop*) OR (Organi?ation* P/1 evol*) OR (Organi?ation* P/1 growth*))))

Database: Web of Science
Searched On: 12 November 2013
Citations Returned: 594

TS=((charit* OR (“charitable” NEAR/1 organi?ation*) OR (“civic” NEAR/1 organi?ation*) OR (“civil society” NEAR/1 organi?ation*) OR (“community-based” NEAR/1 organi?ation*) OR (“community-led” NEAR/1 organi?ation*) OR (“human service” NEAR/1 organi?ation*) OR NGO* OR (“nongovernmental” NEAR/1 organi?ation*) OR NPO* OR (“nonprofit” NEAR/1 organi?ation*) OR (“non-profit” NEAR/1 organi?ation*) OR (“philanthropic” NEAR/1 organi?ation*) OR (“social change” NEAR/1 organi?ation*) OR (“social impact” NEAR/1 organi?ation*) OR (“social” NEAR/1 enterprise*) OR (“third sector” NEAR/1 organi?ation*) OR (“voluntary” NEAR/1 organi?ation*)) **AND** (life?cycle OR “phases of growth” OR “stages of growth” OR (Organi?ation* NEAR/1 behav*) OR (Organi?ation* NEAR/1 change*) OR (Organi?ation* NEAR/1 develop*) OR (Organi?ation* NEAR/1 evol*) OR (Organi?ation* NEAR/1 growth*)))

Database: SCOPUS
Searched On: 12 November 2013
Citations Returned: 471

TITLE((charit* OR ("charitable" PRE/1 organi?ation*) OR ("civic" PRE/1 organi?ation*) OR ("civil society" PRE/1 organi?ation*) OR ("community-based" PRE/1 organi?ation*) OR ("community-led" PRE/1 organi?ation*) OR ("human service" PRE/1 organi?ation*) OR NGO* OR ("nongovernmental" PRE/1 organi?ation*) OR NPO* OR ("nonprofit" PRE/1 organi?ation*) OR ("non-profit" PRE/1 organi?ation*) OR ("philanthropic" PRE/1 organi?ation*) OR ("social change" PRE/1 organi?ation*) OR ("social impact" PRE/1 organi?ation*) OR ("social" PRE/1 enterprise*) OR ("third sector" PRE/1 organi?ation*) OR ("voluntary" PRE/1 organi?ation*)) AND (life?cycle OR "phases of growth" OR "stages of

growth" OR (Organi?ation* PRE/1 behav*) OR (Organi?ation* PRE/1 change*) OR (Organi?ation* PRE/1 develop*) OR (Organi?ation* PRE/1 evol*) OR (Organi?ation* PRE/1 growth*))) OR ABS((charit* OR ("charitable" PRE/1 organi?ation*) OR ("civic" PRE/1 organi?ation*) OR ("civil society" PRE/1 organi?ation*) OR ("community-based" PRE/1 organi?ation*) OR ("community-led" PRE/1 organi?ation*) OR ("human service" PRE/1 organi?ation*) OR NGO* OR ("nongovernmental" PRE/1 organi?ation*) OR NPO* OR ("nonprofit" PRE/1 organi?ation*) OR ("non-profit" PRE/1 organi?ation*) OR ("philanthropic" PRE/1 organi?ation*) OR ("social change" PRE/1 organi?ation*) OR ("social impact" PRE/1 organi?ation*) OR ("social" PRE/1 enterprise*) OR ("third sector" PRE/1 organi?ation*) OR ("voluntary" PRE/1 organi?ation*)) AND (life?cycle OR "phases of growth" OR "stages of growth" OR (Organi?ation* PRE/1 behav*) OR (Organi?ation* PRE/1 change*) OR (Organi?ation* PRE/1 develop*) OR (Organi?ation* PRE/1 evol*) OR (Organi?ation* PRE/1 growth*)))

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Searched On: 12 November 2013
Citations Returned: 371

SU.EXACT((“Community organizations” OR “Nongovernmental organizations—NGOs” OR “Nonprofit organizations” OR “Charities” OR “Tax exempt organizations” OR “Nonprofit management” OR “Public enterprise”) AND (“Organizational change” OR “Organization development”)) **OR** (AB,TI((charit* OR (“charitable” P/1 organi?ation*) OR (“civic” P/1 organi?ation*) OR (“civil society” P/1 organi?ation*) OR (“community-based” P/1 organi?ation*) OR (“community-led” P/1 organi?ation*) OR (“human service” P/1 organi?ation*) OR NGO* OR (“nongovernmental” P/1 organi?ation*) OR NPO* OR (“nonprofit” P/1 organi?ation*) OR (“non-profit” P/1 organi?ation*) OR (“philanthropic” P/1 organi?ation*) OR (“social change” P/1 organi?ation*) OR (“social impact” P/1 organi?ation*) OR (“social” P/1 enterprise*) OR (“third sector” P/1 organi?ation*) OR (“voluntary” P/1 organi?ation*)) **AND** (life?cycle OR “phases of growth” OR “stages of growth” OR (Organi?ation* P/1 behav*) OR (Organi?ation* P/1 change*) OR (Organi?ation* P/1 develop*) OR (Organi?ation* P/1 evol*) OR (Organi?ation* P/1 growth*))))

Database: Global Health (1973 to 2013 Week 44)
Searched On: 12 November 2013
Citations Returned: 21

((Non-governmental organizations/ OR grassroots organizations/) AND Organizational development/) **OR** ((charit$ OR (charitable ADJ organi?ation$) OR (civic ADJ organi?ation$) OR (civil society ADJ organi?ation$) OR (community-based ADJ organi?ation$) OR (community-led ADJ organi?ation$) OR (human service ADJ organi?ation$) OR NGO$ OR (nongovernmental ADJ organi?ation$) OR NPO$ OR (nonprofit ADJ organi?ation$) OR (non-profit ADJ organi?ation$) OR (philanthropic ADJ organi?ation$) OR (social change ADJ organi?ation$) OR (social impact ADJ organi?ation$) OR (social ADJ enterprise$) OR (third sector ADJ organi?ation$) OR (voluntary ADJ organi?ation$)) **AND** (life?cycle OR phases of growth OR stages of growth OR (Organi?ation$ ADJ behav$) OR (Organi?ation$ ADJ change$) OR (Organi?ation$ ADJ develop$) OR (Organi?ation$ ADJ evol$) OR (Organi?ation$ ADJ growth$))).ti,ab

APPENDIX B: INTERVIEW TOPIC GUIDE

Introductory Interview

1. Who founded your organisation, and what was his/her/their motivation?

2. What problem does the organisation aim to address?

3. Who are the organisation's targeted beneficiaries?

4. Tell me about the services your organisation provides.

5. Looking back at your experience working at the organisation, what would you say have been the most significant benchmarks in the organisation's growth? Have there been any major changes in the organisation's structure, outputs, or outcomes?

Leadership

1. How do you organize yourselves? Has this changed over time?

2. Have there been any unexpected changes (surprises) in your organisation regarding leadership?

Mission, Vision, and Strategy

1. What is your organisation's purpose?

2. What is your organisation's plan to reach these goals?

3. What does your organisation do well?

4. What are your organisation's greatest challenges?

Program Delivery and Impact

1. What does the organisation do? Who are its primary targets?

2. Have your organisation's activities or targeted beneficiaries changed over the past three years? If so, how have they changed? What would you say has driven these changes?

Strategic Relationships

1. Does your organisation have any partners?
    - Who are they?

2. Ask the interviewee to explain the history of each partner and their function in the organisation's progress toward its mission.
    - How did you meet them?

- How do their goals align with yours? How are they different?
- What assets does the partner organisation bring to your work?
- Have you had to make any sacrifices or compromises in order to initiate or sustain the partnership?

3. Explain your relationship with your funder (HIV Young Leaders Fund and/or Staying Alive Foundation).

Resource Development

1. How does your organisation financially support its activities?

2. Has your organisation's base of funders changed over the course of its three years? If so, describe these changes.

Internal Organisation Management

1. How has your organisation's structure changed over the past three years?

2. What has driven change?

Governance Leadership

1. Does anyone other than your organisation's executive oversee your work (e.g. a board of directors)?

2. If so, who are they?

3. How has your organisation's governing or advisory boards changed over the course of three years?

4. What role has your organisation's governing or advisory boards played in achieving your organisation's mission?

Environment

1. How would you characterize the environment in which your organisation works?

2. What external forces have the most significant influence on your work? These influences can be 'positive' or 'negative.'

Final Question

1. Do you have any other issues that you'd like to discuss?

<u>Руководство для проведения интервью:</u>

Введение:

1. Кто основал вашу организацию, и какая была у него/нее/них мотивация?

2. На решение какой проблемы нацелена ваша организация?

3. Целевая аудитория/бенефициары этой организации?

4. Расскажите об услугах, которые предоставляет ваша организация.

5. Оглядываясь на ваш опыт работы в организации, какие наиболее значимые этапы роста организации вы бы отметили? Были ли серьезные изменения в структуре организации, целях и задачах?

Руководство

1. Опишите структуру организации? Изменилась ли она с течением времени?

2. Были ли неожиданные изменения (сюрпризы) в вашей организации в отношении руководства?

Миссия, Видение , и стратегия

1. Какова цель вашей организации?
2. Расскажите о плане вашей организации для достижения этих целей
3. Опишите сильные стороны вашей организации
4. Каковы самые большие препятсвия для вашей организации?

Имплементация программы и влияние

1. Чем занимается ваша организация? Кто ее основная целевая аудитория?

2. Были ли изменения в мероприятиях организации или целевой аудитории за последние три года? Если да, то как они изменились? Что на ваш взгляд привело к этим изменениям?

Стратегические партнеры

1. Есть ли у вашей организации партнеры?
    a. o Кто они?

2. Попросите собеседника объяснить историю каждого партнера и их содействие в ходе достижения организацией своей миссии.

    - Как вы с ними познакомились?
    - Как их цели совпадают с вашими? Чем они отличаются?
    - Опищите преимущества этой организации, которые дополняют вашу работу или помогают вам.
    - Были ли случаи когда вам приходилось идти на какие-.либо жертвы или компромиссы для того чтобы инициировать или поддерживать партнерство?

3. Объясните ваши отношения с вашим донором (HIV Young Leaders Fund and/or Staying Alive Foundation).

Мобилизация ресурсов

1. Как ваша организация финансово поддерживает свою деятельность?

2. Поменяласть ли база доноров вашей организации в течение трех лет? Если да, то опишите эти изменения.

Внутреннее управление организации

1. Как изменилась структура управления вашей организации за последние три года?

2. Чем объясняется изменение?

Общее управление организации

1. Контролирует ли вашу работу кто-нибудь еще кроме исполнительного директора вашей организации (например Совет директоров)?

2. Если да, то кто они?

3. Как изменились руководящие или консультативные советы вашей организации в течение трех лет?

4. Какую роль руководящие или консультативные советы играли в достижении миссии вашей организации?

Среда/Внешние факторы

1. Как бы вы охарактеризовали условия, в которых работает ваша организация?

2. Какие внешние факторы наиболее существенно влияют на вашу работу? Эти влияния могут быть как «положительными» так и «отрицательными».

Заключительный вопрос

1. Есть ли у вас другие вопросы, которые вы хотели бы обсудить?

APPENDIX C: INFORMED CONSENT FORMS

UNPACKING EARLY ORGANIZATIONAL DEVELOPMENT IN HIV/AIDS PREVENTION ORGANIZATIONS LED BY YOUNG MEMBERS OF KEY AFFECTED POPULATIONS (YKAP)

Information Sheet for Informed Consent
Principal Investigator: Tyler Spencer

The purpose of my study is to understand how HIV/AIDS prevention organizations that are founded by young members of key affected populations (YKAP) are organized and develop over time.

The study is an exploration into how and why these organizations change over time. It is not an evaluation of how effective YKAP-led organizations are.

You are being asked to participate in this study. Your participation is completely voluntarily. Should you decide to participate, you can refuse to answer any questions for any reason, and you can withdraw from the study at any time.

All efforts will be made to protect the confidentiality of your responses—including assigning pseudonyms (nicknames) to you and to other people and organizations being discussed—and all data will be stored in a locked, password-protected electronic file.

This study has been reviewed and approved by the Central University Research Ethics Committee (CUREC) at the University of Oxford. If you have any questions about the study please contact me (tyler.spencer@dph.ox.ac.uk; +44 (0)7869 701548) or the Research Ethics Committee at the University of Oxford (ethics@socsci.ox.ac.uk; +44 (0)1865 614871).

Thank you for your time and consideration.

Consent to be a Research Subject

Background

The purpose of my study is to understand how HIV/AIDS prevention organizations that are founded by young members of key affected populations (YKAP) are organized and develop over time. This goal will be achieved through the analysis of qualitative data collected from stakeholders in the field of HIV/AIDS prevention for YKAP, including in-depth research on four YKAP-led HIV/AIDS prevention organizations.

Study Procedure

As part of this study, you will be asked to take part in one or more interviews, and I may also record data while observing you during routine organizational practices. I will record interviews with a voice recorder when acceptable, and may also take written notes during interviews or during observation of organizational practices.

Confidentiality

I will transcribe recorded interviews and compile observational notes in an electronic document that will kept in my possession in a locked, password-protected file. All efforts will be made to protect the confidentiality of your responses—including assigning pseudonyms (nicknames) to you and to other people and organizations being discussed —and all data will be stored in a password-protected file.

Risks

The risks of your participation in this study are minimal, but could include feeling uncomfortable discussing personal attitudes and events.

Benefits

There may be no direct benefit to you, but you may find it helpful to reflect on organizational development in YKAP-led HIV/AIDS prevention organizations.

Publication of Data

The University of Oxford is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

If you agree to participate in this project, the research will be written up as a thesis. On successful submission of the thesis, it will deposited both in print and online in the University archives, to facilitate its use in future research.

The data from this study may also be submitted by the researcher for publication in academic journals, and for presentation at meetings and conferences. As detailed above ('Confidentiality'), data will be de-identified in all presentations and publications.

Withdrawal from Study

Participation in this study is voluntary. You can choose not to take part, and you can choose to withdraw from the study at any point in time.

What if there is a problem?

This project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee.

If you have any questions or concerns about any aspect of this project, please speak to the researcher (Tyler Spencer; tyler.spencer@dph.ox.ac.uk; +44 (0)7869 701548) who will do his best to answer your query.

If you remain unhappy and wish to make a formal complaint, please contact the Research Ethics Committee at the University of Oxford (ethics@socsci.ox.ac.uk; +44 (0)1865 614871; Social Sciences & Humanities Inter-Divisional Research Ethics Committee, Oxford University, Hayes House, 75 George Street, Oxford, OX1 2BQ, UK).

Consent:

I confirm that I have read this consent and authorization document and have had the opportunity to ask questions. I will be given a signed copy of the consent and authorization form to keep.

I agree to participate in this research study under the terms of this document.

Participant Signature:_____ **Date:**_____

Participant Printed Name:_____

Researcher Signature:_____ **Date:**_____

Researcher Printed Name: _____

Рассмотр раннего организационного развития организаций по профилактике ВИЧ/СПИДа, возглавляемых молодыми людьми из ключевых пострадавших групп населения (МКПГН)

Информационный лист для обоснованного согласия
Главный исследователь: Тайлер Спенсер

Целью моего исследования является объяснение того, как организованы и развиваются с течением времени организации по профилактике ВИЧ/СПИДа, учрежденные молодыми людьми из ключевых пострадавших групп населения (МКПГН).

Исследование отвечает на вопросы как и почему эти организации меняются с течением времени . Это не оценка эффективности организаций под руководством МКПГН.

Вас просят принять участие в этом исследовании. Ваше участие полностью добровольно. Если вы решите принять участие, вы можете отказаться отвечать на любые вопросы по любой причине, и вы можете прекратить свое участие в любое время.

Все усилия будут направлены на защиту конфиденциальности ваших ответов - включая установление псевдонимов (ников) для вас и для других людей и организаций, которые обсуждаются и все данные будут храниться в закрытом, защищенным паролем электронном файле.

Это исследование было рассмотрено и одобрено Центральным комитетом по университетской исследовательской этике (ЦКУИЭ) при Оксфордском университете. Если у вас есть какие-либо вопросы по поводу исследования, пожалуйста, свяжитесь со мной (tyler.spencer@dph.ox.ac.uk; +44 (0) 7869 701 548) или Комитетом по этике научных исследований в Оксфордском университете (ethics@socsci.ox.ac . Великобритания; +44 (0) 1865 614 871) .

Спасибо за ваше время и внимание.

Согласие на предмет исследования

Введение

Целью моего исследования является объяснение того, как организованы и развиваются с течением времени организации по профилактике ВИЧ/СПИДа, учрежденные молодыми людьми из ключевых пострадавших групп населения (МКПГН). Эта цель будет достигнута путем анализа качественных данных, полученных от заинтересованных сторон в области профилактики ВИЧ/СПИДа для МКПГН, в том числе углубленного исследования четырех организаций по профилактике ВИЧ / СПИДа под руководством МКПГН.

Процедура исследования

В рамках этого исследования, вам будет предложено принять участие в одной или нескольких интервью. А также, я возможно буду записывать данные, наблюдая за вами

во время рутинных организационных практик. Когда это будет приемлемо, я буду записывать интервью на диктофон, а также делать письменные заметки во время интервью или при наблюдении организационной практики .

Конфиденциальность

Записанные интервью, переведенные в текстовый вариант, а также заметки со всех наблюдений будут храниться в моем распоряжении в закрытом, защищенном паролем файле в форме электронных документов. Все усилия будут направлены на защиту конфиденциальности ваших ответов - включая установление псевдонимов (ников) для вас и для других людей и организаций, которые обсуждаются и все данные будут храниться в закрытом, защищенным паролем электронном файле.

Риски

Риски связанные с вашим участием в этом исследовании сводятся к минимуму, но могут включать в себя дискомфорт в обсуждении личных отношений и событий **.**

Преимущества

В данном исследовании может не быть никакой прямой пользы для вас, но вы можете найти для себя полезным анализ организационного развития объединений по профилактике ВИЧ / СПИДа под руководством МКПГН.

Публикация сведений

Оксфордский университет стремится распространять свои исследования на благо общества и экономики, и в связи с этим создал онлайн архив исследовательских материалов. Этот архив включает электронные копии студенческих диссертаций, успешно защищенных в рамках аспирантуры в Оксфордском университете. Онлайн архив предоставляет всем исследователям легкий доступ к полному тексту диссертаций, которые доступны без оплаты, тем самым увеличивая возможное влияние и использование этих исследований.

Если вы согласны участвовать в этом проекте, исследование будет оформлено в виде диссертации. После успешной защиты диссертации, она будет сдана на хранение как в печатном и электронном виде в архив университета, для облегчения ее использования в будущих исследованиях.

Данные этого исследования также могут быть представлены исследователем для публикации в научных журналах, и для презентация на совещаниях и конференциях. Как подробно описано выше ("Конфиденциальность"), данные будут зашифрованы во всех презентациях и публикациях**.**

Выход из исследования

Участие в этом исследовании является добровольным. Вы можете выбрать не принимать участие в нем, и вы можете прекратить свое участие в исследовании в любой момент.

Что делать, если есть проблема?

Этот проект был рассмотрен и получил разрешение по этические представлениям Центральным комитетом по университетской исследовательской этике (ЦКУИЭ) при Оксфордском университете..

Если у вас есть какие-либо вопросы или сомнения по поводу любого аспекта этого проекта, пожалуйста, обратитесь к исследователю (Тайлер Спенсер; tyler.spencer@dph.ox.ac.uk; +44 (0) 7869 701 548), который сделает все возможное чтобы ответить ваш запрос.

Если вы остаетесь недовольны и хотите подать официальную жалобу, пожалуйста, свяжитесь с Комитетом по этике научных исследований в Оксфордском университете (ethics@socsci.ox.ac.uk; +44 (0) 1865 614871; Межведомственный Комитет по этике исследований в сфере общественных и гуманитарных наук, Оксфордский университет, Hayes дом, 75 George Street, Oxford , OX1 2BQ , Великобритания).

Согласие:

Я подтверждаю, что я прочитал это согласие и доверенность и имел/а возможность задать вопросы. Я также получу подписанную копию согласия и форму авторизации.

Я согласен участвовать в данном исследовании в соответствии с условиями данного документа.

Подпись участника: _____ Дата: _____

Имя участника печатными буквами: _____

Подпись исследователя: _____ Дата: _____

Имя исследователя печатными буквами: _____