

Systemic Change in a Community-Based HIV/AIDS Organization:
A Case Study Examining the Response to Affordable Care Act Reforms

A DISSERTATION
SUBMITTED TO THE FACULTY OF
THE UNIVERSITY OF MINNESOTA
BY

MICHAEL G. LEE

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

Advisor: Jean K. Quam, Ph.D.

July, 2015

Acknowledgements

I am forever grateful to the many people who helped make this study possible. First, thank you to the Board, leadership, and staff of the Minnesota AIDS Project (MAP) for their willingness to participate and share so many valuable stories, insights, and feelings about their strategic planning process. Thank you to my committee for consistent feedback, advice, and encouragement. And finally, thank you to my wonderful and loving partner Jaxon, for staying the course with me on this long and interesting journey!

Dedication

This dissertation is dedicated to the tireless workers on the frontline of HIV/AIDS services, the grassroots movements in which these organizations were founded, and the countless numbers of people who have utilized their assistance.

Abstract

Background: The United States' HIV medical and social service systems remain "a fragile edifice with disparate parts" (Sherer, 2013, p. 133). While the Affordable Care Act (ACA) offers several opportunities, considerable uncertainty remains concerning its influence on HIV-affected populations, who face persistent socioeconomic service barriers. Since the early AIDS crisis, nonprofit HIV/AIDS service organizations ("ASOs") have provided a critical link between healthcare providers and consumers. This qualitative case study examined the systemic change experiences of a nonprofit ASO, with specific attention to technological considerations, members' identification with HIV-affected consumers, and perceptions of the organization's history and service values.

Methodology: This study aimed to examine an HIV/AIDS service organization's systemic change experiences via the perspectives of its members. Four central questions guided the investigation: 1) How do members of an HIV/AIDS service organization (i.e., Board, leadership, and staff) experience systemic change in the current policy environment? 2) What technological changes do members of the organization consider (i.e., interventions selected to carry out its mission) as they develop a strategic response to Affordable Care Act legislation? 3) To what extent does ASO members' knowledge of and/or identification with HIV-affected constituencies (e.g., gay/bisexual men, injection drug users, communities of color) influence the organization's systemic change process? 4) To what extent does ASO members' understanding of the organization's history and service values influence the organization's systemic change process? Data collection

coincided with strategic plan implementation in 2013-2014 and included analysis of 40 documents, observation of 10 implementation meetings, and semi-structured interviews with 20 Board and staff members. This study was determined to be exempt by the university's Institutional Review Board.

Results: Findings revealed ten unique themes. Members recognized an opportunity to reckon with external factors, including uncertain policy shifts and changing public perceptions. The rationale for change included both survival and positioning the organization as a sector leader and service destination. Technological considerations included defining measurable outcomes, identifying expansion opportunities, and addressing barriers to growth. Members described personal, longstanding familiarity with consumers, especially concerning stigma and marginalization. Consumers' needs were characterized as both medically and psychosocially complex. Defining organizational characteristics included nonjudgmental services tailored to consumers' needs and identities and longevity of operations. Perspectives on workplace culture were less settled concerning staff and leadership relationships, professionalism, and accountabilities. Appraisals of how to proceed included competing desires for quick, decisive action and cautious, collaborative deliberation. While most members expressed enthusiasm for the changes, some indicated waning confidence in leaders' decisions and communication, and staff departures sharply increased as the study concluded.

Significance: This study is timely and relevant for understanding how changes in the U.S. health and human service system influence services targeting historically marginalized populations. Research and practice implications include the influence of

shared historical trauma in organizational development and conceptually reframing community-level HIV suppression efforts around contributing social service factors. Social workers in this study demonstrated a continuing role for the profession in HIV services, including organizational leadership, policy advocacy, program supervision, and direct services to consumers.

Table of Contents

LIST OF TABLES.....	ix
LIST OF FIGURES.....	x
COMMONLY USED ACRONYMS.....	xi
CHAPTER 1: INTRODUCTION	1
HIV/AIDS Services in the Current Health Policy Environment.....	2
Affordable Care Act Reforms and Domestic HIV Care.....	5
Potential Limitations to ACA Reforms.....	7
The Minnesota AIDS Project (MAP)	10
Significance to Social Work Research.....	13
CHAPTER 2: HISTORY AND LEGACY OF HIV/AIDS SERVICE ORGANIZATIONS.....	14
Historical and Political Origins of HIV/AIDS Services.....	14
The Evolving Role of HIV/AIDS Service Organizations.....	18
Table 1: Evolving role of domestic ASOs.....	23
ASOs' Current Circumstances and Legacy.....	24
CHAPTER 3: THEORETICAL INFLUENCES IN HIV/AIDS ORGANIZATIONS.....	28
Organizational Theory and HIV/AIDS Services.....	28
Accounting for Complexity in Human Service Settings.....	35
Theoretical Alternatives for Human Service Systems.....	37
Organizational Change in Human Service Settings.....	40
Theoretical Significance.....	44
Figure 1: Factors influencing the systemic change process of nonprofit HIV/AIDS service organizations.....	45
Philosophical Orientation to the Research Approach.....	46
CHAPTER 4: METHODOLOGY.....	49
Orientation to the Research Design.....	49

	vii
Table 2: Logic linking data collection strategies to the research questions.	52
Sampling and Recruitment Strategies.....	54
Data Collection Procedures.....	57
Figure 2: Data collection timeline.....	58
Data Collection Site.....	63
Data Analysis.....	63
Validation Strategies.....	65
Relationship of Researcher to Informants.....	66
Methodological Limitations.....	67
Protections for Human Subjects.....	69
CHAPTER 5: RESULTS.....	71
Overview of Findings and Sample Characteristics.....	71
Table 3: Characteristics of documentary evidence.....	72
Table 4: Interview participants.....	74
Summary of MAP’s (2013) Strategic Plan.....	74
Overview of Thematic Findings.....	75
Table 5: Thematic findings.....	77
ASO Members’ Systemic Change Experiences (Part I)	78
Table 6: Summary of data sources for Research Question 1 (part I).....	78
Technological Considerations.....	89
Table 7: Summary of data sources for Research Question 2.....	89
Knowledge Of and/or Identification With HIV-Affected Populations.....	113
Table 8: Summary of data sources for Research Question 3.....	114
Organization History and Service Values.....	121
Table 9: Summary of data sources for Research Question 4.....	122
ASO Members’ Systemic Change Experiences (Part II)	133
Table 10: Summary of data sources for Research Question 1 (Part II)	134
Coda.....	141
CHAPTER 6: DISCUSSION.....	143
Theoretical Implications.....	145

	viii
Figure 3: Factors influencing the systemic change process of a nonprofit HIV/AIDS service organization (revised)	147
Organizational Theory.....	148
Implications for a Community-Based HIV/AIDS Service Organization.....	159
Applications of the Treatment Cascade.....	159
Implications for Social Work Research and Practice.....	162
 CHAPTER 7: CONCLUSION.....	 165
 REFERENCES.....	 167
 APPENDICES.....	
Appendix A: Application to University of Minnesota Institutional Review Board.....	174
Appendix B: Letters of Assent.....	207
Appendix C: Solicitation Materials.....	216
Appendix D: Informed Consent.....	221
Appendix E: Participant Demographics Form.....	224
Appendix F: Data Collection Protocols.....	226

List of Tables

Table 1: Evolving role of domestic ASOs	23
Table 2: Logic linking data collection strategies to the research questions	52
Table 3: Characteristics of documentary evidence	72
Table 4: Interview participants	74
Table 5: Thematic findings	77
Table 6: Summary of data sources for Research Question 1 (part I)	78
Table 7: Summary of data sources for Research Question 2	89
Table 8: Summary of data sources for Research Question 3	114
Table 9: Summary of data sources for Research Question 4	122
Table 10: Summary of data sources for Research Question 1 (Part II)	134

List of Figures

Figure 1: Factors influencing the systemic change process of nonprofit HIV/AIDS service organizations	45
Figure 2: Data collection timeline	58
Figure 3: Factors influencing the systemic change process of nonprofit HIV/AIDS service organizations (revised)	147

Commonly Used Acronyms

Acronym	Definition
ACA	Patient Protection & Affordable Care Act, aka “Affordable Care Act” of 2010
ADAP	AIDS Drug Assistance Program. Federally funded support for HIV medication procurement, administered through the states.
AIDS	Acquired Immune Deficiency Syndrome. A medical diagnosis characterized as acute HIV, when the immune system has weakened substantially and/or at least one opportunistic infection has been detected.
ASO	HIV/AIDS Service Organization (aka “AIDS Service Organization”)
CPG	Community Planning Group. A federally mandated jurisdictional advisory group that provides input and oversight for state and territorial decisions concerning HIV funding allocations and services. By federal regulations the CPG must include proportional representation by people living with HIV.
HAART	Highly Active Antiretroviral Therapies. A combination of medications used to suppress HIV and reduce its harmful effects on an individual’s immune system.
HHS	U.S. Department of Health & Human Services
HIV	Human Immunodeficiency Syndrome. A medical diagnosis characterized by the presence of a specific antibody in a sample of blood or mucosal fluid.
HOPWA	Housing Opportunities for People With AIDS. Federally funded housing assistance for people living with HIV, administered by the Department of Housing & Urban Development through state and local agencies.
HUD	U.S. Department of Housing & Urban Development
MAP	The Minnesota AIDS Project
NHAS	National HIV/AIDS Strategy of the United States
ONAP	White House Office of National AIDS Policy
PLWH	People Living With HIV
PWA	People With AIDS. A term used more commonly during the self-empowerment movements of the early AIDS crisis.

Chapter 1: Introduction

This qualitative case study examined how members of a nonprofit, community-based HIV/AIDS service organization (ASO) experienced systemic, organizational change in response to the federal government's Patient Protection and Affordable Care Act (aka "Affordable Care Act" or ACA). The study involved a single subject, the Minnesota AIDS Project (MAP) of Minneapolis, MN, as represented by its employees and governing board members via documentation, meeting observations, and semi-structured interviews. The Minnesota AIDS Project was founded in 1983 and has operated continuously to the present time (MAP, 2015). A central concern of this study addressed how MAP's grassroots origins, as an organization founded during the early AIDS crisis by gay activists, would influence its members' experiences with organizational change by identifying the key values, technical responsibilities, and service features that distinguish HIV/AIDS services from other health-care related settings. Its findings contribute to the following bodies of knowledge: organizational policy and practice in the health and human services; HIV/AIDS service provision; public health; and social services that have arisen from social movements such as lesbian, gay, bisexual, and transgender (LGBT) communities.

The investigation utilized the following approaches to collect and analyze data concerning the subject: 1) analysis of organizational documents pertaining to MAP's 2013 strategic planning process (e.g., by state and federal policy, practices adopted by similar organizations, published research, staff and/or consumer input, local needs assessments, etc.); 2) observations of organizational meetings that explicitly addressed

implementation of the strategic plan between September 2013 and August 2014; and 3) oral interviews with MAP employees and governing board members between January and September 2014.

HIV/AIDS Services in the Current Health Policy Environment

The circumstances in which HIV/AIDS service organizations operate reflect challenges associated with the prevalence and incidence of domestic HIV cases, along with the myriad of governmental institutions charged with addressing the ongoing epidemic. The Centers for Disease Control and Prevention (CDC) presently estimates 1.2 million Americans living with HIV, with annual infection rates of roughly 50,000 new cases per year (CDC, 2015). While early detection and treatment are recognized to greatly reduce harmful health outcomes as well as infectiousness to others (Sherer, 2013), CDC (2012) calculates that currently only about one-quarter of people living with HIV in the U.S. have suppressed their virus, with disparities especially noted among younger populations (ages 13 – 24) and communities of color.

Current strategies for control and containment of HIV. Examining the potential impact of Affordable Care Act legislation on HIV-related medical care, Crowley and Kates (2012) note that among Americans who are estimated to be living with the virus, 82% have actually received an HIV-positive diagnosis, about two-thirds (66%) have been linked to medical care, while only 37% have been retained in care. Once retained, approximately 89% of this group receives anti-retroviral therapy. From this percentage, approximately 76% are able to suppress the virus. Thus, in the current

health system HIV treatment benefits only the small number of HIV-positive persons who can actually achieve retention in medical care.

Federal policy as outlined in the National HIV/AIDS Strategy (2010) aims to address these shortcomings by adopting a multi-faceted approach, which emphasizes the following key elements: 1) Expanding HIV testing to increase the percentage of HIV-positive individuals who are aware of their infection; 2) Increasing rates of linkage (i.e., clinical follow-up) from screening to medical care when individuals are diagnosed HIV-positive; 3) Increasing the percentage of HIV-positive individuals who are retained in long-term care; 4) Offering intensive risk reduction interventions that encourage behavior change among those living with HIV; 5) Reducing viral load through anti-retroviral therapy to suppress patients' HIV levels; and 6) Using behavioral interventions to maintain long-term adherence to anti-retroviral medications (Kilmarx & Mermin, 2012). Key to this long-term strategy, however, remains the challenge of increasing healthcare utilization among populations living with or at highest risk for contracting HIV.

Coverage of HIV care in the United States. The current system for HIV-related medical and social services in the U.S. remains, in the words of Sherer (2013), "a fragile edifice with disparate parts" (p. 133). Medicaid serves as the largest provider of health insurance for HIV-positive persons, with 42% receiving coverage compared to 13% who hold private insurance (Crowley & Kates, 2012). The Ryan White Care Act, which offers funding of last resort for uninsured individuals living with HIV, accounts for 24% of the HIV-positive population, while Medicare-eligible individuals (age 65 or older, or under age 65 and disabled) comprise 12% of this population. The potential for gaps in coverage

remains especially perilous for uninsured Americans living with HIV. As Crowley and Kates (2012) note, even Ryan White coverage is not intended to serve as insurance, as its funding levels are subject to Congressional discretion. In fact throughout their history, Ryan White and the federally funded AIDS Drug Assistance Program (ADAP) have maintained waiting lists because the number of HIV-positive individuals needing assistance has consistently outpaced the resources available to serve this population (Crowley & Kates, 2012).

With respect to preventive care for HIV-negative individuals, the federal government acknowledges that resources are relatively limited compared to the number of people who are potentially at risk for infection (Office of National AIDS Policy [ONAP], 2010). The current national strategy emphasizes increasing public funding to support HIV testing and evidence-based behavioral interventions within high-risk populations, as well as increasing operational research to develop new behavioral, pharmaceutical, and microbial approaches for inhibiting the transmission of the virus between HIV-positive and HIV-negative individuals. Whereas Ryan White and ADAP legislation support the health care needs of people diagnosed with HIV, public funding for preventive services flows largely through the CDC, which in 2012 administered more than \$555 million in resources both through allocations to state and local municipalities, as well as direct funding to community-based organizations (CDC, 2013). Additionally, HIV-related programming is administered through other parts of the federal bureaucracy such as the Substance Abuse and Mental Health Services Administration (SAMHSA) and

Housing Opportunities for People Living With AIDS (HOPWA), which is located in the Department of Housing and Urban Development (HUD).

Affordable Care Act Reforms and Domestic HIV Care

The Affordable Care Act's stated goal is to ensure "quality, affordable health care for all Americans" (U.S. Department of Health & Human Services, 2012). By shoring up existing public and private sector mechanisms, the legislation presumes that the federal government will be able to contain costs for individuals who purchase insurance from the private sector while reducing the cost burdens associated with treating low-income citizens. To accomplish this goal, the law introduces individual and group insurance plan reforms, ending exclusions for pre-existing conditions and lifetime caps while providing tax incentives both for employers, and for individuals not covered by an employer-based health plan (Kaiser Family Foundation, 2011). State-level insurance exchanges aim to lower purchasing costs for individual consumers by increasing competition among health plans, while an expansion of both Medicaid eligibility criteria and low-cost community health centers will be key for making primary care available to more low-income citizens (Gusmano, Fairbrother, & Park, 2002; Kaiser Family Foundation, 2011; Sommers & Epstein, 2010). Finally, the legislation aims to reduce the number and severity of future chronic illnesses (and their associated costs) by limiting new health plans' ability to impose costs on routine preventive care services (Koh & Sebelius, 2010).

To help educate HIV service providers on opportunities provided by ACA legislation, a consortium of national and regional provider organizations, policy and research centers, and technical assistance providers developed HIV Health Reform, a web site devoted to sharing information with the field via webinars, blogs, and electronic newsletters (HIV Health Reform, 2015). With respect to HIV/AIDS services, the ACA is presumed to offer opportunities in the following key areas: 1) Expansion of Medicaid eligibility for childless adults with incomes up to 138% of the federal poverty level; 2) Medicare prescription drug coverage reforms, including recognition of ADAP spending as an out-of-pocket expenditure; 3) Expanded protections for individuals with pre-existing conditions (including HIV) in the private insurance market; 4) Increased public spending on prevention and wellness initiatives, including free screenings; and 5) Expansion of dependent coverage for adult children up to age 26 (Crowley & Kates, 2012). Given Medicaid's prominent role in providing health insurance for a majority of HIV-positive people, its expansion may potentially benefit those low-income individuals who were previously ineligible, yet faced severe cost burdens due to having a previously-existing condition and the prohibitive expense of HIV medications. Similarly, reforms to prescription drug coverage in Medicare as well as private sector reforms may help to boost health care utilization among HIV-positive persons who do not use Medicaid, and the expansion of coverage for adult children age 26 and younger may fill a critical gap within a population that experiences substantial disparities in HIV care retention (Crowley & Kates, 2012).

Additionally, the ACA may offer an opportunity for HIV/AIDS service organizations to expand their capacity through its emphasis on community health centers (Martin & Shackman, 2012), which are intended to increase access to primary care for low-income populations who lack the financial means to purchase health insurance (Gusmano, Fairbrother, & Park, 2002; Sommers & Epstein, 2010). The Department of Health and Human Services' Healthy People 2020 web site mentions several efforts intended to reduce sexual minority health disparities including dissemination of interventions to prevent HIV infection, increased sensitivity to sexual minority issues among health care and social service providers, and establishment of health centers to address sexual minority community needs (2012). In this specific arena, ACA may provide an opportunity for lesbian, gay, bisexual, and transgender (LGBT) community services to establish and/or expand clinical programs that work to diminish stigma among their recipients, while also increasing these populations' capacities for educating and training LGBT-affirming professionals who more effectively understand the needs of their population members.

Potential Limitations to ACA Reforms

As outlined above, the Affordable Care Act aims to increase Americans' utilization of medical services through market reforms, an expansion of Medicaid eligibility for Americans below the poverty line, and tax subsidies to support individuals purchasing their own private health insurance. However, because ACA legislation largely addresses economic factors and sidesteps the issue of explicitly guaranteeing all citizens'

rights to health and welfare, the minority populations overrepresented in domestic HIV cases must still combat social discrimination and stigma that may represent powerful barriers to health care utilization.

Social barriers to health care utilization. The ACA's ability to increase health care access for all citizens (including populations disproportionately impacted by HIV) may be adversely influenced by a number of social and economic factors. Stigma and perceived discrimination, which have been found to negatively impact a broad range of health behaviors (Pascoe & Richman, 2009), may represent an especially powerful barrier for individuals who experience various forms of anti-gay bias, including employment discrimination, housing discrimination, and hate crime violence (Herek, 1991; Herek, 2009). Gay and bisexual men, who have borne a disproportionate amount of the HIV/AIDS epidemic in the United States since the early 1980s, have been overrepresented in a number of other health risk categories including chemical dependency, untreated depression and anxiety, mental illness, and tobacco use (Greenwood et al., 2005; Stall et al., 2003). Among sexual minority youth, these negative consequences have been associated with family rejection, which may also increase their risk for other poor outcomes including suicide, incarceration, and homelessness (Ryan, Huebner, Diaz, & Sanchez, 2009).

Additionally, employer-based insurance may prove more elusive when social discrimination influences an individual's ability to participate in the wage labor market. Previous studies have found evidence of bias against gay men in the employment pre-screening process (Tilcsik, 2011), income gaps between sexual minority males and

heterosexual men (Badgett, 1995), and disproportionately higher levels of poverty among sexual minority adults, same-sex couples, and children of same-sex couples (Albelda, Badgett, Schneebaum, & Gates, 2009). Finally, although the expansion of dependent coverage for adult children may benefit younger populations experiencing higher levels of new HIV infections, sexual minority youth who face rejection from their families may not be able to directly benefit from this provision.

Coverage gaps between Medicaid and Ryan White. As previously noted, Medicaid remains the largest provider of insurance coverage for people living with HIV, while Ryan White funding provides a stopgap to pay for uninsured individuals who would not otherwise qualify for publicly subsidized insurance. Its expansion under the ACA may help to provide public insurance for previously ineligible, low-income individuals; however, the Supreme Court ruled in 2012 that the decision to expand Medicaid eligibility remains in the purview of each state (Crowley & Kates, 2012). This decision may in fact create a great deal of uncertainty with respect to the ACA's impact on HIV care. Differences in rules from state to state may create "coverage gaps" among those unable to qualify for Medicaid who cannot afford to purchase their own health insurance even with the support of ACA's new tax subsidies (Crowley & Kates, 2012). Additionally, the implications of transitioning individuals from Ryan White services to Medicaid introduces uncertainty with respect to other essential services such as medical case management, dental care, mental health, and outpatient care, which are covered by the former but not the latter (Minnesota AIDS Project [MAP], 2012 - a). Finally, the ACA excludes undocumented immigrants from key portions of the law, which may

compound some HIV-positive individuals' difficulties with receiving medical care and other essential services, while paperwork requirements and high premium costs may deter those HIV patients who already experience high levels of social service needs (Martin & Shackman, 2012). These limitations raise the possibility that a number of HIV-positive individuals, as well as those with higher risks for becoming infected, may fall through the cracks in this emerging network of care coverage (Martin & Shackman, 2012). To understand how an ASO's response to these concerns is manifested in practice, this chapter will conclude with a brief examination of the organization examined in this study.

The Minnesota AIDS Project (MAP)

The following description is derived from a number of information sources, including the organization's web site, official documents (e.g., annual reports and newsletters), and direct knowledge gained by the investigator during his more than 10 years of involvement with the organization as an employee, grant writing consultant, and research partner. The Minnesota AIDS Project began in 1983 as Minnesota's first ASO when a small group of gay men affected by HIV founded the organization (MAP, 2015-a). At that time, MAP assisted those living with AIDS through the provision of practical direct services and assistance, delivered initially by volunteers. In addition, MAP developed its capacity for public advocacy on behalf of people living with AIDS, both through educating the general public and through advocacy with the state's legislature. Over time, MAP has adapted its prevention and care efforts to meet the changing needs of people living with HIV, with a gradual reduction in end-of-life and home-based

assistance and greater emphasis on prevention education, early detection of HIV, and stronger linkages between medical care and social services for HIV-positive individuals. Its stated mission is to lead Minnesota's fight to stop HIV through prevention, advocacy, awareness, and services (MAP, 2015-a).

An organization of more than 50 employees, MAP is structured into different operational divisions of varying sizes, based on the technical responsibilities of its employees. The organization is governed by a board consisting of 18 community members, employs a volunteer base of over 1,000 people, and annually provides services to more than 3,500 Minnesotans living with HIV (MAP, 2015-a).

Current services. MAP presently administers a range of social services addressing HIV prevention, early detection, and linkages to medical care. The agency oversees Minnesota's statewide, toll-free telephone and online service for information and referral (the MAP AIDSLine), which maintains a comprehensive directory of HIV prevention and care services covering the entire state. AIDSLine staff also administers initial consultations with newly diagnosed persons, addressing short-term medical or emotional needs related to HIV while helping individuals establish access to ongoing services (MAP, 2015).

Annually, MAP provides a comprehensive range of social services for approximately half of people living with HIV in Minnesota (MAP, 2015). This includes benefits counseling, emergency financial assistance, direct legal representation and brief consultation, transitional housing, transportation for medical appointments and food shelf/grocery deliveries, and case management. Its HIV prevention initiatives include

outreach and testing, syringe exchange, and behavioral interventions targeting those at highest risk including men who have sex with men; individuals who experience chemical dependency issues including injection drug use; and HIV-positive gay and bisexual men. In 2013, funding from government contracts accounted for \$3.7 million of MAP's \$4.4 million in revenue (84%), with private contributions and other revenues accounting for the remaining portion (MAP, 2014).

Representativeness of the case. MAP offered an especially suitable case for this study owing to the following key attributes: 1) its origins in the local gay community's response to AIDS in the early 1980s; 2) its continuous operation as an HIV/AIDS service organization from that time to the present; 3) its provision of multiple government-funded social services for HIV-positive and high-risk populations over several years and across multiple funding periods; and 4) its efforts to reconfigure its mission and services to match the stated outcomes of the ACA and National HIV/AIDS Strategy (MAP, 2014).

MAP was also unique among ASOs nationally due to the state of Minnesota's position as the first state to proceed with full implementation of the law (i.e., expansion of Medicaid, development of an online insurance exchange, and assembly of a basic health program) (Richert, 2013). Thus, this case depicts the rare example of a community-based service provider operating in an environment in which all conditions presumably favored full implementation of national policy as it was intended. To understand the larger context in which members of an ASO experience systemic change, the chapters to follow will address their historic development and legacy, and situate their current circumstances within the larger body of organizational theory.

Significance to Social Work Research

Since domestic HIV's earliest years, social workers have contributed to understanding and confronting the epidemic's many pressing problems, including challenges to the profession's HIV/AIDS workforce. At the scholarly level, these efforts have included identifying occupational stress and burnout prevention strategies for HIV care providers (Ross, 1993), specifying areas for expanded education and training in the post-HAART era (Strug, Grube, & Beckerman, 2002), and identifying barriers to care among populations historically underrepresented in behavioral research (Cavaleri et al., 2010). Social work researchers have identified unique sociocultural needs related to prevention and screening among underserved HIV-affected communities (Auerbach & Beckerman, 2010), addressed HIV stigma in women at midlife (Jacobs & Kane, 2010), and called out stigmatizing attitudes and behaviors within the HIV/AIDS provider workforce (Rutledge et al., 2011). In the present era of Affordable Care Act reforms, social work scholarship has continued to advocate for interdisciplinary models of practice that incorporate context into engagement strategies with HIV-affected populations (Wheeler, 2011). This study contributes to a rich body of research that has documented and clarified how social workers continue to contribute to community-based HIV/AIDS service organizations' efforts, with implications for reframing organizational theory and practice considerations around present-day circumstances.

Chapter 2: History and Legacy Of HIV/AIDS Service Organizations

The discovery of HIV/AIDS in the early 1980s precipitated wide-ranging changes to health and human services in the United States, the impact of which continues to influence health care delivery, social policy, and grassroots community organizing. Writing in commemoration of the epidemic's twenty-fifth anniversary, author David Jefferson (2006) argues that the early responses to AIDS shaped patient activism and awareness efforts in a number of other health-related causes-- for example, yellow bracelets supporting cancer research and pink ribbons promoting breast cancer awareness, emulating the success of red ribbon AIDS awareness campaigns. With respect to the American health care establishment, he also attributes changes in the federal government's responses to other threats, such as avian flu or SARS, to lessons learned from HIV/AIDS including more rapid development and dissemination of pharmaceutical therapies to prevent or slow down the progression of viral agents. Founded in the early 1980s by gay activists in large urban centers, community-based nonprofit HIV/AIDS service organizations (ASOs) became an essential component of the response to HIV and continue to operate in many U.S. cities at the present time (Andriote, 2011).

Historical and Political Origins of HIV/AIDS Services

The history of HIV/AIDS service organizations can be found in a variety of collections concerning gay and lesbian social movements, administrative records, personal documents, individual interviews, and news articles from communities across

the U.S. The sources utilized in this brief review draw primarily from existing publications, including federal briefs, research articles, and the historical accounts of authors Randy Shilts (1987) and James Gillett (2011). Shilts' bestselling work, *And the Band Played On: Politics, People, and the AIDS Epidemic*, remains widely recognized for depicting a perfect storm of converging ideologies, flawed assumptions on the part of public officials and medical researchers, and competing social movements that enabled HIV to spread widely, rapidly, and unchecked during the early 1980s. Gillett's more recent work, *A Grassroots History of the HIV/AIDS Epidemic in North America*, situates the domestic response to HIV in the self-empowerment movement that galvanized early AIDS activists to become informed decision makers in their own health care. This unique synthesis, he argues, continues to influence health care policy in various ways today.

Both of these sources offer guidance for linking the origins of HIV/AIDS policy to current circumstances. Shilts' account chronicles the early absence of direct federal responsiveness, yet concludes before several noteworthy policies were enacted in response to AIDS, including the Ryan White Care Act and inclusion of HIV status in the Americans With Disabilities Act, and well before medical breakthroughs such as highly active antiretroviral therapies (HAART). Gillett's analysis builds on this historic account and connects the initial response to HIV/AIDS with subsequent advancements, struggles, and conflicts in the public policy arena.

Initial recognition and medical responses to AIDS. Although HIV had already begun to spread among gay men and injection drug users, recognition of its presence by the Centers for Disease Control and Prevention (CDC) began quietly in June 1981, when

the *CDC Morbidity and Mortality Weekly Report (MMWR)* published a brief article noting unusual occurrences of *Pneumocystis carinii* pneumonia (PCP) among a small number of homosexual men who were unknown to each other and shared no known contacts (CDC, 2006; Shilts, 1987). Although it was initially dubbed “gay cancer” or “Gay-Related Immune Deficiency,” by mid-1982 the symptoms of severe immune depression, as indicated by the presence of rare illnesses such as PCP and Kaposi’s Sarcoma, were recognized among other populations including heterosexual injection drug users, blood transplant recipients, Haitian refugees, and hemophiliacs, leading to the adoption of AIDS (Acquired Immune Deficiency Syndrome) as the official diagnosis for a fatal illness whose origins at the time remained unknown (CDC, 2006; Gillett, 2011; Shilts, 1987).

By the middle of the 1980s, scientists had isolated the causal agent of the illness, a retrovirus that would eventually be named Human Immunodeficiency Virus (HIV) and which for the first time opened the possibility of developing antibody testing to measure the extent of its presence in the general population (CDC, 2006; Shilts, 1987). In 1987, CDC released its first guidelines for antibody screening, recommending routine counseling and testing for all individuals seeking treatment for sexually transmitted infections (STI), those with a history of injection drug use, anyone who believed themselves at risk for HIV infection, women of childbearing age with known risks for infection, prisoners, couples considering marriage, and sex workers (CDC, 2006). Through the early 1990s, prognoses for individuals infected with HIV remained bleak, despite attempts to move a number of medications to market. With respect to this period,

CDC (2006) reports, “From 1981 through 1996, a total of 573,800 persons with AIDS who were 13 years and older were reported to CDC by state and local health departments” (p. 5). By 1995, HIV infection would represent the leading cause of death for individuals aged 25 – 44 years, representing approximately 19% of all cases. Approximately 85% of AIDS cases were reported among males, with 47% of cases occurring among Caucasians, 35% among Black individuals, and 18% among Hispanic people (CDC, 2006).

In the mid-1990s, a number of breakthroughs in medical science and health care policy indicated promising movement toward stemming the epidemic. Most significantly, the introduction of highly active anti-retroviral therapies (HAART) provided new opportunities for attacking the virus, slowing down its replication in the body while helping the immune system to regain its capacity to fight off opportunistic infections and enabling HIV-negative individuals to substantially reduce their chances for infection through daily prophylaxis (CDC, 2014; Cohen, 2011; Gillett, 2011; ONAP 2010). Additionally, changes in HIV testing technologies increased the availability of screening for the general population (CDC, 2006) and enabled health providers to detect infections and begin treatment before patients’ immune systems weakened. Beginning in the late 1990s, an increasing emphasis on evidence-based prevention education for those living with HIV represented a shift in thinking away from a strictly care-focused orientation, toward recognition that as HIV-positive persons sustain longer and more active lives, the opportunity to transmit the virus to HIV-negative individuals may increase as well (CDC, 2006; Gillett, 2011).

Beginning in the early 2000s, the domestic epidemic's third decade saw a number of key medical advancements, combined with persistent epidemiological challenges that continue to influence disparate outcomes between the populations most affected by HIV and the larger society. Over this period, continuing innovations in HIV therapies have shown success with not only slowing the progress of the virus, but also preventing new infections by keeping individuals' viral load at low, potentially undetectable levels (Cohen, 2011; ONAP, 2010). At the same time, Marks (2006) and colleagues estimate that the risk of disease transmission by those unaware of their HIV-positive status, who represent approximately 25% of those living with the virus, is 3.5 times higher than transmission from those aware of their infection and receiving medical care. Given the virus' persistently disproportionate prevalence among sexual minority males, who are believed to represent 2% of the population but more than 50% of annual infections (CDC, 2010), providers' ability to reach and substantively engage with those at highest risk for infection may continue to be hampered by sexual minorities' experiences of stigma and socioeconomic discrimination (Herek, 1991; Herek, 2009). These challenges may also be compounded by gay and bisexual men's overrepresentation in a number of health risk categories including chemical dependency, untreated depression and anxiety, mental illness, and tobacco use (Greenwood et al., 2005; Stall et al., 2003).

The Evolving Role of HIV/AIDS Service Organizations

As domestic responses to HIV/AIDS have changed over thirty years, the role of ASOs within the larger matrix of American health care systems has changed as well.

Beginning with the availability of HIV antibody testing and passage of the Ryan White Care Act through the mid-1990s when the introduction of highly active anti-retroviral therapies (HAART) altered the trajectory of HIV infection from a likely terminal to long-term chronic illness, ASOs experienced critical shifts in mission toward an emphasis on supporting medication adherence, early testing and entry into care systems, and prevention education tailored for both HIV-negative and HIV-positive constituencies (CDC, 2006; Gillett, 2011). The history of HIV/AIDS services over the past three decades therefore depicts an evolving process in which these organizations have attempted to associate their technical operations and continued relevance with the values associated with their origins, which emphasize nonjudgmental, compassionate care, often delivered by members of clients' own peer groups (e.g., HIV-positive staff, gay and lesbian workers, former substance users, etc.) (Andriote, 2011).

ASO “identity crises.” Reflecting on these experiences, journalist and author John-Miguel Andriote (2011) identifies five “identity crises” through which ASOs have struggled to define their identity and mission. First, in the epidemic's earliest years, organizations dealt with defining their purpose, specifically concerning whether to simply provide services to AIDS patients or to engage in direct political advocacy as well. The first community-based HIV/AIDS organization was founded in New York City by author and activist Larry Kramer, who organized the initial meetings and fundraising efforts of what would become Gay Men's Help Crisis (Jefferson, 2006; Shilts, 1987). Growing out of volunteers' efforts to care for friends and loved ones, a pattern of services would emerge that included in-home care during severe bouts of illness, accompanying and

advocating for AIDS patients at local hospitals, providing emotional support via telephone hotlines, and raising awareness to the larger gay community using what little information that was available. Noting that similar organizations emerged in cities around the United States, Jefferson (2006) observes that ASOs became rapid responders to a wide range of patient needs, including direct medical care, food, housing, and counseling.

Andriote (2011) characterizes the second identity crisis in the 1980s as a struggle involving ASO professionalization, as services formerly provided by volunteers became part of an integrated matrix of programs administered by paid, increasingly credentialed health specialists, including social workers, nurses, and other members of the human service workforce. This period, Gillett (2011) notes, is distinguished in part by the growing frustration of early AIDS activists, many of whom helped to found ASOs on principles of self-help and self-representation and who felt that HIV/AIDS services were becoming increasingly bureaucratized. The expansion and formalizing of these services, he notes, coincided with a broader cultural movement that mainstreamed public attitudes toward people living with HIV (PLWH) and HIV/AIDS services, contributing to the development of stable, government-subsidized models of service provision that in many ways contradicted the aims of the grassroots movement in which they were founded. At the same time, the PLWH movement's insistence on having a voice in their own health care practice and policymaking gained a measure of lasting influence in the form of community planning groups (CPG), state-level advisory bodies mandated by the federal government to ensure broad-based participation in service planning by requiring membership to include HIV-positive persons and members of the populations most

affected as well as the medical and social service providers who work with them (CDC, 2003).

The early 1990s brought the advent of Ryan White Care Act funding, a period Andriote (2011) recognizes as ASOs' third identity crisis as organizations struggled to integrate substantial new federal funding. By this time, the burgeoning network of AIDS organizations had become an essential component of the nation's response to HIV, relying heavily on government funding, but operating as private, non-governmental services (Gillett, 2011). Because legislation included a number of stipulations distancing ASOs from their identification with the gay communities in which they originated, Andriote (2011) notes a splintering effect in some large cities where dissatisfied sub-populations carved out organizations of their own, presumably to meet the needs of groups they felt were slighted by agencies serving a largely white, gay male clientele.

The emergence of highly active antiretroviral therapies (HAART) in the mid-1990s changed the HIV prognosis from terminal to a chronic and manageable illness. Although universally recognized as a significant pharmaceutical breakthrough, this development rendered many of ASOs' end-of-life services obsolete as organizations struggled to discern their relevance within the larger health and human service context (Andriote, 2011; Gillett, 2011). This fourth crisis, Andriote (2011) notes, also marked a shift in gay community philanthropy as donors and volunteers began to focus their donations on other issues. Examining this period and the decade that followed, Gillett (2011) depicts an increasingly global focus among HIV activists, with growing recognition of a worldwide need for not only medical solutions, but also for remedies to

the fragile social and economic circumstances contributing to heightened risk for HIV's most vulnerable populations. During these years, efforts both domestically and abroad reflected an increasingly permanent commitment by the U.S. government to underwrite and oversee the technical delivery of HIV-related services, as evidenced by the National HIV/AIDS Strategy for the United States (ONAP, 2010).

Observing that some advocates during the early AIDS crisis predicted the eventual "mainstreaming" of HIV/AIDS service organizations, Andriote (2011) frames this latest, fifth ASO identity crisis by simply asking, "Has this time arrived?" (p. 22) He notes that a number of technical services offered by ASOs (e.g., case management, benefits counseling, preventive care, individual and group counseling, etc.) can be efficiently delivered by mainstream health and social service institutions. In combination with HAART, these offerings can greatly reduce the most adverse effects of HIV infection while diminishing the individual's likelihood of transmitting the virus to others (ONAP, 2010; Sherer, 2013). Yet, Andriote (2011) observes, the populations most affected by domestic HIV still disproportionately include gay and bisexual men, increasingly from communities of color and lower socioeconomic status, who face a number of barriers to health care access and risk falling through the cracks in mainstream service systems.

Table 1: Evolving role of domestic ASOs

Era & Characteristics	Role / Relevance of ASOs
<p style="text-align: center;">1981 – 1985</p> <ul style="list-style-type: none"> - Lack of information or awareness - Widespread deaths among gay men, injection drug users, transfusion recipients - Unresponsive federal government 	<ul style="list-style-type: none"> - End of life support - Advocacy in hospitals and clinics - Information and emotional support for patients
<p style="text-align: center;">1985 – 1989</p> <ul style="list-style-type: none"> - Discovery of HIV and causal behaviors - Development of antibody testing - Increasing death toll - Prevention education campaigns emerge - 	<ul style="list-style-type: none"> - Increasing professionalization - Linking patients to medical care - In-home supports - Legal and political advocacy
<p style="text-align: center;">1990 – 1995</p> <ul style="list-style-type: none"> - Ryan White Care Act & ADAP legislation - Substantial new funding for HIV/AIDS care - “De-gaying” of ASOs due to Congressional funding rules 	<ul style="list-style-type: none"> - Splintering of services among population groups - Emphasis on safer sex and HIV testing - Formalized case management and related social services
<p style="text-align: center;">1996 – 2000</p> <ul style="list-style-type: none"> - Introduction of HAART - Dramatic reversal in AIDS-related deaths and long-term health of PLWH - Increasing attention to disproportionate HIV in communities of color, especially women 	<ul style="list-style-type: none"> - Drawing down of end-of-life services - Emphasis on early detection and medication adherence - Introduction of effective behavioral interventions to prevent new infections
<p style="text-align: center;">2001 – 2009</p> <ul style="list-style-type: none"> - Recognition of high costs and substantial side effects of HAART - Increasing new HIV cases among gay/bisexual men, especially younger and communities of color - Increasing evidence of HAART as preventive measure 	<ul style="list-style-type: none"> - Emphasis on long-term retention in medical care, linkages to other support services (e.g., housing, mental health, substance abuse treatment) - Continued adoption and refinement of behavioral interventions in HIV prevention
<p style="text-align: center;">2010 – Present</p> <ul style="list-style-type: none"> - Passage of ACA - Adoption of National HIV/AIDS Strategy - Increasing focus on testing and medical treatment as a primary prevention approach - Introduction of pre-exposure prophylaxis 	<ul style="list-style-type: none"> - Emphasis on increasing HIV testing among HIV-positive who are unaware - Focus on collaboration and consolidation of services with similar health service providers

for HIV-negative individuals

- Re-evaluation of mission, function, and funding in light of ACA

ASOs' Current Circumstances and Legacy

Since 2010, two changes in federal health care policy have served as guideposts for transformation in HIV/AIDS health care delivery, for which ASOs continue to offer a critical linkage between service consumers and the institutions charged with meeting their often complex medical and psychosocial needs. First, Congress in 2010 enacted the Affordable Care Act, a voluminous set of reforms intended to increase Americans' access to affordable health care through private sector reforms, expansion of Medicaid, and tax incentives to support the private insurance market (Kaiser Family Foundation, 2011). Second, in that same year the White House Office of National AIDS Policy (ONAP) released its National HIV/AIDS Strategy for the United States, an executive document aligning all federal and state efforts within a unified set of common long-term objectives for drawing down and eventually ending the domestic epidemic. For community-based ASOs, this era has offered both challenges and opportunities for realigning their operations to match these historic national goals.

A limited body of knowledge exists to guide ASOs on how they might continue to operate within this policy context. It may be argued that the mainstreaming of ASOs into the larger continuum of health and human services has already occurred and thus would render their current change processes undistinguishable from other human service organizations. However, several factors may influence this process in ways that organizational theory may not anticipate. First, the emphasis on service consumers'

involvement in formally planning and carrying out HIV/AIDS service policy provides institutional space within the public bureaucracy for voicing and acting upon the concerns of PLWH themselves. Second, the persistent presence of HIV in disproportionate levels among gay and bisexual men may contribute to a continuing sense of close identification between service users and providers, who may closely identify either with the minority communities served by ASOs or may be living with HIV themselves (Dodd & Meezan, 2003). Third, the visibility ASOs brought to sexual minority communities may contribute to their representation as professional footholds for LGBTQ and HIV-positive social workers and medical providers, who may feel especially protective of programs and/or consumers who have historically been judged negatively by mainstream society (Dodd & Meezan, 2003).

One legacy of the domestic response to HIV/AIDS, Andriote observes, is “the model of compassionate, culturally relevant, holistic health care and social services created and practiced by AIDS service organizations,” (p. 23) which has influenced American approaches to health care and philanthropy in a number of other settings (Andriote, 2011; Jefferson, 2006). To that end, he identifies two possible ways for ASOs to maintain their relevance in the current health care environment. On one hand, he described a *vertical* option, by which HIV/AIDS services have consolidated into a single or small number of ASOs that coordinate their efforts closely with the local health department. By necessity, he notes, urban ASOs needed to establish a comprehensive range of services available in one organizational setting, the concentration of which may continue to narrow. Alternatively, the *horizontal* option offers ASOs the opportunity to

build on the success of HIV/AIDS service models by expanding their focus to include populations affected by other chronic illnesses. Describing the experiences of Food and Friends, a Washington, D.C. ASO that expanded its mission in this way, Andriote notes that the approach has sustained the organization while fulfilling a gaping service need in the District's largely underserved populations.

Both Andriote (2011) and Jefferson (2006) describe ways in which ASOs' values for compassionate, nonjudgmental care have influenced other aspects of the American health care system. Yet at the same time, many technical functions of an ASO may appear redundant with the expansion of health care access via Affordable Care Act legislation and the availability of comparable services within mainstream health care systems. With respect to relevance, Andriote argues that ASOs may in fact be essential for delivering health and social services to populations who experience the most severe levels of marginalization, especially within communities of sexual minority men of color.

Given the historical origins of HIV/AIDS service organizations in the context of a domestic epidemic that has disproportionately impacted gay men, ethnic minorities, and drug-using populations (CDC, 2006), the current policy environment raises questions about the role of community-based HIV/AIDS services in the emerging health care arena including: In what ways can an HIV/AIDS service organization maintain its relevance within the larger continuum of health care services? To what extent do the origins and identification of an ASO with its constituent communities influence its experiences with present-day systemic change? These historical and political circumstances, which have influenced the development and characteristics of HIV/AIDS service delivery, will guide

the examination of organizational theory and its specific relevance to these health and human service organizations in the chapter to follow.

Chapter 3: Theoretical Influences In HIV/AIDS Service Organizations

While community-based ASOs came to embody a set of values drawing from gay liberation movements' emphases of empowerment and inclusion, in a practical sense their founding and long-term survival depended on the adoption of organizational policies and practices that would meet the standards of existing funding bureaucracies (Andriote, 2011; Dodd & Meezan, 2003; Gillett, 2011). Thus, the focus of this chapter begins with an examination of organizational theory's bureaucratic origins, with attention paid to the ways in which it has evolved to account for variations within human service and other settings where institutional "output" is conceptualized in terms of human health outcomes.

Organizational Theory and HIV/AIDS Services

As an entry point for understanding the underlying formation and survival processes of HIV/AIDS service organizations, classic organizational models developed by Weber (1947), Parsons (1960), and Katz (1978) provide useful constructs for understanding the founding of bureaucratic structures as an outgrowth of social action. At the same time, while noting that human service organizations generally develop using a bureaucratic model, Hasenfeld (2009) and others have applied a number of alternative theories to explain the development of complex human service systems. While subsequent sections will address these alternative models' relevance for understanding

community-based HIV/AIDS services, the following subsections use bureaucratic theory and social psychology to address several elements concerning ASOs' founding and survival, including rational versus intuitive thinking, environmental pressures, goal attainment, and the establishment of legally recognized lines of authority.

Social action and organizational development. Emphasizing the pursuit of rational understanding (i.e., making total sense of one's environment based on interpretations of unambiguous empirical evidence) as the primary means for clarifying the underlying meaning of social actions, Weber (1947) delineates three major characteristics defining the modern bureaucracy: 1) a principle of fixed jurisdictions ordered by a general set of rules; 2) a stable line of authority through which the organization's duties and rules are distributed; and 3) the provision for ongoing fulfillment of these duties, for which only qualified individuals are hired to administer their discharge. At the same time, however, he also notes that the more radically a course of action appears to differ from one's own intuitive and empathic values, the more difficult it becomes to understand intellectually. Katz (1978), expanding on Thelen's (1972) models of social action, observes how the interaction of environmental pressures, shared values among constituents, and rule enforcement mechanisms will shape social systems by bringing stability and reducing variation in the behaviors of human actors, who thus collectively carry out the organization's intentions.

The coalescence of these factors contributes to the emergence of shared norms, values, and role-specification within the context of an organization's structure for making and enforcing its rules (Katz, 1978). These perspectives help delineate the way ASOs

have worked to synthesize both the rational and values-driven goals of HIV/AIDS services, which emerged at a moment when mainstream hospitals, clinics, and other charities often refused to accept AIDS patients or individuals suspected to be carriers, namely gay men, sex workers, and/or drug users (Gillett, 2011; Jefferson, 2006; Shilts, 1987). The rational function of ASOs as a form of social action is derived from the accumulated evidence that with direct specialized services attending to linkages between care services, PLWH exhibit improved medical outcomes that ultimately prolong their lives and productivity while reducing burdens on the United States' public and private health care systems (CDC, 2006; ONAP, 2010; Sherer, 2013). Yet, these rational outcomes were in many ways secondary at the outset of the HIV/AIDS crisis, when the initial founding of ASOs came as a moral reaction to circumstances that deeply affected onlookers' emotions while challenging their core values concerning how people should be treated, irrespective of public perceptions (Andriote, 2011; Gillett, 2011; Shilts, 1987).

Building on this notion of intertwining value-driven and rationalistic goal setting, the founding of HIV/AIDS services bore relationship traits characterized by Weber (1947) as both "conflict" and "communal." With respect to conflict, the very existence of AIDS-specific organizations bears witness to their founders' willingness to engage in politically contentious organizing and activism (directed when necessary at government funders and their own ASOs) to safeguard the rights of those affected by the epidemic (Dodd & Meezan, 2003; Jefferson, 2006). At the same time, the origins of ASOs reflect solidarity relationships between individuals who shared a number of critical experiences

and perspectives, shaped in large part from key liberation movements (Dodd & Meezan, 2003; Gillett, 2011; Jefferson, 2006).

The HIV/AIDS service organization therefore represents the legacy of a besieged community's attempts to bring order to a chaotic set of circumstances in which people with AIDS and their loved ones experienced institutionalized discrimination and social ostracism while at the same time enduring an illness that severely diminished both quality of life and life expectancy. People living with HIV/AIDS needed recognizable, incorporated entities to advocate on their behalf to other well-established legal, medical, and social service bureaucracies, yet at the same time, to gain this legitimacy, organizations needed to adopt and exhibit recognizable operational standards for how human service organizations deliver end products to their consumers (Andriote, 2011; Dodd & Meezan, 2003; Gillett, 2006). Parsons (1960), by relating the concept of organizational growth to specific goal attainment, delineates the social organization as providing a specialized function within larger societal institutions. Where he emphasizes the values that define a social system's functions, these normative rules also guide an organization's adaptive processes.

Environmental circumstances. With respect to HIV/AIDS service organizations, adaptation to environmental circumstances has occurred at key moments as the disease's medical prognosis shifted from terminal, to chronic and increasingly manageable. Yet, these improved outcomes hinge on a number of contingencies concerning both individual circumstances (e.g., propensity to engage in risky sexual or drug-taking behaviors, utilization or avoidance of medical care, past experiences with discrimination and stigma,

etc.) and structural factors (employment, funding for public services, affordable coverage, access to medications, etc.).

Thus, although gaining control and eventually drawing down the amount of virus in the population remains the ultimate (medical) goal of HIV/AIDS service delivery, its successful achievement will depend on the mitigation of social and economic conditions spanning a number of critical systems, including: 1) access to affordable preventive care and medical treatment; 2) health and human services that avoid stigmatizing and/or alienating people living with or at increased risk for HIV; 3) dissemination of medically accurate, culturally appropriate information concerning the transmission and prevention of new infections; and 4) adoption of social and cultural norms that emphasize health-promoting behaviors, especially among populations with higher risks for exposure (ONAP, 2010).

Authority and leadership. Commenting on the notions of representation and responsibility, Weber (1947) notes that various conditions may influence the development of social relationships into a communal or corporate group, “which is closed or limits the admission of outsiders by rules” (p. 145). Katz (1978), meanwhile, draws from von Bertalanffy’s (1968) open systems theory to further delineate the characteristics of both open and closed systems as they relate to organizational structures. Parsons (1960), observing that no organization is ever fully independent from the larger social system, identifies three main forms of control that interact to influence the managerial system: 1) universal societal norms; 2) formal oversight bodies such as advisory boards or shareholders; and 3) public authorities such as governments or religious denominations

that function to mediate the relationship between society's broader interests and the technical operations of the organization. In response to the environmental pressures necessitating their formation, social organizations, in concert with society's regulating mechanisms, will adopt the components necessary to operate within larger systems including production and maintenance structures, formal role patterns with clear lines of authority, and mechanisms for collecting and adapting to feedback from the surrounding environment (Katz, 1978). Critical to understanding how these lines function in corporate entities is an examination of the executive as central authority.

Weber (1947) bases the legitimacy of "pure" organizational power on three main premises: rational authority, traditional authority, and charismatic authority. The acceptance of legal legitimacy, he notes, is contingent upon several key contingencies between those in authority and those who are governed, including the claim to obedience on the part of organization members; the consistent application of intentionally established rules for overseeing the organization's administrative processes; the designation of a specific officeholder whose issuance of commands is associated with this authoritative status; the limitations on member obedience to the executive beyond the function of their corporate role and; the understanding that members maintain obedience to authority within the corporation's impersonal order, rather than to the individual him or herself. The role of the authority, therefore, is upheld to the extent that the organization's administrative functions proceed according to his or her instructions.

Building on this delineation of organizations' administrative hierarchies, Parsons (1960) classifies the role of managerial oversight into two main functions. The

bureaucracy simultaneously acts to control the technical operations that deliver the corporation's products to its consumers while managing the organization's relationships with those external resources needed for performing its core functions. With respect to formal organizations, his depiction locates the corporate entity within higher-order institutional mechanisms. Parsons (1960) also notes the differing roles of executives in nonprofit settings which, in contrast to for-profit corporations, operate under the premise of achieving a set of nonmonetary goals that in the case of health and human services produce what could be considered "social" objects, meaning an outcome that is in some way exemplified by changes in their human constituents.

Therefore, the ability of the HIV/AIDS service organization to achieve its goals, as may be the case in other health care institutions, relies on consent and cooperation between service consumers and the organization. In order for the corporation to produce its intended outcomes, there must be some incentive for the consumer to participate, and thus the organization's HIV-affected constituents may represent or come to identify themselves as "members" of the agency itself. As Dodd and Meezan (2003) have noted, traditional approaches to evaluating these services may be complicated by the ways in which conflict, perceived judgment, and community ownership have shaped the development of ASO.

Relevance to human service settings. The influence of rational bureaucratic theory on the founding and survival of ASO is meaningful given that, as Hasenfeld (2009) has observed, the bureaucratic model frequently forms the basis for human service systems' operational structures. At the same time, recognizing the conflicting

circumstances in which human service organizations often operate, he notes that rational theory may not adequately account for critical factors including the fluctuating environments within which these systems often operate; unclear goals and technologies; shifting, often informal relationships among colleagues and between workers and service consumers; and limitations on both authority and accountability. The following section will briefly describe a number of factors highlighted in the study of human service organizations.

Accounting for Complexity in Human Service Settings

As previously noted, while the technical aspects of HIV/AIDS service delivery may be difficult to distinguish from those of other health and human service settings, the service values of ASOs and their longstanding identification with elusive sexual minority and drug-using communities may contribute to their continuing relevance within the U.S. health care system. Where traditional organizational theory may presume a linear relationship between organizational actors and various systems, the notion of complexity has evolved as a counter-construct, encompassing issues related to non-linearity, emergence, dynamical interactions, adaptiveness, uncertainty, and coevolutionary processes (Patton, 2011). By accounting for unpredictability among actors, complexity recognizes the independence and turbulence between interacting systems, which adapt to each other in ways that may be previously unexpected and mutually emergent (Patton, 2011). Eoyang (2004) draws a contrast between *complex* systems and *complicated* ones by noting, “A complicated pattern is one that is intricate in the number of parts and their

hidden relationships to each other,” while a complex pattern “involves the weaving together of parts into an intricate whole” (p. 19).

Although ASOs may in some ways fit the characteristics of a complicated system, this study adopted the view that in fact they represent a complex one. The domestic HIV/AIDS service system as a whole—including its historical development, constituencies served, and indigenously developed service values—may in fact represent more than the sum of its numerous operational parts as a service addressing a distinct group of underrepresented consumers. In fact, the ASO has provided a mechanism for voicing HIV-affected populations’ concerns to government and the larger society while offering a professional destination for workers who closely identify with these populations. In fact, while the National HIV/AIDS Strategy outlines a response that targets relatively straightforward outcomes for reducing the domestic epidemic, its targeted outcomes rely on a number of unpredictable contingencies including: 1) the state by state adoption of Medicaid expansion; 2) sustained Congressional funding for Ryan White, ADAP, and other HIV-specific legislation; 3) successful implementation and consistent delivery of effective service models by health and human service workers; and 4) the willingness of service consumers to adopt a range of health-related behaviors relating to their intimate sexual activities, patterns of health care utilization, pharmaceutical adherence, and disclosure of sensitive personal information to providers and other sex or syringe-sharing partners.

Theoretical Alternatives for Human Service Systems

Noting the turbulent environmental circumstances that may contribute to complexity in human service organizations, Hasenfeld (2009) outlines several alternative theoretical models attempting to account for the variations most common within these organizational structures. Although each in some way builds upon elements of Weber's (1947) rational-minded bureaucracy, there is also expanded emphasis on concepts of social space, organizational climate, and culture, which Katz (1978) observes, have been largely overlooked in the study of social organizations. To the extent that alternative theories recognize the varying degrees of openness that organizational systems may exhibit, these models in practice help to further explain the development and continued survival of HIV/AIDS service organizations. Beginning with a brief examination of human service-related organizational theories as elaborated by Hasenfeld (2009), this section will address the emergence of quality-focused organizational transformation, which represents an approach to managerial discourse that may prove especially useful for considering changes in HIV/AIDS service in the context of new and emerging federal health care benchmarks.

Human relations, negotiated order, and political-economy theories. Hasenfeld (2009) illuminates several key strengths and limitations within the existing body of knowledge by examining a number of alternative theories for explaining organizational behavior. At the same time, no single theory is likely adequate for encompassing the numerous factors that influence the organizational structure and culture of community-based HIV/AIDS services. By highlighting Hasenfeld's (2009) appraisal of three

alternative theories here, this subsection concerns itself with addressing the ways in which each model contributes to further understanding the key question of how ASO constituent members can be expected to experience organizational transformation under new and emerging federal policy.

Building on elements of human relations theory as outlined by Argyris (1962) and others, Hasenfeld (2009) emphasizes the linkages between organizational leadership, worker wellbeing, and client wellbeing. With respect to the human services, tending to the personal needs of staff is assumed to play a key role in avoiding burnout and thus optimizing the potential for successful service outcomes. Among this theory's limitations, he stresses that its social-psychological perspective still views the organization primarily as a closed system, with less attention paid to the intervening influence of various environmental circumstances. With respect to ASOs, the model helps to account for these organizations' origins in empowerment-based movements, where concerns related to democratic participation and holding traditional powers accountable point toward the need for managerial approaches that emphasize a less impersonal approach to operational relations. Its limitations, as Hasenfeld (2009) notes, stem from inattention to external forces, which in the case of domestic HIV have played a role in shaping service delivery from the epidemic's earliest origins.

Hasenfeld (2009) characterizes Strauss and colleagues' (1985) theory of negotiated order, on the other hand, as taking a more evolutionary and consensual approach to organizational development, recognizing that different actors within the system (including clients) play a role in defining both the work to be done and the skills

and values needed to achieve the desired outcomes. By recognizing the client's role in shaping service delivery mechanisms, negotiated order theory acknowledges a role for self-empowerment and self-determination that echoes the sentiments of early PLWH organizing efforts as documented by Dodd and Meezan (2003), Gillett (2011), and Shilts (1987). At the same time, Hasenfeld notes that the theoretical model is focused primarily on micro-level relationships, with vague conceptualizations of the larger social worlds in which human service organizations operate.

Recognizing the critical role that power and legitimacy play in determining organizational survival, Hasenfeld (2009) highlights the environmental focus of Walmsley and Zald's (1976) political economy theory, emphasizing the notion that resource dependence, i.e., the extent to which an organization relies on assets from an external source, plays a key role in determining the degree to which that element influences organizational processes. Human service organizations' typically high levels of dependence on external forces, he notes, produce a number of adaptive survival strategies for which this theoretical model may be suited. For example, an ASO's acceptance of federal and/or state funding for HIV prevention activities depends on its willingness to disseminate information to the public in accordance with the rules and recommendations of state-level AIDS material review panels (CDC, 1992). However, despite these factors and its recognition of consumers' role as an important interest group, he notes this theory's limitations with respect to considering the influence of values and ideology in shaping organizational behavior.

Collectively, these alternative theories build on the rational perspective toward organizational development and shed light on important factors bearing consideration with respect to American responses to the HIV/AIDS epidemic. Still, despite their usefulness for describing and explaining the complexity of HIV/AIDS services within the American health bureaucracy, less can be discerned with respect to the transformation of its organizational structure and culture, owing to the lack of consideration in existing theory for variations and contingencies that may occur in organizations founded by (and historically representing) marginalized groups such as sexual minorities and drug-using populations.

Organizational Change in Human Service Settings

Addressing social work practice in community settings, Hardcastle, Wenocur, and Powers (2011) identify three pathways through which uncertainty enters the organizational context: structural complexity, technological indeterminateness, and human variability. With respect to structural complexity, the differentiation of tasks based on the need to address a greater multitude of concerns may influence workers' ability to efficiently and effectively deliver the intended services. Understanding which intervention best suits the needs of the organization's constituents contributes to technological uncertainty, while variability among organization members' personalities and beliefs may influence the understanding and execution of key activities (Hardcastle, Wenocur, & Powers, 2011).

Noting that nonprofit human service organizations largely rely on government funding to subsidize their services, Gronbjerg (1991) suggests that organizations that are able to develop a market niche with relatively stable client patterns and staffing controls are more likely to develop stable and predictable revenue patterns. Among nonprofit ASOs, the ability to achieve this long-term equilibrium may be influenced by numerous shifting circumstances concerning HIV prognoses, funding levels, population demographics, and philanthropy. For example, in a nationwide study of the financial health of ASOs, Ferris, Pike, and Schaefer (2007) note a trend toward decreasing budget surpluses and increasing reliance on government funds in HIV/AIDS nonprofit organizations, with participants reporting grave concerns about the long-term stability of these public resources.

Reframing the organizational change process. Compared to organizational development, less has been written to document the organizational change process in nonprofit human service settings. Bolman and Deal (2008) emphasize the need for conceptual reframing, which enables decision makers to “break” the mental map guiding their previous attempts to define pathways for achieving key service outcomes. Adopting the mindset of continuous learning, they stress, will enable organization members to better understand the intricate processes by which systems develop and take hold. In their examination of the practices of “high-impact” nonprofit organizations, Crutchfield and Grant (2012) identify six common attributes: 1) Engagement in both policy advocacy and service to constituents; 2) Working with members of the private sector to influence business practice in other realms; 3) Cultivating emotional experiences among core

“evangelists” who share their enthusiasm with other potential stakeholders; 4) Maintaining collaborative networks that help other nonprofits (including competitors) survive and thrive; 5) Adopting an adaptive mindset that responds to changing circumstances with innovation; and 6) Distributing power so that multiple actors may develop leadership within their spheres of influence. As a normative prescription for organizational success, these characteristics offer a clear destination for stakeholders. However, the pathway to achieving these optimal conditions remains context-dependent and highly variable from one setting to another. As a critical next step, an examination of Martin’s (1993) application of total quality management (TQM) to human service organizations will help to link a model for engaging in an outcome-based change strategy to the explicit benchmarks specified by changes in federal health care policy.

Total quality management. Total quality management (TQM) emphasizes the ethic of continuing improvement, in the sense that the pursuit of a “zero defect” product helps the organization’s actors to collectively and systematically examine, refine, and enhance their modes of production, thus ultimately delivering increasingly optimized services to a variety of consumers (Martin, 1993). Derived in large part from the writings of Edward Deming, TQM synthesizes the rational, technical precision of quantitative analysis with the participatory values of the human relations perspective to engage management, workers, clients, and funders in the process of conceiving, operationalizing, and agreeing upon a recognizable set of measurable outcomes. Although mindful of the bureaucratic origins underpinning traditional American management systems, Martin (1993) emphasizes key philosophical differences, including the pursuit of quality as a

single, overarching goal; a focus on continuous improvement over homeostatic, self-maintaining processes; multi-directional communication and feedback channels; and development of relationships with external resources based on mutual estimations of quality instead of lowest pricing.

Within this school of thought, the composite dimensions of “quality” have been synthesized into five main components, including reliability, responsiveness, assurance, empathy, and tangibles. The emphasis on customer satisfaction is apparent in the placement of reliability and responsiveness as the highest order factors in this model, with “customer” taken to encompass a number of constituencies ranging from internal (i.e., departments or workers who receive goods or services from each other) to external (consumers and funding sources). While there are no set rules for how to transform an organizational setting into a culture of quality, Martin (1993) emphasizes the necessity of combining explicit change rhetoric with key leadership actions. Among these potential actions, he includes the following: development of a shared strategic plan, recognition of workers already known to be change agents within the organization, and encouragement to work with and through the existing culture rather than launching a head-on attack against the current hegemony. Doing so, he notes, requires a commitment to a lengthier change process that shifts power downward toward employees, who are recognized for having an intimate understanding of the organization’s policies and processes.

In this way, TQM’s emphasis on redistributing power within the organization is echoed both by Crutchfield and Grant’s (2012) formula for organizational effectiveness, and Dodd and Meezan’s (2003) alternative model for evaluating effectiveness in

HIV/AIDS services. These models emphasize broad-based participation and consensus building around organizational priorities, from which key research questions are formulated and investigated with the aim of informing the larger community of ASO members. At the same time, current changes to the American health care system continue to represent a top-down, market-oriented approach to increasing healthcare utilization and reducing adverse health outcomes in the larger population, and thus represent an impetus for organizational change that may run counter in key ways from the bottom-up approach emphasized in the original service values of HIV/AIDS service organizations.

Theoretical Significance

Representing a movement-initiated response to the AIDS crisis, nonprofit HIV/AIDS service organizations have survived more than thirty years of changes by utilizing multiple government funding streams targeting the persistent social and economic barriers to HIV/AIDS care within the private health care market. In the current policy environment, a number of structural factors may influence the way ASOs experience systemic change. This study adopted the proposition that a nonprofit HIV/AIDS service organization's systemic change experiences would be influenced not only by its technological responses to ACA legislation, but also by the perspectives of its members (e.g., governing board, leadership, and workers) in two distinct ways (see Figure 1). First, ASO members' perspectives would be informed by the extent to which they knew and identified with the experiences of communities persistently and disproportionately impacted by domestic HIV, namely gay and bisexual men, injection

drug users, and communities of color. Second, members' perspectives toward systemic change would to a certain extent be informed by their understanding of the organization's history and service values drawn from grassroots, gay-identified social movements, which emphasized nonjudgmental, peer-delivered services in settings that paralleled or complemented those of mainstream health providers.

Figure 1: Factors influencing the systemic change process of a nonprofit HIV/AIDS service organization



HIV/AIDS service organizations have facilitated opportunities for healthcare utilization, civic participation, and employment among people who have historically experienced exclusion, mistreatment, and invisibility in mainstream service systems (e.g., sexual minorities, drug using populations, communities of color). At the same time, due to their heavy reliance on public funding, ASOs have necessarily maintained relationships with institutions that have traditionally represented the status quo both in terms of bureaucratic functioning and social attitudes concerning worthy versus unworthy recipients of social welfare benefits. Simultaneously then, ASOs function both as a foothold for these marginalized communities to influence existing health and human service policy, and as a vehicle for implementing the wishes of the majority population as conveyed by their elected policymakers and administrative representatives. While no single theory may fully account for these operational characteristics, within a broad understanding of human service development and social change, ASOs may represent an especially noteworthy phenomenon where traditional bureaucracies and militant (often anti-establishment) social movements have mutually influenced each other's philosophical and operational approaches over time.

Philosophical Orientation to the Research Approach

Given the limited knowledge of ASOs' experiences in the ACA implementation era, very few recent approaches present credible options for widespread study of these organizations. Because local service delivery and community involvement in an

organization may be shaped by regional demographics and political factors, this study adopted an approach that identified and addressed its central subject matter in context, rather than attempting to control for variables that may not have fully emerged at the outset of the investigation. Where ASOs appear to fit the description of a complex, adaptive system (Eoyang, 2004; Patton, 2011), an approach that was informed by utilization-focused and developmental evaluation (Patton, 1978; Patton, 2011) helped to clarify key questions concerning the impact of organizational goals and procedural decisions, differing values and priorities between organizational actors, and potential conflicts among ASO stakeholders concerning both the organization's stated priorities and the pathways selected for their implementation.

By adopting Dodd and Meezan's (2003) stance toward research with ASOs, the investigator from the study's outset established an orientation that fostered participation from constituencies whose perspectives may be overlooked in an outcome-oriented study. At the same time, taking the initial steps toward understanding the change processes of contemporary ASOs may have larger significance for a number of stakeholders including federal and state health and human service institutions, large-scale funders, ASOs' leadership and management, frontline workers, and the communities most closely served by these uniquely-shaped service organizations.

Previous literature addressing the history of domestic HIV offers a foundation for understanding their service values and relationships to key constituencies (Andriote, 2011; Gillett, 2011). However, many of these studies occurred during the first two decades of the AIDS epidemic, when the collective memory of early failures and

widespread unrest influenced these organizations' formation and legitimization within the larger health care system. Given the paucity of recent research on ASOs as well as the system-wide significance of current health policy reforms, the single-subject case study offered a suitable approach for examining organizational change as it occurred within the context of a community-based ASO.

Chapter 4: Methodology

The central aim of this study was to bring into focus the systemic change experiences of a current-day HIV/AIDS service organization via the perspectives of its members. This study asked the following central questions:

- 1) *How do members of an HIV/AIDS service organization (i.e., Board, leadership, and staff) experience systemic change in the current policy environment?*
- 2) *What technological changes do members of the organization consider (i.e., interventions selected to carry out its mission) as they develop a strategic response to Affordable Care Act legislation?*
- 3) *To what extent does ASO members' knowledge of and/or identification with HIV-affected constituencies (e.g., gay/bisexual men, injection drug users, communities of color) influence the organization's systemic change process?*
- 4) *To what extent does ASO members' understanding of the organization's history and service values influence the organization's systemic change process?*

Orientation to the Research Design

Five key components are considered critical to the case study research design: 1) a study's questions (described above); 2) its propositions; 3) units of analysis; 4) logic linking data to the propositions; and 5) criteria for interpreting the findings (Yin, 2009).

This framework enables researchers to add depth to their understanding of how an HIV/AIDS service organization experiences top-down changes in the health care delivery system brought about by the Affordable Care Act.

Central propositions. The rationale for this study was based on two central propositions, which guided the selection of its central aim and four principal research questions.

Proposition A: Organizational survival among ASOs depends on the adoption and integration of top-down changes in federal health care policy. However, the organization's change process would be influenced not only by the technological aspects of HIV-specific policy and programs, but also the extent to which ASO members perceived congruence between these changes and their understanding of the organization's history and service values.

Proposition B: Because domestic HIV has disproportionately impacted historically underserved constituencies-- including gay, bisexual, and other men who have sex with men, injection drug users, and communities of color-- ASO members' perceptions of the organization's change process would be informed by their knowledge of and/or identification with the distinct needs and perspectives of these groups.

Unit of analysis. The unit of analysis for this research design was a single organization; however, the character of a bureaucratic structure is made recognizable by the formal and informal interactions of its constituent members (Weber, 1947; Parsons, 1960; Katz, 1978). The impact of human actors on the organization as a whole may be especially influential in the human services, where organizational output is often associated with changes in constituents' health and/or behaviors (Hasenfeld, 2009).

Logic linking data to the proposition. To gain the most salient information regarding this study's central questions, the following data sources were examined: 1)

organizational documents pertaining to the current strategic planning process (e.g., notes from official meetings, state and federal guidelines, practice strategies adopted by similar organizations, published research, documented input from staff and/or consumers, local needs assessments, etc.), adopted, and communicated to its stakeholders; 2) interactions between members during organization meetings that address implementation of the new strategic plan; and 3) attitudes and opinions of organization members who directly experience the change process in their work and/or interactions with the agency.

Table 2 outlines the rationale linking each data collection strategy to its specific research question. Documentary analyses informed the understanding of contextual factors considered and technological changes adopted by the organization (Questions 1, 2). The observation of meetings addressing the change process permitted the researcher to analyze the ways in which technological changes were communicated to stakeholders, as well as members' immediate reactions to these encounters (Questions 1,2). Third, semi-structured interviews with ASO members enabled the investigator to assess the extent to which members' responses to the change process were informed by their knowledge of and/or identification with the ASO's core constituencies (Question 3) and their perceptions of the organization's history and service values (Question 4).

Table 2. Logic linking data collection strategies to the research questions.

Strategy	Research Questions	Rationale
Analysis of organizational documents (including strategic planning notes and drafts, informants' input, needs assessments, supporting research, meeting agendas)	- How do members of an HIV/AIDS service organization experience systemic change in the current policy environment? What technological changes do members of the organization consider as they develop a strategic response to Affordable Care Act legislation?	- Orient the researcher to the organization's strategic plan - Identify specific technological changes to be adopted by the ASO
Observation of organization meetings (specifically addressing strategic plan implementation)	- How do members of an HIV/AIDS service organization experience systemic change in the current policy environment? What technological changes do members of the organization consider as they develop a strategic response to Affordable Care Act legislation?	- Examine how specific changes are communicated to members of the organization - Understand how organization members interact with each other in response to the change process
Semi-structured interviews with ASO members	- To what extent do members relate the current change process to their understanding of the organization's history and service values? To what extent are members' perspectives toward systemic change influenced by their knowledge of and identification with HIV-affected constituencies (e.g., gay/bisexual men, injection drug users, communities of color)?	- Understand how members define and distinguish the characteristics and of the ASO (i.e. historical origins and service values) from other health and human service settings. - Examine how members use their understanding of the ASO's history and service values to inform their perspectives toward systemic change

Criteria for interpreting the findings. By addressing potential rival explanations in the study design, the investigator worked to address their influence as a part of data

collection, thus strengthening the rigor of analyses and their subsequent conclusions (Creswell, 2007; Yin, 2009). With the respect to the current study, two primary rival explanations were considered:

1. *Differing perceptions of the organizational change period.* In the two years prior to commencement of the study, the Minnesota AIDS Project undertook a change in executive leadership that influenced several facets of its operating structure. First, in 2011 its Executive Director of twenty years retired, and her successor was appointed following a months-long search process. In the interim and continuing over subsequent months, a number of senior directors and managers also left the organization. Some of these individuals were replaced, while others' functions were consolidated into different sections of the organization. Given these relatively recent occurrences, members may view the organization's shift in strategy as reflective of these recent changes in leaders' personalities and work styles, rather than as part of a larger systemic change process.

2. *Lack of differentiation between ASO experiences and those of other health and human service constituencies.* The Affordable Care Act represents a broader realignment of the U.S. health care infrastructure, within which HIV/AIDS services represent only one aspect of systemic change. Therefore, it is possible that the experiences of individuals in this study were not uniquely influenced by the origins of HIV/AIDS service organizations, but rather were emblematic of experiences broadly shared in the larger health and human service sector.

Recognizing these possible alternatives, the research design explicitly addressed their potential influence in the following ways. 1) A review of organizational documents

identified changes that could be attributed to larger policy objectives, as opposed to the discreet preferences of current organizational leaders. 2) The observation of governing board and staff meetings addressing policy implementation aided the researcher in differentiating organizational actors' responses to each other's personalities and work styles, as opposed to facets of the systemic change process. 3) Interviews with constituents specifically addressed how members define and distinguished the characteristics and values of HIV/AIDS organizations from other health and human service settings. By sensitizing participants to this specific service context, the research design used members' own views and experiences to shape the conceptual boundaries distinguishing the ASO from other health and human services in the current policy environment.

Sampling and Recruitment Strategies

This study's sampling strategy represents a form of operational construct sampling, whereby the selection of cases for inclusion occurs sequentially as a phenomenon is examined, which is appropriate for studying "real-world" examples of the construct of interest to the investigator (Patton, 2002). Consistent with the principle of theoretical saturation, data collection and analysis were conducted concurrently, with the final sample size determined by the point at which the researcher encountered redundancy, i.e., the point at which no new themes were found in the data (Corbin & Strauss, 2008). Three types of data sources were used:

Agency documents. The selection of strategic planning documents was negotiated with the organization's management prior to commencement of this study in August 2013, at which point senior management shared all agreed-upon document files electronically with the researcher. Documents were included in analysis if they provided previously unknown or unique information about MAP's strategic planning process and had been created within the twelve months prior to August 2013, when the plan was formally adopted. Documents were excluded if they simply repeated information from earlier planning documents (e.g., electronic files with newer date stamps but no new content), or if they addressed content unrelated to the current planning process (e.g., copies of strategic plans from previous years).

Meeting observations. From the outset of data collection, the selection of meetings to observe and permissions for attending were negotiated with MAP's executive management. Although leadership agreed to allow the researcher to attend meetings directly addressing the implementation of its strategic plan, this permission did not include MAP's routine staff or Board meetings, where updates on implementation may have been addressed, but with less detail than other operational topics. Given these constraints, to maximize the amount of relevant observational data collected, investigator focused specifically on observing sessions when the plan was introduced to staff and when Board and senior management met to review its progress and strategize their subsequent decisions.

Board and staff interviews. To recruit interview participants for this study, the investigator selected informants based on findings gleaned from documentary analysis

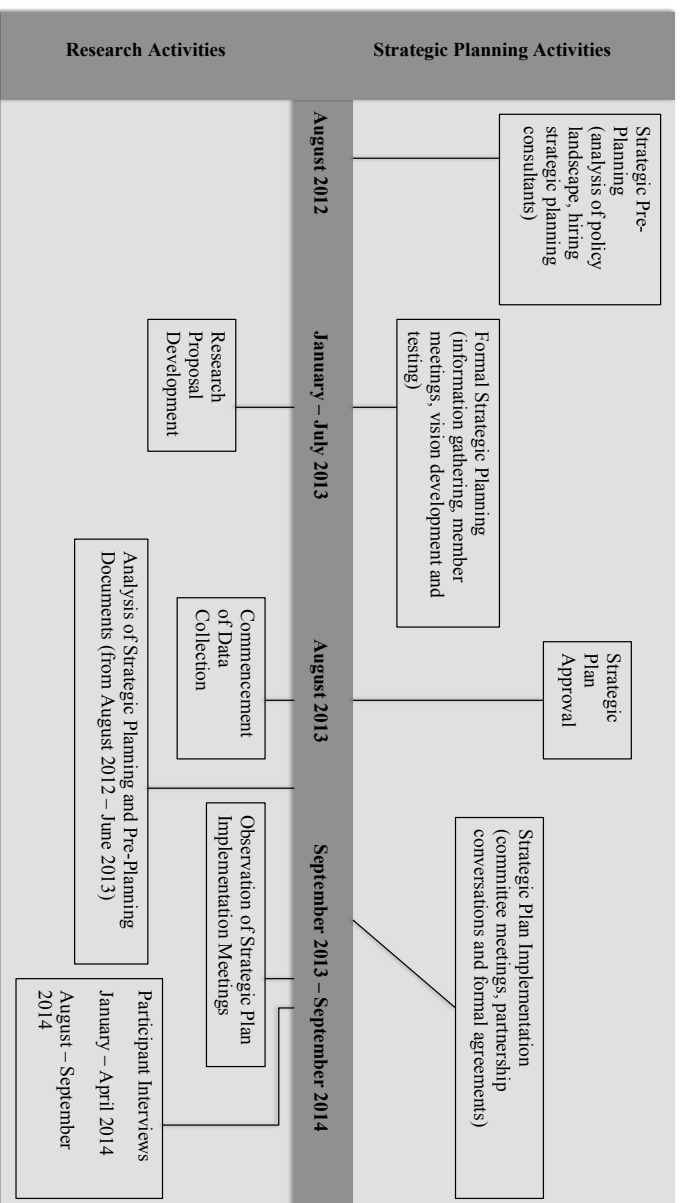
and meeting observations. The following stakeholders were considered for participation: 1) employees who experienced substantial changes in their technical responsibilities due to ACA-related obligations; 2) employees with lengthier records of employment, who may have experienced numerous changes in HIV/AIDS services over time; 3) employees who closely worked or identified with populations disproportionately affected by HIV; 4) members of MAP's governing board who participated in drafting and implementing its strategic plan. Because the organization's service area is bounded geographically, its members were located within or adjacent to the state of Minnesota. Recruitment targets were derived from the above-mentioned data sources and included 6 to 8 Board members, 5 members of senior management, and 7 to 12 staff members were identified as potential interview participants. Thus, the target participant sample ranged from 18 to 25 members.

Initially, executive management of the Minnesota AIDS Project sent an email to its employees and governing board members explaining the study and introducing the principal investigator (see Appendix C: Solicitation Materials). The investigator explained the study in person at the organization's monthly governing board meeting, as well as its monthly all-staff meeting. At that time, the investigator distributed a postcard asking members to indicate their willingness to participate in the study and provide their name and preferred mode of contact (email or telephone). Materials were provided for members who were absent from the meetings as well.

Data Collection Procedures

Figure 2 below illustrates the timeline for data collection with respect to MAP's strategic planning implementation process.

Figure 2: Data collection timeline



The following procedures were embedded into data collection to help the investigator focus his analyses on findings most relevant to the study's central topics (see Appendix F: Data Collection Protocols).

Collection of existing literature and organizational documents. Literature searches that shaped the development of this study yielded information from a variety of sources. The University of Minnesota libraries' databases were searched for journal articles from 1981 to present concerning the history and epidemiology of HIV/AIDS, with Google Scholar consistently yielding the most useful and relevant findings. The Centers for Disease Control and Prevention's web site was already known by the investigator for providing current information on HIV incidence and prevalence within the United States. Andriote's article "Five crises: A brief history of ASOs" was shared with the investigator by Bill Tiedemann, Executive Director of the Minnesota AIDS Project at the time. The organization's web site (www.mnaidsproject.org) also provided background information, including historical synopses, recent annual reports, and current service descriptions.

New documents considered in this study included the following: 1) the organization's 2013 - 2016 strategic plan; 2) documentation from the 2013 strategic planning process leading up to its adoption (e.g., supporting evidence, alternative approaches, noted concerns); 3) relevant constituent data such as needs assessment findings; and 4) meeting notes and official communications with members concerning implementation of the strategic plan. All documentary evidence was classified according to information type, dates of occurrence, and contents; this review helped orient the

researcher to the formation processes resulting in the organization's new strategic plan, so that observation sessions and participant interviews would occur as parallel processes to its implementation of the plan.

Organizational meetings. Observing and analyzing meetings that addressed the current change process allowed the researcher to understand the context in which organization members interacted and to detect other social dynamics that might escape notice in other forms of data collection (Patton, 2002). On all occasions, the researcher maintained the role of nonparticipant before, during, and after the conclusion of meetings.

Sensitizing concepts. Field observations were recorded and written up by the investigator shortly after data collection, and then similarly sorted into types. The following sensitizing concepts, derived from the work of Patton (2002), guided the investigator's attentions while observing organizational meetings: 1) The physical environment in which organizational change topics are addressed were examined to capture participants' interactions with the space in which information and feedback were shared; 2) The social environment was examined to capture the ways in which organization members interacted, placed themselves into groups and subgroups, and made decisions concerning the conduct of the meetings; 3) Members' historical perspectives were noted to document how programs have developed over time, including previous challenges that inform members' current perspectives; 4) Planned implementation activities and formal interactions were considered in order to understand how each self-contained event progressed from beginning, to midpoint, to closure. 5)

Members' informal interactions and unplanned activities were examined to understand moments when organization members were able to talk with each other about their experiences related to the organizational change process.

Semi-structured interviews. Building on findings from documentary evidence and direct observations, interviews with ASO members served to directly address this study's third and fourth questions concerning the perspectives of MAP's stakeholders.

Interview procedures. Qualitative interviews were digitally recorded and then manually transcribed by the investigator using VLC Media Player, an open-source platform for digital audio that allows for variable speed playback (Video LAN Organization, 2015). The semi-structured interview guide adhered closely to the four central questions of this study identified at the beginning of Chapter 4 (see Appendix F, Data Collection Protocols).

To sensitize interviewees to the study topic, the open-ended questioning route began by addressing the following topics: 1) how the individual member came to be involved in the organization; 2) how the interviewee viewed its defining characteristics, including the organization's history and service values; 3) which characteristics the interviewee perceived as distinguishing an HIV/AIDS service organization from other health and human services; and 4) how the interviewee described the organization's new strategic plan in his or her own words, with respect to technical aspects (i.e., job functions and responsibilities), cultural aspects (i.e., organizational history and values), and population aspects (i.e., potential impact on HIV-affected constituencies). The use of probes and follow-up questions throughout this sequence (e.g., "How did that come to

happen? Could you say some more about that? How did that make you feel?” etc.) aided the researcher in gaining further details from each participant while clarifying potential misunderstandings in the data (Patton, 2002).

Building on these responses, the interviewer asked participants to give their opinion of the current systemic change process on a 4-point scale: Hot (Very positive), Warm (Somewhat positive), Lukewarm (Somewhat negative), and Cold (Very negative). Using this information, the interviewer verbally reviewed the participant’s prior responses and asked each individual to identify which of these factors had the strongest influence on this estimation. To conclude the interview, the researcher summarized each participant’s responses and asked him or her to identify any unaddressed factors they believed to be valuable to consider, and what types of support they felt were needed for the change process to be successful. Debriefing procedures included follow-up contact via email to share initial analyses (“member checking;” [Patton, 2002; Yin, 2009]) and to encourage the solicitation of additional suitable informants. To consider the extent to which members’ perspectives may have changed over the course of the study, the investigator identified a small subset of cases ($n = 6$) based on participants’ self-described proximity to the change process, which were approached for follow-up interviews six months later, during which participants were encouraged to reflect on their previous comments in light of their subsequent experiences with the organization’s change process.

Data Collection Site

The primary site for meeting observations and interviews was the Minnesota AIDS Project office building in Minneapolis. The building's multiple meeting spaces were able to accommodate individual interviews and meetings of up to 60 people, with flexible scheduling options based on time of day and staff's needs. For constituents who were unable or uncomfortable with meeting at this site, the researcher arranged for a face-to-face interview to be conducted at a location mutually agreeable to both parties.

Data Analysis

Consistent with principles of qualitative research, data analysis for this study utilized an inductive approach, whereby meanings were assigned based on patterns found in the data rather than imposed by categories pre-determined by the researcher (Creswell, 2009; Patton, 2002). This study employed pattern matching to build an explanation for the case, with open coding facilitating the comparison of initial cases (e.g., coded documents) and preliminary conclusions drawn concerning organizational policy and behavior, comparing subsequent cases to those initially collected, and revising conceptual explanations accordingly. This approach allowed for the integration of all three types of data – documents, observations, and interviews – into an overarching matrix for identifying and refining themes found across the entire body of evidence.

Coding began with the analysis of all strategic planning documents, which pertained specifically to deliberations and decisions made prior to the plan's adoption, and which were coded in chronological order of their creation to help the researcher

understand how members had discovered and incorporated new information into their planning. At the conclusion of documentary analyses, the initial codes were organized according to the study's research questions and rechecked against the original data to ensure their plausibility. This preliminary set of codes formed the basis for the subsequent analyses of meeting observations, followed by interview transcripts, whereby meanings assigned to these proceedings were checked against preliminary definitions and either refined or assigned new labels to differentiate phenomena as they were identified.

Open coding continued until no new information was gained (i.e., theoretical saturation), at which point the entire list of codes was rechecked against the study's research questions. At this stage, the researcher employed axial coding to identify patterns of similarity within these open codes, grouping them together when possible and formulating a list of preliminary themes that would encompass and integrate meanings derived from each of the aforementioned data sources. These themes would continue to be revisited and refined as study results were written, reflecting an iterative process by which potential mischaracterizations were addressed and rechecked against preliminary coding assignments in the original data. During all phases of data analysis, the practice of memoing assisted these efforts to thematically organize the information by prompting the researcher to reflectively consider and make note of the potential inter-relatedness of discoveries culled from these different sources.

Validation Strategies

To enhance the possibility that findings accurately reflected the meanings attributed to its participants, the investigator adopted a flexible research design that evolved from a carefully selected topic to encompass the range of themes expressed by these individuals (Creswell, 2009; Lincoln & Guba, 1985). Several validation strategies were employed to address potential error, which included prolonged engagement, triangulation of sources and methods, and member checking (Corbin & Strauss, 2008; Creswell, 2007; Patton, 2002).

The researcher maintained a prolonged engagement period of slightly more than twelve months, both to establish trust with participants and to allow for the discovery and inclusion of evidence that would clarify or counter any initial assumptions made during open coding. From the study's outset, the researcher clarified his own personal experiences and potential biases (see "Methodological Limitations" below) and sought rival explanations and disconfirming or negative cases for analysis, which in this study specifically involved identifying Board or staff interview participants who expressed perspectives that countered the prevailing decisions outlined in strategic planning documents or implementation meetings.

To triangulate data sources, the researcher sought evidence from a variety of planning documents, observed meetings intended primarily either for staff or Board members, and solicited interviews with members with different organizational roles (e.g., Board member, senior leadership, middle management, staff) and variable proximity to the plan's implementation (e.g., including members who had participated in formal

planning or implementation and those who did not). By triangulating methods, the researcher gained the ability to capture information that would not have been apparent from any single modality; for example, while a review of planning documents allowed for the retrospective chronicling of the organization's decisions, meeting observations enabled the researcher to consider the influence of members' interactions with each other around the change process, and semi-structured interviews invited participants to reflect and share their observations and insights on the systemic change experience.

Finally, the semi-structured interview process included member checking, whereby the researcher verbally debriefed each participant at the conclusion of the interview to verify that the notes he had collected were accurately portrayed. Members were invited to clarify any areas where the researcher had misunderstood them, as well as to add any information that would help the researcher to better understand their intentions. After the interviews were coded, the researcher emailed each participant a document containing passages he would consider quoting to allow them an opportunity to omit any comments that would potentially reveal their identity within the organization.

Relationship of Researcher to Informants

Several key factors helped to facilitate the investigator's relationship with the organization and its members. The researcher was previously employed at the Minnesota AIDS Project, first in coordinating a health education and outreach program targeting gay and bisexual men and then as manager for the organization's volunteer program. His position within the organization afforded the opportunity to gain familiarity with

numerous staff, Board members, volunteers, donors, and service consumers. After leaving the organization, the investigator maintained contact with management and staff, working both as a research partner and grant writing consultant on various ad hoc projects.

Beginning in 2011, the organization underwent substantial changes in its management structure. The Executive Director at the time of data collection and its governing board agreed to facilitate MAP's participation in this case study by introducing the investigator to MAP's management and staff. All methods and consent procedures were shared with the Executive Director, and his signed letter of understanding on behalf of the organization is included in Appendix B, Letters of Understanding.

Methodological Limitations

The methodological rigor of study should be considered in light of the following limitations. First, with respect to sampling bias, the results presented are based on evidence as it was provided to the researcher (i.e., documents shared, meetings observed), and thus may only selectively reflect the change process that members experienced. Members who agreed to be observed or interviewed may reflect a limited range of viewpoints held within the organization. For example, if a member of the organization did not consent to be observed during a meeting, but expressed views criticizing or questioning management's approach to the change process, that individual's comments and behaviors were not included in data analysis. Also, volunteers and service recipients did not complete semi-structured interviews, owing to the absence of changes for them to

appraise during this phase of data collection. To the fullest extent possible, however, constituent feedback collected by MAP in 2013 was included with documentary analysis to ensure that the views of unpaid members of the organization were considered.

Second, while the investigator's familiarity with HIV/AIDS, sexual minority health issues, and the Minnesota AIDS Project brought a number of advantages to the research design, his prior experiences and perspectives may have potentially influenced the orientation of this study toward his existing views, including the following: 1) his commitment to reducing health and socioeconomic disparities experienced by lesbian, gay, bisexual, and transgender (LGBT) populations over 15 years of work, both in Minneapolis/St. Paul and Lansing, Michigan; 2) his generally positive view toward the necessity of LGBT-specific services as competent alternatives to mainstream health and social service environments; and 3) his generally positive view toward the organization's mission, services, staff, volunteers, and service consumers. Also, oral interviews may have been biased by the fact that the researcher was familiar with a number of the participants from his previous work and generally holds them in friendly regard.

Additionally, the researcher's past work experiences and continued familiarity with the organization presented a number of risks concerning his subjective views of the organization's change process. For example, the investigator may have favored the perspectives of certain informants such as non-managerial staff, given his background working as a member of these groups. His experiences writing successful state and federal grants for the organization may have influenced him to hold more positive regard for certain programmatic changes, if he viewed their adoption as advantageous for

programs he helped to create. He may have negatively viewed decisions to end initiatives on which he had previously worked or, conversely, his positive feelings toward a policy's adoption may have cause past feelings of frustration to surface, if he perceived that the move would bring about changes he had hoped to achieve in his previous role as a MAP employee.

Finally, the research design did not incorporate a second, independent rater during open and axial coding, which may bias the findings toward the researcher's subjective interpretations. To address these limitations, the researcher maintained an audit trail by keeping a data collection diary throughout the evidence gathering process. To enhance the possibility that findings reflected a neutral perspective, the researcher used this diary as a tool for collecting and reflecting on his subjective reactions to the data and its sources. While the diary itself did not collect data concerning this study's central questions, it enabled the investigator to identify, explore, and clarify key moments when he may experienced feelings that may have influenced the neutrality of his perspective as an independent researcher.

Protections for Human Subjects

Participants were invited to sign an informed consent agreement to be interviewed, observed, and quoted (see Appendix D, Informed Consent). The consent procedures included language specifying the interview participant's right to review all direct quotations and delete portions that they did not wish to have quoted due to potential risk of exposure. All interview participants were asked to complete a

Demographic Information Form (see Appendix E, Participant Demographics Form) when they completed the informed consent process, which included age, race/ethnicity, gender identity, sexual orientation, and length of involvement with the organization.

Meeting participants who did not consent to being included in the study were excluded from the researcher's analysis of field notes. Informants quoted in this study were identified by pseudonyms instead of real names, and specific position titles were changed to general ones such as "Board member" or "staff member." However, due to the small number of potential participants, the investigator cautioned all informants that the identities of those quoted, even with generic identifiers, might be recognizable to individuals familiar with the organization. All procedures were submitted to the University of Minnesota's Institutional Review Board (IRB), which determined that the study did not require IRB review or approval.

Chapter 5: Results

Overview of Findings and Sample Characteristics

Results in this chapter are organized to respond to the study's four central research questions, beginning with a description of the sample characteristics and a summary of the Minnesota AIDS Project's 2013 - 2016 strategic plan, around which its systemic change process was organized. At the same time, within each theme, the narrative aims to convey the story of systemic change as it occurred by presenting evidence in a chronological fashion whenever possible.

Sample

The final sample for the study is comprised of organizational documents (n = 40), observations from meetings that addressed implementation of the organization's strategic plan (n = 10), and interviews with twenty members of the organization, six of which completed brief follow-up interviews with the investigator (n = 26).

Documents shared with the investigator spanned a period of ten months from August 2012 through June 2013, during which the Minnesota AIDS Project's governing board, senior management, and staff engaged in a series of activities (including literature reviews, planning retreats, conversations with local and national informants, and focus groups) focusing on the creation of its new strategic plan. Table 3 summarizes the content of these documents, which covered multiple topics and reflected the views of numerous sources consulted by MAP's Board and senior management.

Table 3: Characteristics of documentary evidence

Document Type	n	%
Strategic Visioning (i.e., scenarios imagining MAP's fit in the emerging HIV healthcare sector)	12	30
Stakeholder Input (i.e., summaries of surveys, individual interviews, and focus groups conducted with local stakeholders (e.g., staff, Board, clients, volunteers, state funders, clinics, HIV specialty doctors, social service providers, etc.))	12	30
Meeting Agendas & Minutes (i.e., strategic planning retreat agendas and minutes)	4	10
Strategic Planning Process (i.e., timelines with detailed activities and project benchmarks)	3	7.5
Evidence (i.e., summaries of local epidemiology and service usage, reviews of published research articles concerning HIV-affected populations' unmet needs)	3	7.5
Contextual Appraisals (i.e., critical evaluation of local, state, and national HIV and healthcare-related government policies, funding sources, and providers)	3	7.5
Consultant Proposal & Work Plans	2	5
Email Communications From Leadership to Staff	<u>1</u>	<u>2.5</u>
Total	40	100

Meeting observations occurred on ten unique occasions between September 2013 and August 2014. Two initial meetings involved the staff, which was invited by senior management to share questions, concerns, and feedback about the strategic plan following its final approval by the Board. The remaining eight occasions were monthly meetings held by MAP's strategic planning implementation committee, an ad hoc council of Board members, the Executive Director, and one administrative assistant, with senior

managers participating when topics germane to their expertise were discussed. Meeting attendance ranged from 4 to 12 individuals, with a median attendance of eight participants.

Table 4 below lists interview participants by pseudonym and general affiliation with the organization. Participants completed a brief questionnaire to provide demographic information including age, gender identity, race/ethnicity, and length of involvement with the organization. The twenty participants ranged in age from 30 to 64 years, with a mean age of 41.5. Men (55%) comprised a majority of the sample compared to women (45%), while 65% identified as gay, lesbian, or bisexual compared to 35% who identified as straight/heterosexual, and a substantial majority (95%) identified as White. One individual openly identified as HIV-positive. Length of involvement with the Minnesota AIDS Project ranged from 7 months to 19 years; half of the sample (50%) reported less than 5 years involvement with the organization, while 45% estimated their engagement to be at least 10 years. Seven participants (35%) were members of MAP's Board; five individuals were from senior management (25%); and eight interviewees (40%) identified as middle management or staff.

Table 4: Interview participants

Name	Affiliation
Amber	Board Member
Douglass	Board Member
Craig	Board Member
Naomi	Board Member
Audrey	Board Member
Wyatt	Board Member
Reese	Board Member
Ted	Senior Management
Amelia	Senior Management
Levi	Senior Management
Stella	Senior Management
Leo	Senior Management
Nathaniel	Middle Management – Staff
Felicity	Middle Management – Staff
Ava	Middle Management – Staff
Paige	Middle Management – Staff
Sophie	Middle Management – Staff
Gabriel	Middle Management – Staff
Owen	Middle Management – Staff
Dominic	Middle Management – Staff

Summary of MAP's (2013) Strategic Plan

As data collection in this study focused both on the development and implementation of MAP's new strategic plan, a summary of its content is offered here as a point of reference for the thematic results to follow. Approved by its Board and released

to the public in August 2013, MAP's strategic plan for 2013 to 2016 focused the organization's work on five strategic goals:

1. Increase access to health care, treatment, and prevention education for individuals living with, at risk for, and affected by HIV.
2. Improve health outcomes for people living with and at risk for HIV.
3. Decrease HIV-related health disparities.
4. Reduce stigma and discrimination associated with HIV.
5. Strengthen MAP's business processes in order to ensure long-term sustainability.

For the specified three-year period, the plan stated, "Organizational and programmatic growth will be guided by the goals of the National HIV/AIDS Strategy in concert with the Patient Protection and Affordable Care Act." Also guiding the plan were nine specific principles, which included an emphasis on compassion, fairness, and respect for all HIV-affected peoples; belief in the strength of diversity; reliance on the professionalism and dedication of MAP's staff and volunteers; willingness to engage broadly with others to plan, deliver, and evaluate services; belief in the role of consumers to achieve optimal outcomes; adherence to fiscal responsibility; a desire to continuously improve MAP's work; willingness to collaborate; and a value for learning as part of the organization's process.

Overview of Thematic Findings

Analytic results, including themes and sub-themes, are summarized in Table 3. Initial data analyses resulted in 199 unique codes, which were subsequently organized into 10 distinct themes. Detailed results are described below in correspondence with the study's central questions concerning 1) ASO members' systemic change experiences, 2)

technological changes considered by the organization, 3) the influence of members' knowledge of or identification with HIV-affected populations on the systemic change process, and 4) influence of the organization's history and service values on the systemic change process. With one exception, themes are organized sequentially to match the ordering of the research questions. Appraisal of the Change Process, which corresponds with Research Question 1, is presented at the end of this chapter to account for the timing of participants' reflections on changes adopted by the organization.

Table 5: Thematic findings

Research Question	Theme	Subthemes
1: Members' systemic change experiences	External Factors	Systemic considerations Perceptions – expectations
	Rationale for Change	Continue to exist Positioning the organization: - To lead the local HIV service sector - To be attractive to consumers
	Appraisal of the Change Process	How changes should be facilitated Changes that have already occurred
2: Technological considerations	Measurable Outcomes	Estimating service worth Evidence-gathering processes
	Opportunities	Alignment with providers Building on strengths Marketing and selling
	Barriers	Environmental limitations Obstacles within the organization
3: Knowledge/ identification with HIV-affected constituencies	Population Characteristics	Members' attributes Stigma – marginalization
	Service Needs	Medical Psychosocial
4: History and service values	Defining Service Characteristics	Emphasis Longevity
	Workplace Culture	Unsettled Professionalization

ASO Members' Systemic Change Experiences (Part I)

Table 5 summarizes the number of data sources for each theme pertaining to Research Question 1 (Part I). Three themes emerged concerning members' systemic change experiences, two of which are detailed here. External Factors and Rationale for Change correspond to considerations that informed decision makers during MAP's initial planning and early implementation phases. Appraisal of the Change Process, although present during all phases of members' experiences, relates more fully to members' reflections after specific changes had been introduced, and is therefore presented at the end of the chapter.

Table 6: Summary of data sources for Research Question 1 (part I)

Theme	Number of Documents (n = 40)	Number of Meeting Observations (n = 10)	Number of Interviews (n = 26)
External factors	9	1	24
Rationale for change	4	1	17

Theme 1: External factors

From the outset of its strategic planning process, MAP's members recognized that circumstances outside of the organization would exert substantial influence on the organization's future. Specifically, these factors included systemic considerations (i.e., changes in HIV-specific public policy and funding) and perceptions or expectations held by constituencies outside of the organization (e.g., public attitudes toward HIV/AIDS,

expectations of the community toward MAP, approaches taken by ASOs with comparable histories and services).

Systemic considerations. Systemic considerations warranted especially close attention before, during, and subsequent to strategic planning. In documents developed just prior to commencement of the planning process, MAP's leadership outlined its analysis of the current and emerging policy environment for non-profit ASOs, which highlighted two major concerns: 1) incongruence between the federal government's stated emphasis on providing comprehensive social services and the increasingly medical focus of HIV-specific government funding, and 2) the increasing necessity for collaboration between community-based HIV/AIDS organizations to preserve the continuum of social services available for PLWH. Noting several changes in HIV policy that had recently occurred or were in the process of changing—including NHAS, ACA, Ryan White, and Open Doors (addressing homelessness)—MAP's policy analysis argued that these shifts would alter the ways in which HIV-focused organizations must work together. For example, the NHAS (2010) posits that meeting the comprehensive service needs of those living with or at risk for HIV would enhance the achievement of HIV-related health outcomes, such as reducing new infections and increasing medication adherence. However, MAP's analysis notes, if federal funding continues to prioritize medical services disproportionately compared to these other "wraparound" supports (e.g., mental health, substance abuse, housing, food, child care, etc.), then non-medical service providers such as MAP would be left at a fiscal disadvantage.

Interview participants characterized the task of fitting MAP's services, historically defined and funded by the Ryan White Care Act, to the emerging system of reimbursement regulated by Affordable Care Act reforms as challenging, with a number of uncertainties concerning future government funding and new mechanisms for reimbursement. Staff member Levi observed:

So, there's this big, complicated health care system that's built up around HIV. And there's this big new complicated health care... change that's coming. And how do those two... mesh together? I think that we have a blessing; you know, the Ryan White program is a blessing and a curse, in that I think that... ASOs can do things, I think, that other agencies can't because of the Ryan White funding that's available. But then we're also kind of a slave to that very specific funding stream.

With respect to these longstanding funding streams, members noted a trend toward declining government resources for HIV social services in recent years, with additional cuts anticipated in the coming years. Gabriel, a member of the staff for more than ten years, commented, "You know, I think that when Ryan White comes up again, they're going to look at it and say, you know, people are not dying and... I think that's the whole medical care model, is to get people into health care so they can stay healthy." Attributing at least part of this decline to Minnesota's comparatively low incidence of HIV compared with other states, Board member Amber speculated on the challenge of determining where and how to mobilize the locus of support for MAP's services:

And I think part of the challenge we have in Minnesota is it's not just seen as a high-risk area; you know, compared to some areas, it's a lower incidence state, and so it's harder to get funding for that. And so, from a priority standpoint, of course we want to get to zero new incidence, and that's important to us, but you know, when you're at that government higher level, they don't always see it that way.

To that end, although members cited the need for a new fund development strategy to acquaint MAP's donors to the organization's emerging plans, more central to the immediate change process was MAP's need to attract nongovernmental payers for its social services. In this respect, members differed somewhat in terms of what opportunities for expansion they believed the Affordable Care Act could facilitate. While some interview participants spoke of MAP's need to position itself to capitalize on ACA-related changes relevant to HIV-affected Minnesotans and the nonprofits serving them, staff member Levi downplayed this potential, observing:

The ACA is not really a radical change in Minnesota. You know, ideally by the end of... 2016, almost every Minnesotan will have health insurance. A lot of it is gonna be people who already qualified for public programs, who actually sort of get that push to get into it. It's gonna be people who buy health insurance on the individual market, who will now have plans that are a little bit cheaper and a little bit more comprehensive than what they had before. I'm not sure that it's as big a game changer as perhaps it gets talked. It's helping more people afford private health insurance.

His colleague Amelia, on the other hand, viewed the ACA as providing ways for MAP to coordinate patients' utilization of the healthcare system via its case management program, but noted the lack of clear funding mechanism for doing so:

And I think, you know, one place, at least as far as I can tell, the ACA requires that there be this community coordination, and you're supposed to be working with community-based organizations to do this work and it's all well and good, except nobody thought of the payment mechanism for it. [You] know, we could take on a lot of that community coordination. We're good at it. But, I'm not sure how we get paid.

Perceptions – expectations. A second subtheme relating to external factors concerned the perceptions and expectations of people and organizations outside of the organization’s membership. These constituencies ranged from organizational peers and medical providers (both within and outside the state of Minnesota) to local HIV service consumers, current or potential funders, donors, and the broader public regarding a number of salient issues such as MAP’s position within the service marketplace, the viability of emerging HIV service models in comparable jurisdictions, and perceptions of HIV as a declining threat to the public’s health.

As a starting point for examining service models to consider, MAP closely studied the approach taken by its peer in a neighboring state, where an organization with a comparable history and service portfolio had expanded to become a comprehensive provider of medical, dental, pharmaceutical, and social services for its HIV-affected constituencies. Board member Wyatt related how the experience of visiting and studying this ASO led his enthusiasm for MAP’s change process to rise substantially, noting, “My god, look at what they’ve got going here. There’s a pharmacy, there’s a professional medical facility, here’s how they’re doing the services that MAP provides now to the community and so forth... that really got me excited.”

To understand the viability of establishing a comparable “full service” model in Minnesota, members would need to consider a number of possibilities, which emerged as a distinct theme relating to technological opportunities (described below). However, certain contextual factors would complicate the prospect for effectively replicating the approach taken by this organizational peer from a state with political and economic

circumstances that differed from Minnesota's. For instance, this peer organization's ability to take on medical and dental care, as well as pharmacy services, was aided by the closure of a local medical provider that had served a substantial portion of the local HIV-positive community.

Members also observed how differing political climates and funding priorities from state to state had created divergent scenarios. Where one state may have cut social service funding and forced a consolidation within its HIV service sector, Minnesota's commitment to underwriting a collection of social service providers associated with and situated in communities disproportionately represented in HIV demographics had, in the view of some members, slowed its sector's movement toward a centralized model that would integrate HIV social services with medical care. As Board member Wyatt observed, "I think we're playing a little bit of catch-up, too. I think because of what I would deem the strong response in Minnesota from a policy perspective and even from the insurer perspective, we have in the care provider, persons with HIV... we've become a little complacent. We didn't maybe have the budgetary challenges that forced other states to get to this point earlier."

Multiple interview participants from the Board and staff reflected on ways in which the public's perception of HIV, as they viewed it, had influenced MAP's systemic change experiences. Some felt that the general population lacked knowledge of the epidemic in its current stage, citing outdated perceptions of HIV as a white, gay male disease or one that had been cured, while another lamented what he considered the perception of HIV as manageable, leading to increases in risky behavior such as sex

without condoms among younger gay men. Tying perceptions of the general public to challenges experienced by the organization, staff member Leo described the difficulty of communicating how HIV services address not just the disease, but also concomitant issues concerning psychosocial health and access to basic necessities such as housing, transportation, and financial assistance.

Consistent across these observations, participants noted how gaps in the public's knowledge translated into operational challenges for MAP in its quest to survive and remain relevant in the emerging healthcare environment. To summarize, Board member Wyatt observed, "HIV is one of those issues... I heard a lot about growing up, and frankly had just become concerned about the... kind of the diminishment of public interest and public attention," adding:

...back in the late 90s, you could slap a red ribbon on anything and the philanthropic dollars would flow in. Now, it's you know, as you see the numbers and what the priority the public places on HIV, for the most part people think the issue's been dealt with, if they don't think it's been cured. You don't see people at the Oscars wearing red ribbons anymore.

Theme 2: Rationale for change

Where several of the above-mentioned external factors had raised the possibility of obsolescence, members of the Minnesota AIDS Project sought to clarify the reasons for undertaking a wholesale change in the organization's systemic approach. Supporting the rationale to change were two main subthemes concerning first, MAP's justification for continuing to exist, and second, perspectives on how MAP should position itself both as a leader within the local HIV service sector and as an attractive destination for consumers.

Continue to exist. During one of its initial strategic planning retreats in 2013, Board and staff considered one scenario that would envision a phased “sunset” period and closure of the organization, but members shared a consensus that MAP’s closure could potentially harm the local community by eliminating a longstanding provider of services to clients, destabilizing the local HIV services sector, and silencing a highly regarded voice for advocacy in the arena of state and federal policymaking. Thus, the rationale for change was justified as being essential for MAP’s continued survival.

Members shared a belief that the organization would cease to exist within a few years without fundamental restructuring to replace its declining government funding with other sources of revenue. For multiple interviewees, the notion of survival was therefore closely linked to sustainability or a self-sustaining income model. Staff member Amelia succinctly summed up this sentiment: “Sustainability. We absolutely cannot continue living on government grants.” Board member Audrey expanded on this reasoning, commenting, “The vision, or the goal of the change process is to bring MAP to a place where it has the income to be self-sustaining as a nonprofit. It expands your presence in the community market, which you serve. It helps bring better services to the community, it does all of those things under that umbrella, but... I honestly think it’s about not having to nickel and dime, and taking an opportunity that’s been presented by Affordable Care and Ryan White and all those kind of things.” Beyond the financial implication, the timeliness and urgency of the current change process also caught the attention of Ava, a longtime staff member with memories of previous strategic planning periods at MAP:

Well in some ways... it’s like, oh, we’re doing another strategic plan. You know. I think this one, though, there’s a little more of an edge to it because the need is

more... acute. I mean we kind of knew on the horizon, if we're doing our job, HIV infections are gonna drop and health keeps improving. We kind of knew there was an end to services as we know them coming, but it wasn't, it was on the horizon. Now it's like... down the street. So there's more urgency to figuring out what we're gonna be.

Positioning the organization. Multiple documents and interview participants communicated a perception that MAP had been “the model” ASO locally for much of its past, to which other organizations look to guide their own decisions, service offerings, and positions on policy matters. Joined with the responsibility to establish a new, sustainable operating model for the organization was the sentiment that MAP's changes were necessary for the viability of the broader local HIV service sector. Board member Amber explained:

I think we are seen as a leader in the AIDS service organization community, which is another interesting spot to be in. There's a lot of pressure, I think, that goes along with that, a lot of eyes to see what we do next. But with that also comes power, and you have to try and leverage that in a good way. If you want to stay a leader, you have to stay on the changes and you also have to be a good partner to the other organizations in the community, too. It's sort of an interesting spot to be in.

Board member Naomi linked this call to leadership with the aforementioned matter of organizational survival: “We will become obsolete if we don't do something, so it's getting out ahead of the curve, trying to do the strategic plan before the other ASOs and then stand at the front and say, ‘Here, we'll help you. We'll share our information.’”

During formal strategic planning in mid-2013, MAP's senior leadership consulted with leaders representing a range of organizations and interests, both locally and from outside the state, to solicit feedback on its circumstances. These informants included

leaders from comparable organizations, technical assistance providers, state agency heads, local ASO leaders, and local infectious disease specialists. The perception of MAP as a sector leader both locally and regionally was shared by multiple informants, who stressed the need for a community-based nonprofit like MAP to stand as a model for other ASOs to emulate. This exhortation to lead came across most pointedly in conversations with the head of another local ASO, the notes from which included the following key statements: “MAP must take the lead, put the stake in the ground and move forward on the strategic plan. The community is waiting for MAP to take the lead; we have been waiting for the past decade.”

Key to this call for sector leadership, however, would be MAP’s need to clarify its own positioning with consumers as a service provider. Concerns that Board and staff members had raised in MAP’s initial strategic planning survey would be addressed more directly as members convened its strategic planning retreat in early 2013, with top concerns/questions including best models for treating people “facing barriers to maintaining and accessing consistent care” and finding out more about the community’s current needs. Speaking to this issue of relevance, staff member Leo observed, “There’s not a lot of organizations that do specific things in HIV, and... we have not... communicated to the community particularly well what we do and what our relevance is in the community.”

During strategic planning, MAP invited its clients and volunteers to participate in a series of focus groups addressing perceptions of MAP in the local community, reasons why people come to MAP for services, appraisals of the quality of MAP’s services, and

insights into how MAP could attempt to more fully meet the unmet needs of HIV-affected populations. Findings from these groups were characterized as differing largely by age and ethnicity of participants, with contrasts in how individuals perceived the organization's length of service ("was around in the beginning" versus "dated appearances/concepts"), identification with HIV-affected communities ("visible presence/voice representing HIV issues" versus "not welcoming" or "less than welcoming" for communities of color), and service value ("referral source for accurate information for newly infected people" versus "not in line with changes in the disease").

Perceptions of MAP as dated and out of touch with some of its constituencies were echoed by Board member Wyatt, who cited the need for MAP to update its relevance to the HIV epidemic's most affected populations at the current time: "I think everybody's kind of been acknowledging that MAP needs to evolve, that we've kind of been the model, and... the model is... you know, great for 2002. We just have to figure out what it means for 2014." Addressing the needs of consumer needs more directly, he added:

I think to better reflect the reality of the HIV marketplace, so to speak. You know, in the past, it was easy enough for MAP just to focus on condom distribution and syringes and kind of the traditional prevention efforts. Well, I think we're kind of maxed out on much of that. It's very important, but I would assume we've reached a plateau.

Thus, as members sought to better understand the current marketplace for MAP's services, the organization's emerging strategic vision attempted to capture and prioritize this positioning to meet consumers' needs, with an emphasis on promoting access to healthcare and supportive services of high quality (including HIV testing and linkages to

care for newly diagnosed individuals); addressing a range of comorbidities associated with barriers to health care, heightened risks for acquiring or transmitting HIV, and quality of life; and attending to the emerging needs of aging PLWH.

Technological Considerations

Three themes concerning the technological changes considered by organization members emerged from the analysis: Measurable Outcomes, Opportunities, and Barriers. Table 7 provides a summary of data sources for the thematic evidence presented below.

Table 7: Summary of data sources for Research Question 2

Theme	Number of Documents (n = 40)	Number of Meeting Observations (n = 10)	Number of Interviews (n = 26)
Measurable outcomes	5	3	21
Opportunities	16	6	26
Barriers	6	5	23

Theme 3: Measurable outcomes

As members moved to consider the possibilities for reorganizing MAP's central focus and function as a service provider, the question of how to operationalize the organization's influence on its clients' health outcomes and on the health of the broader community arose at several stages. From the evidence collected, two main concerns emerged with respect to evaluating services' worth and processes for gathering evidence to determine MAP's effectiveness and value.

Evaluating service worth. Over several funding cycles, the Minnesota AIDS Project had been awarded numerous grants to provide services specified by state and federal contracts, for which the organization had been commended for fulfilling its obligations in a consistent and thorough manner. While these accomplishments provide evidence that the organization may be a reliable choice for government funders, the question remained with respect to how MAP could derive the value or worth of its services and thus establish competitive pricing in the emerging healthcare marketplace. In strategic planning documents and numerous interviews, members described MAP's work as "high quality" and "great," but in the absence of a verifiable metric, staff member Ted noted, "We think we're doing good work, but we don't know that we're doing good work."

With pharmaceutical developments altering HIV's long-term prognosis from manageable to suppressible (and potentially non-transmittable), the opportunity for MAP to adopt a central medical focus to its services emerged in the form of what members called the "treatment cascade" or "Gardner cascade," in reference to the published work of medical researcher E.M. Gardner and colleagues (2011). Using current modeling to presume that only 80% of HIV-infected Americans are aware of their diagnosis and only 50% are retained in HIV care, the cascade estimates that approximately 19% of PLWH possess an undetectable (aka, suppressed) viral load, a condition that greatly reduces risk both to their own health and the health of any non-HIV positive individuals with whom they share syringes or engage in unprotected intercourse. By running a number of simulations to roughly project the impact of success in any single component of HIV

treatment and care (e.g., increased detection, linkage to care, retention in care, adherence to antiretroviral medication), Gardner and colleagues concluded that to substantially increase viral suppression in PLWH, the healthcare system must achieve substantial increases in all aspects of engagement:

Diagnosis of 90% of HIV infections, achievement of 90% engagement in care, treatment of 90% of engaged individuals, and suppression of viremia in 90% of treated individuals could lead to considerable improvement in the proportion of HIV-infected individuals in the United States with undetectable viral loads. (p. 797)

The treatment cascade offers a proximal standard by which to measure progress toward the achievement of a single end goal, the elimination of detectable and transmissible HIV, which can be attained by detecting a substantial majority of new cases, facilitating and sustaining relationships between clients and their medical providers, and rendering the virus incapable of infecting new hosts through consistent use of antiretroviral medications. Adopting the cascade as a central focus, MAP's leadership prioritized this emphasis on measurement as a defining service outcome that would inform members' ideation and decision making from the outset of strategic planning through the plan's implementation. For example, when introducing the finalized strategic plan to staff, leadership raised the possibility of constructing an organization-specific cascade, using its primary indicators (viral detection, engagement with care, retention in care, adherence to medications, and viral load) to estimate the extent to which MAP's client population had achieved viral suppression. By matching these indicators with services in which each client had enrolled (e.g., case management, housing assistance, transportation, legal assistance, benefits counseling, etc.), MAP would gain a critical

evidence base for determining the extent to which a relationship existed between each of its service offerings and the achievement of an undetectable viral load. At the Board level, members viewed the cascade as a tool for identifying possibilities for expanding, packaging and selling, or relocating core services, such as case management, and for communicating the organization's mission and function to its champions and financial supporters in the larger community.

Although members of the organization seemed to agree that the treatment cascade represented a new organizing principle for MAP, opinions varied somewhat in terms of its influence at the operational level. From the perspective of one Board member, the cascade appeared to be “fantastic” and a demonstration of “true,” not just theoretical, cause and effect. At the staff level, longtime employee Felicity observed:

I think one way of framing it is that we are shifting from being a social service organization to an organization that sees our role in public health as more significant. And I think that was always there, but I think that there's also the medicalization of HIV, using many more medical models, and I think particularly the treatment cascade is really sort of the template against which we imagine our work.

With this movement toward the cascade, however, would also come differences of opinion concerning MAP's longstanding emphasis on quality of life as a service outcome. From Ted's perspective, the focus on achieving an undetectable viral load superseded all other objectives: “In the long run, I'm only interested in your viral suppression. If all 400 of our clients... are virally suppressed, we're doing something right. We need to identify what we are doing right so we can continue our good work.” On the other hand, Nathaniel countered:

[One] way to distill it, for me is as a social worker serving people living with HIV, my end result is improving the quality of life for people living with HIV. From the public health - medical standpoint— eh, sure, improved health outcomes are good, but the bottom line is reducing the infectiousness and the transmission of HIV, so it kind of shifts the view from the person... as a person, to the person as a disease carrier in a way.

Evidence gathering processes. The opportunities considered by the organization, described in detail below, would be informed substantially by MAP's desire to align its service outcomes to the treatment cascade. Yet, the cascade itself offers no guidance in terms of specifying and prioritizing the supportive services that most effectively facilitate the HIV-positive service consumer's pathway from initial viral detection to sustained viral suppression. To understand how MAP can measure its effectiveness and develop a quantifiable market value for its offerings, members would also need to consider the processes by which the organization gathers and shares evidence of its work.

A summary of staff focus groups held in 2013, as members considered and gave feedback on potential changes, included mention of the possible improvements to current data tracking processes, should MAP either open a clinic or align its work more closely with an existing medical provider. During implementation meetings, concerns around information gathering included gaps in current data availability such as clients' medical records, establishing quality assurance and regulatory compliance with any new services and partnerships, projecting client usage numbers and potential revenues as new services are introduced, and ensuring that individual workers had an adequate understanding of how their tasks contributed to the achievement of MAP's intended service outcomes via the treatment cascade. Commenting on how MAP's data collection efforts have been largely tied to government funders' requirements, staff member Amelia speculated that

with a potential move toward diversified revenue streams, MAP would gain an ability to more nimbly respond to trends at the client population level, given that “your funding doesn’t change as quickly as the populations change.”

A question largely unsettled throughout these deliberations remained with respect to just how much growth in service usage (and therefore revenues) could the organization anticipate. With respect to projecting future service use, staff member Levi raised the question of just how many interested and eligible consumers there would be, given MAP’s position in the local healthcare marketplace, while Board member Audrey, addressing issues such as quality assurance, client satisfaction, and future service and budgetary projections, noted:

[The] statistics show that [MAP is] having a positive impact in the community. The people that they help will verbally talk about what kind of big change that they’ve had, what impact they’ve had on everything. But in some of the things that make people nervous or the things we have to start talking about, okay, what do our funds look like vis-à-vis our expenses versus our income, and that kind of thing?

With respect to measurable outcomes, members of the organization gained a considerable tool in evaluating MAP’s effectiveness by adopting the treatment cascade as a central focus. At the same time, this realignment raised the question of how to shift MAP’s internal processes so that members could adequately benchmark their accomplishments and establish a market value for non-governmental payers. As members continued to address issues of technological change, both of the subsequent themes (opportunities and barriers) would be informed by the challenge of what outcomes to

measure, how to measure them, and how to market and sell MAP's value to potential payers for its services.

Theme 4: Opportunities

Guided by members' awareness of changing context and its intention to align service outcomes to the treatment cascade, MAP's leadership addressed the question of which technological changes to adopt as the core consideration of strategic planning and subsequent implementation activities. Three subthemes came to light within this category concerning MAP's alignment within the local sector of HIV providers, its efforts to identify and build a service model based on identifiable strengths, and strategies for marketing and selling its services to HIV-affected consumers and their healthcare providers.

Alignment with providers. To determine what services to add, expand, or prioritize, the organization would need to ascertain the ways in which its offerings aligned within the continuum of assistance for local PLWH. As mentioned above, MAP's closest model for organizational change was an ASO in a neighboring state, which possessed a comparable history and service portfolio and had added full clinical and pharmacy services to its array of HIV social services. Although a number of contextual factors differed, some members viewed this peer's enhanced position in the marketplace and associated revenue increases as a desirable outcome to replicate, while others expressed skepticism toward its potential replication within the local sector. From its initial strategic planning sessions through the implementation period, MAP would give close consideration and additional study to the feasibility of establishing a specialty clinic

and pharmacy either on its own or in partnership with an existing medical provider. However, key to this determination would be an examination of the local sector's current offerings, gaps, and potential areas for growth in services that could address the unmet needs of PLWH.

National and local informants, solicited as part of strategic planning, offered a variety of opinions and perspectives about how MAP should proceed with respect to positioning its services in the new healthcare marketplace. Common among respondents was an emphasis on establishing partnerships with medical providers whose patients could benefit from MAP's service offerings, identifying which of MAP's services could be billed to insurance providers, addressing health disparity and social justice issues currently experienced by PLWH, and exploring the potential for expansion into other health conditions and illnesses. Prior to its first formal strategic planning retreat in January 2013, MAP's leadership drafted a document presenting three strategic scenarios for participants to consider, with each test vision presenting a different opportunity for the organization to align itself within the local sector. A fourth scenario, mentioned above with respect to MAP's rationale for change, was added and addressed during this first strategic planning retreat: a merger of the Minnesota AIDS Project ("sun setting") into another organization as the relevance of a distinct, community-based ASO disappears.

Scenario 1: MAP would position itself to become an HIV-specific Center of Excellence, with a formal affiliation with institutions of research in higher education and an emphasis on developing community-based interventions focused on the science of viral suppression and the elimination of new HIV infections vis-à-vis the aforementioned treatment cascade.

Scenario 2: MAP would function as part of a strategic network or alliance of services committed to creating a community-based HIV medical home, whereby

HIV-affected consumers would gain access to a continuum of linked care services that would include medical services, pharmacy access, case management, behavioral health (i.e., mental health and substance abuse treatment), dental care, HIV testing, and interventions to reduce the risk of transmission or infection.

Scenario 3: Working in partnership with an existing healthcare organization, MAP would establish itself as a medical center servicing PLWH and those with related illnesses (e.g., STI, mental illnesses, substance abuse disorders, Hepatitis, etc.). MAP would also expand its portfolio to serve broader segments of the population, such as the local LGBTQ community (without limiting itself to PLWH).

Notes from the retreat highlighted members' responses to these scenarios, which included perceived advantages (e.g., potential for innovation, new revenue streams, connections to MAP's existing expertise, optimized engagement with consumers, etc.) and drawbacks (e.g., maintaining status quo, becoming tied to research grant funding, competing directly with local medical partners, losing community-based identity, lack of startup funds versus projected and hidden costs, etc.). When prompted for consensus on which scenario was most appealing, retreat participants' responses coalesced around "...something between Scenario 2 and 3 (or Scenario 2.5)," whereby MAP would retain its longstanding mission and focus but expand its portfolio to include chronic health conditions closely relating to HIV, while also offering service eligibility to HIV-negative individuals with heightened risk for infection and HIV-positive individuals with incomes above the federal poverty guidelines specified by many of its existing government contracts. Changes to the organization, members emphasized, should be incremental and follow a step by step approach, with subsequent actions in the planning process to include refinement of communication with the larger staff, development of a fully-formed "Scenario 2.5," background research on medical and behavioral health home

qualifications, and (most salient to this subtheme) a feasibility study to explore the market for this service model as members had imagined it.

The next few months of strategic planning involved refinement and testing of a vision that would logically link population-specific outcomes (e.g., unobstructed access to medical care, treatment, and supportive services for PLWH; increased opportunities for Minnesotans at heightened risk to receive testing and assistance with HIV-related comorbidities) with MAP's intentions to grow and expand its services, its partnerships with other local providers, and its ability to bill nongovernmental payers for services rendered. During this period, MAP's leadership undertook a number of information-seeking activities mentioned in findings above, such as literature searches on current research, focus groups with MAP staff, volunteers, and program participants, and conversations with local informants in the HIV healthcare sector, with the intention of clarifying MAP's identity and function in the local HIV service sector and gaining feedback on these potential changes.

Focus group responses to these proposed changes included a mix of affirmation and concern. Participants in the staff groups saw potential for MAP to fulfill an identifiable need in the community, expand its consumer population, offer a comprehensive range of supports for PLWH, and increase the organization's "clinical legitimacy" by adding behavioral health services to its portfolio. At the same time, members also cited a number of potential drawbacks, including MAP's infrastructure and financial readiness to adopt changes of this nature, the public's perceptions concerning MAP's identity as a community-based provider, "credential bias" among staff with

respect to hiring and compensation, and added competition from existing medical providers that currently work in partnership with the organization. Focus groups involving MAP program participants and volunteers showed similarly mixed sentiments. Clear majorities indicated they would utilize MAP if it expanded to include mental health (24 out of 29), substance abuse treatment (18 out of 29), and medical care (19 out of 29), but were more evenly split on whether they would use MAP to fill prescriptions or other pharmaceutical needs (15 out of 29). To the question of utilizing MAP if it were to move to a different site, nearly as many indicated “It Depends” (8) as “Yes” (11).

Consultative conversations in 2013 between MAP’s leadership and local HIV healthcare and social service providers would inform both the finalization of its strategic plan and subsequent decisions made during the implementation phase. Leaders of multiple organizations reiterated their belief that MAP’s continued existence would be essential to the local sector’s success; however, informants’ opinions varied with respect to how they might develop a formal business partnership. Some providers found MAP’s suggestion of partnering to create a formal, community-based clinic at its current location appealing, while others immediately expressed their disinterest. A number of clinic representatives viewed MAP’s case management program, with its emphasis on psychosocial assistance in support of medical objectives (i.e., retention in care and medication adherence), as an asset they would like to offer to patients, while MAP’s supportive services such as transportation, legal assistance, care linkage, and chemical health appealed to others. As implementation of the plan continued from late 2013 into early and mid-2014, MAP’s leadership would revisit these conversations with potential

partners while conducting a market study to gauge the viability of offering its own clinic and pharmacy.

Building on strengths. Where conversations concerning potential partnerships had yielded various hypothetical opportunities (and thus no single, coalescent direction to follow), the information seeking process shed light on a number of assets for MAP to consider packaging and selling to other providers. During formal planning, staff made mention of its case management program, chemical health and syringe exchange, transitional housing, prevention, and legal services, while volunteers and program participants noted MAP's lengthy service history, its reputation as a vocal advocate on behalf of PLWH, and its capacity to refer clients to a variety of supportive services. To these service-related assets, members added one critical material consideration, namely that MAP in the past had purchased its office building and the surrounding property on the edge of downtown Minneapolis. This circumstance, which Board member Wyatt described as different from that of most other ASOs, would represent both a fortunate position and an organizational pressure: "We've got too much land for what we do, so we've got an asset, but it costs money to maintain that asset and pay it down as well, and it also requires that we're managed in a certain way because of debt covenant and so forth, too."

Interviews conducted during the implementation phase revealed multiple perspectives concerning how to leverage these various assets into opportunities for growth. Characterizing the process as "typical" for what an ASO and its leadership would

need to undertake, staff member Ted emphasized the necessity to think like a business entrepreneur:

So, we're talking to folks about... multiple opportunities on the table, and at any given point, I have to be nimble so that I can move into different conversations, and so I have multiple projects going on at the same time to get us to a point where we are seeing more of a sustainable income coming into the organization... so that we can have longevity as a business.

While consensus had been widely gained with respect to the need to change, not all interviewees were in agreement concerning how to focus its emerging business model. For example, Board member Reese cautioned against recreating or replicating existing clinic infrastructure:

There are many hospitals in the state of Minnesota that need our expertise... [on] knowing the community, knowing other challenges just than the disease, right? There's a doctor that knows a lot about infectious diseases and how to treat that, but we can be more about, okay, let's talk about the socioeconomic impact of that. We just bring our knowledge base into the existing clinic and hospital.

With respect to maintaining an HIV-centered focus, staff especially appeared more inclined to disagree with the proposed strategic vision, with multiple interviewees contending that the expertise gained in serving PLWH could be marketed for an expanded range of consumers and their medical providers. Staff member Ava characterized MAP's direction as:

...where we run into some tension, because... we can limit ourselves, if we're gonna just really focus on HIV and only HIV. I think we need to identify places in the agency... where we can easily expand to people who are not HIV-positive. You know, I think there's some people that say... we're about AIDS. We're the Minnesota AIDS Project, and... we're gonna close up shop eventually. And then there's other people like me who say, I think there's more that can be done here, and we've got great skills and systems and... let's leverage them into something new.

This sentiment, reinforcing a belief in competencies that could be leveraged beyond HIV, was echoed in comments by staff member Amelia:

You know, my personal opinion is, I think...the Board saying we are not going outside of HIV, I think, was a mistake, and it could impact our sustainability. You know, I don't think we want to travel too far outside of HIV, but I think that there are some obvious tangents to that, that we could easily... that put people at risk for HIV. Mental health, chemical health... [Hepatitis C]. We have a lot of experience in working in the LGBT community.

During this extended period of strategic planning and implementation, two examples came to light that illustrated ways for MAP to utilize its existing strengths to expand programming. One instance involved the procurement of state government funding for a collaboration by which MAP and other LGBT-serving organizations would assist uninsured Minnesotans in gaining access to the state's new healthcare exchange ("MNSure"). The MNSure Navigator program emerged from a process that closely matched the organization's historic strengths, namely its awareness and active involvement in public policy issues, a proven record of compliance and achievement of public contract goals, and close work and identification with LGBT communities.

The funding allowed for expansion of MAP's existing benefits counseling program, multiple new staff, and a consumer population that included but was not exclusive to uninsured HIV-positive or LGBT Minnesotans. Staff member Levi commented:

One of the things that [MNSure] was interested in seeing was collaboration. So, we worked... to build this coalition to say we'll do specific navigating and outreach and education to the LGBT community. They're like phone banking everyone, their entire list from the... legislative issues that they're working on

right now, and they ask, are you uninsured or under-insured? And if the answer is yes, I can patch you through to a MAP navigator who can help walk you through that process or set an appointment for you to do that.

A second example came to light with respect to building a provider-focused professional education program, whereby MAP would formally train health and human service workers, administrators, educators, and the general public about HIV and concomitant health and psychosocial issues (e.g., mental health, substance abuse, Hepatitis C, et al.), with revenue coming in the form of individual fees and continuing education units (CEUs) rather than grant funding. Staff member Sophie, who oversaw its startup and coordinated the work of 1.5 additional staff, described the process of moving from a nonprofit mindset to that of a businessperson:

There was a period of time where we would be operating in the red, and it takes a while to establish yourself as a program. We had to show, no, we're gonna make a profit or at least break even the first year... out on our own. So I sometimes found myself making a lot of promises that I didn't know if I could keep, just to get us to the point where we could prove either way if we could or not. And so... whereas case managers, they just have a contract and they just do their work and that's... they don't have to worry about it. We're going 150 miles an hour, and we're not just doing the actual work, but we're having to make sure on a daily basis that we're bringing in all this money. So it's this different mindset that isn't always supported by everyone in the agency who understands what our goal is.

MAP's fledgling training and education initiative required the organization's leaders, in Sophie's words, to "really consider the expertise they already have inside the building" without the immediate assurance that the program would attract sustainable revenue. The initiative's trajectory, she observed, showed a positive trend from a first year gross income of \$21,500, to just over \$47,000 in its second, with a third year goal of approximately \$100,000. Achieving sustainability, Sophie noted, would require MAP to

proactively seek out and sell its services to providers that do not currently have a relationship to the organization:

[We are] used to working with the same partners, who understand or are supportive of our clients. We are very invested in the entire HIV community, but when we're going to a business plan in order to bring in money, you go outside the box. You're working with other professionals in the community that don't have as high expertise in the HIV field." Taking this approach, she posited, was necessary to avoid market saturation and eventual irrelevance, while also raising the profile and perceived market worth of the program's product: "I also think, to some extent, when you start charging for your services, your reputation increases. You know, we are creating a product that deserves to be reimbursed, and I think that puts a little more value on your program.

The above examples illustrate the variety of assets that MAP would need to employ to advance new initiatives. Whereas the MNSure navigator initiative had utilized MAP's longstanding strengths to execute a strategy it had historically done well (i.e., spearhead a provider partnership and secure a publicly funded contract), the teaching and education program showed staff the potential for incremental growth based solely on selling a service to the provider marketplace. Where member interviews had pointed to a desire for MAP to adopt more of this "business startup" mindset, the organization would also need to consider how to market and sell its social service products to a definable marketplace of HIV-impacted consumers, their various attendant providers, and the philanthropic sector.

Marketing and selling. During formal strategic planning, questions of how to realign MAP's services in the emerging marketplace largely overshadowed the challenge of how to market and sell its products. However, staff focus groups in 2013 raised two related concerns, the first of which addressed MAP's current name including the word

“AIDS”: Would stigma associated with the disease impede the organization’s efforts to expand supportive services to HIV-negative consumers with risk-heightening psychosocial needs (e.g., mental illness, substance abuse, sexual risk, etc.), so that should MAP consider changing its name? Second, “How will we get access to clients we don’t reach well now? We don’t know the number of potential clients.”

To the extent that MAP possessed prior experience communicating its brand name, accomplishments, and capabilities, some interviewees noted limitations to its past approaches that included inadequate resources for public relations and advertising, project budgets that lacked funding to sustain specific communication efforts, and a general emphasis on communicating success to a narrow audience of consumers and existing supporters. One implementation meeting and at least two interviewees mentioned pro bono assistance that could potentially enhance MAP’s efforts to promote its brand and combat HIV-related stigma, but in the view of longtime staff member Felicity, this reliance on donated creative work had brought drawbacks to MAP’s branding efforts over time:

A lot of the work is donated and pro bono, and... sometimes that shows. And I know for financial reasons, that’s what happens. But... sometimes. And I think it’s been getting better, but there have been instances where it’s, in my opinion, it has not been great for representing the organization.

Conversations concerning how to communicate its new strategic plan and the attractiveness of its services would continue as MAP moved from planning to implementation, with meetings especially focusing on dissemination of the plan to potential donors and projections for service use and revenues as new services became

available. Staff's previous experiences with startup ventures tempered expectations concerning how long it would take to see profit, although questions would arise with respect to encouraging MAP's workforce—largely human service professionals oriented toward offering assistance—to promote or sell new services to MAP's consumers, especially as the possibility of adding pharmacy services came to be considered.

Speaking to this challenge, staff member Amelia observed:

[Our] case managers don't have that skill set of... I don't want to say sales. That's maybe too strong, but, you know maybe there's a little bit of urgency that maybe we don't normally have with clients. It's the first time it'll be something that benefits MAP and benefits the client, and that's a little bit of a shift for them.

The opportunity to market and sell MAP's emerging service model—and in fact its viability within the local healthcare market itself—offered possibilities for new developments mixed with potential pitfalls, most of which concerned its members' lack of experience and expertise or the absence of resources in the past to carry out these promotional endeavors in a sustained fashion. However, while subthemes related to opportunities are somewhat tempered by anticipation of these obstacles, the presence of more established and enduring technological barriers would constitute their own theme, to be discussed more fully in the passages to follow.

Theme 6: Barriers

As members attempted to tailor potential changes (and investments in change) to what they viewed as the organization's recognizable strengths, they also faced the necessity of reconciling their intentions with a number of persistent barriers. Two critical subthemes emerged concerning first, environmental limitations surrounding community-

based HIV services and second, concerning perceived obstacles within the structure of the organization.

Environmental limitations. Obstacles within the HIV service provider environment gained consideration early in 2013, as leadership began to test the feasibility of the strategic vision around which participants had achieved consensus in MAP's first strategic planning retreat. One planning document, which summarized staff's search for recently published HIV healthcare research (labeled as a "feasibility test"), noted such trends as a decline in the number of providers across several relevant disciplines (e.g., behavioral health, dental, primary care, etc.), coupled with shortages of rural healthcare providers and those lacking training in issues relevant to HIV care such as minority health and LGBT cultural competence; PLWH who were uninsured or underinsured, owing to their ineligibility for means-tested public assistance programs such as Ryan White or Medicaid; and a general lack of research on the needs of PLWH as they age.

Echoing concerns about HIV-positive individuals lacking insurance, staff focus group findings during this phase raised the related apprehension toward having limited referral resources for PLWH whose incomes fall outside of the Ryan White care system's eligibility requirements, while also posing questions concerning the "fit" between MAP's plans and the perceived intentions of ACA legislation, especially those related to finding a medical "home" for patients situated within larger, more comprehensive healthcare organizations. Staff focus group participants also raised concerns about potential expansion to address conditions related to HIV (e.g., mental health, substance abuse, Hepatitis C, etc.) with consumers not living with the virus, which begged questions

concerning how the services would be funded and whether or not MAP would be simply replicating its current dependence on government grants without gaining long-term, sustainable revenue.

The aforementioned staff focus groups raised concerns specific to the local HIV service sector as well, which were later echoed by interview participants during the implementation phase of MAP's strategic plan. In some instances, members expressed skepticism concerning MAP's ability to compete with larger, well-established healthcare organizations in the local sector, while in other conversations, members shared the viewpoint that MAP still operated alongside several smaller community-based ASOs that were funded by the state to serve specific demographic categories within Minnesota's PLWH population, and it had thus been segmented as a provider for older, white gay men. MAP's ability to expand its services, in the eyes of at least one Board member, had been held back by the state's desire to fund its Ryan White care services broadly and shallowly, versus investing in one provider of consolidated services that would have the infrastructure needed to meet the regulatory needs of the private healthcare system. Speaking to this point, staff member Sophie observed, "HIV organizations are quite different from other establishments because there's such a small funding stream, and so, we don't always come together, and so there's kind of that constant fight for this piece of the pie."

Obstacles within the organization. In various documents, meetings, and interviews, members inevitably made mention of these systemic considerations in light of obstacles they recognized in the internal structure of the organization. Financial

considerations (including funders and revenue streams, startup costs, sustainability, and potential profit margins) stood out chiefly as the most cited barrier, with concerns raised with respect to several questions, including how MAP will find the startup money for new services that are not tied to grant funding; how MAP will operate services that may experience periodic drops in usage and revenue; how MAP will build its capacity for billing Medicaid and private insurers; how MAP will attract new donors and reengage with previous supporters who had lapsed; and how would MAP overcome the multiyear trend of declining fundraising, which had greatly reduced its access to discretionary funds.

Related to financial concerns were structural issues that members raised across the study, including frequent turnover (especially in MAP's finance department), a lack of human resources management, and the inability to purchase and maintain new technologies, which could aid in multiple areas such as billing (as mentioned above), philanthropy, and accessing consumers' medical records. Turnover proved to be especially challenging to the organization during the implementation phase, when data collection involved more direct contact between members and the researcher. The departure of senior level finance staff during early the implementation months (late 2013 to early 2014) led to a period of slower progress on the plan, while a restructuring in later months that caused a longtime programmatic leader's departure resulted in members' expression of a loss of morale and declining trust in MAP's current decision makers.

Staff interview participants counted 22 employee departures between January and September 2014, with contributing factors including low and stagnant compensation, lack

of training and development opportunities, and lack of advancement opportunities within MAP. Relating these conditions to concerns about MAP's potential changes, one longtime worker observed, "[Another] staff member... once said to me was, this is an organization that hires people who have bachelor's degrees, and that there isn't the investment in the staff to... really help the staff become more professional." To this point, the absence of a dedicated human resources staff may have contributed to the difficulties associated with turnover, as members lamented the ways in which they were drawn away from their assigned roles to manage "drama" in the workplace and cited the lack of senior staff with expertise in change management, who would be able to skillfully facilitate communication between MAP's leadership and its workforce.

Technology also earned frequent mention as a barrier, with limitations including old computers and software systems, the inability to afford training for its workers on new software systems, and lack of access to consumers' health records. Whereas clinics and hospitals have widely adopted software systems that allow for easier entry and sharing of patient health information, MAP staff continued to rely on consumers' self-reports for vital information such as current viral levels and concomitant health conditions. Staff member Nathaniel, describing MAP's technology as "nowhere near what it would need to be," described the present situation:

I mean right now, pretty much everything is in a paper chart and then typed into a system, and then maybe entered somewhere else, so... we have a lot of paper shuffled back and forth and... just not what I see when I go to a clinic setting anymore, not even what I see in a lot of nonprofit organizations, where you're signing consent forms on a touch screen and you're just... wasting time moving paper back and forth. So I think, the technology aspect of it would be big. And in general... the agency infrastructure needs to be stronger.

Mindful of these barriers but determined to leverage MAP's perceived strengths into programmatic expansion, its leadership made two key decisions that reflected both its need to pursue revenue-generating opportunities and its consideration of barriers that could not be quickly overcome. First, with respect to offering clinical mental health services, staff determined that MAP lacked the infrastructure to skillfully conduct its own billing; however, using a Board member's familiarity with a local behavioral health provider, MAP entered a contractual relationship by which first one and then a second licensed therapist began seeing clients at the MAP office site. This clinical partner managed all billing, and therapists were able to see persons referred by MAP staff regardless of the individual's HIV diagnosis. When consumer usage had reached a certain agreed upon level, MAP would begin sharing in the profits, and the provider also agreed to show staff how to eventually establish its own billing practices. Despite the lack of projected new revenues at the outset, to at least one member the service represented "a value and a commodity," in that it enabled MAP to bring potential new consumers through its doors, gain recognition in the community as a place where clinical mental health services were offered, and eventually gain revenues through profit sharing. Reflecting on these developments during a follow-up interview, staff member Amelia concurred:

[We] wanted to do mental health ourselves and do billing for it, and it became really clear to us that we didn't have the internal capacity to really pull it off... as quickly as we wanted. So, instead we decided to develop a working agreement with another agency so they come in and do it. So our clients are getting the service they need, and... there was no risk to us, because it's their risk. And, yet we are filling a need, I think, of the community. But I think had we tried to do the billing ourselves... Boy. I don't know where we'd be in that process. I mean it sounds silly, billing. But it is just a formidable task, because it's a lot of... when

you're billing in terms of [Medical Assistance] or Medicare... you have to have a lot of pieces beyond the billing in place, and the billing itself is formidable.

A second expansion, concerning pharmaceutical services, would gain traction as MAP's leadership was forced to reconcile itself to other structural barriers. First, while the feasibility of adding a pharmacy had been studied in tandem with adding a community-based clinic to the organization, leadership saw limited evidence that a substantial number of local PLWH needed or would desire an additional, standalone HIV medical provider; potential clinic partners, meanwhile, had been receptive to discussing formal collaborations with MAP, but any decisions to move forward would take months to develop. By mid-2014, leadership faced another critical issue concerning funding, fund development, and discretionary revenues: continuing a ten-year pattern of decline, MAP's signature annual fundraiser had failed to produce its anticipated level of revenue, leaving Board and staff with several questions about how to proceed with programs that were commonly regarded as necessary and well executed, but chronically lacking the infrastructure to fully support their efforts.

One avenue for ameliorating these declining revenues would present itself in the form of 340B drug pricing, a program guided by federal law and administered by the U.S. government's Health Resources and Services Administration (HRSA), whereby providers of medical services to Ryan White-eligible PLWH could partner with a contract pharmacy to deliver medication (both HIV and non-HIV specific) to consumers and receive a share of federally-specified rebates on each sale (Health Resources and Services Administration [HRSA], 2015). By virtue of its Ryan White-funded case management program, MAP would be considered eligible for "covered entity" status, enabling it to

enter a contractual partnership with a pharmacy outside of Minnesota, which would supply any MAP clients who enrolled in the service via mail order. With virtually no projected startup costs, the organization could begin seeing new revenues due to pharmaceutical sales by the final quarter of 2014.

By mid-July of 2014, MAP had secured its federal status as a covered entity and entered into a contractual relationship with a pharmaceutical provider that would manage all regulatory compliance issues and train MAP's case management staff on how to promote the service to consumers. Concerns would continue to arise, however, with respect to how a contract pharmacy would shore up and diversify MAP's revenue streams. Most salient was the question of how many consumers were eligible to use the out of state pharmacy, as state law did not permit the granting of rebates in instances when state-run medical assistance recipients (i.e., Minnesota's Medicaid program) utilized an out-of-state pharmacy. Initial projections of up to 200 case management consumers were revised downward to 50 to 75 by the time data collection had concluded; however, because MAP's leadership had negotiated a non-exclusivity clause with its out-of-state pharmacy partner, the organization had begun searching for a local partner to address this gap in projected consumers.

Knowledge Of and/or Identification With HIV-Affected Populations

Largely from participant interviews and to a lesser extent from documents and meeting observations (as summarized below in Table 8), two distinct themes illustrate the extent to which members of MAP's Board and staff identified with the characteristics,

experiences, and needs of HIV-affected constituencies: Population Characteristics and Service Needs.

Table 8: Summary of data sources for Research Question 3

Theme	Number of Documents (n = 40)	Number of Meeting Observations (n = 10)	Number of Interviews (n = 26)
Population characteristics	2	1	13
Service needs	3	1	8

Theme 6: Population characteristics.

Within this category, two subthemes emerged. The first concerns members' self-described attributes identifying themselves with MAP's constituencies, which in this context include identity (either as LGBTQ or HIV-positive), experiences, and/or motivations for working in a community-based ASO; the second addresses the ways members recognize the influence of stigma and marginalization on the daily lived experiences of HIV-positive populations and those with elevated risk for infection.

Member attributes. Members' self-characterizations came mainly from participant interviews, when Board and staff were asked to describe how they came to be involved with the organization. Some members had formed a relationship with MAP as recently as within the past year, while others traced their history with the organization to the early 1990s, with ties to HIV reaching even earlier to the epidemic's first decade. For

these members with longer memories, the traumatic circumstances of a period when patients grew sick and died rapidly continued to influence their involvement, which staff member Ted described as “having an axe to grind with the epidemic.” Reflecting on this period in his life, Board member Douglass recounted losing more than 100 acquaintances, losing count of the losses, and wondering how he had managed to avoid infection. Relating these experiences to present day, he commented:

So, those of us that kind of came through that, I think we're really angry. A lot of us are really angry. And, I try not to be judgmental, and I try not to, but it takes a real serious kind of effort. And I'm only talking to you about this because I haven't really talked to anybody other than my friends about this.

These memories seemed to motivate longer-serving members to achieve a measure of victory over the disease for past losses it had inflicted; for members with more recent histories, their involvement with MAP represented an opportunity to fulfill a personal desire to positively impact the community, either through working as a social service professional or volunteering with a cause they identified closely with themselves or their loved ones. In their interview responses, staff and Board mentioned the attraction to nonprofit work as an alternative to for-profit corporate settings, “[putting] my money where my mouth is” in terms of volunteering and fundraising, and strengthening the feeling of a personal connection to one's professional identity. In staff member Levi's words, “You know, I have... family and friends that have been impacted by HIV, and so it's just an issue, a personal issue that's been important to me for a long time. And I thought, you know, geez, this is sort of what I got into this... profession to begin with.”

Numerous respondents characterized MAP's workforce as dedicated and passionate, qualities viewed by some members as key contributors to the fulfillment of MAP's mission. From the perspective of Audrey, a recent addition to the Board, this commitment represented an especially clear focus on carrying out the organization's mission:

When you talk to the people, when you look at the programs, you look at the offerings, what you see is an organization that is truly committed to serving the area of their focus, right? So, the HIV/AIDS community, reducing HIV/AIDS instances, all of that kind of thing. You see it in the programs, you see it in the conversations with the people. I think that's been key.

With this dedication, staff member Sophie observed, also came diversity of ideas concerning how to adequately and equitably carry out the work, which she described as challenging but also rewarding: "You're kind of always fighting the other systems and people's attitudes... beliefs and opinions, and... at some points that makes for a stronger staff within HIV organizations, because you feel like you're fighting toward... a basic [set of] human rights."

Stigma and marginalization. Accompanying this close identification with MAP's constituencies was a recognition that stigma, meaning a sense of discomfort or shame in being identified with behaviors viewed as inappropriate or morally wrong by society, and marginalization, as it relates to historical discrimination against minority populations within society, were especially endemic to the lived experiences of the organizations main service consumers. External research reviewed during MAP's initial strategic planning phase offered evidence in support of these distinct conditions for PLWH and those with perceived risks. In addition to documenting self-reported incidents

of provider discrimination or insensitivity, for example, background literature described how people of color living with HIV experience the concept of intersectionality, i.e., the combination of multiple traits such as race or ethnicity, sexual orientation, gender identity, and HIV diagnosis, in ways that contribute to a lingering sense of concern or apprehension over how they will be treated by service providers.

For some interview participants, the issue of stigma and shame related to HIV's disproportionate representation among men who have sex with men and thus the larger sexual minority identity of LGBTQ, while for others the connection centered more on specific behaviors, such as unprotected intercourse and substance use. For these reasons, members characterized the virus as a "pariah disease" that "just stands alone" due to underlying shame and societal discrimination, while describing MAP as an organization "uniquely sensitive" to conditions experienced by populations with a "constellation of identities." Speaking to the marginalized identities of HIV-positive constituents, staff member Gabriel framed his comments around a common identification with communities that have been historically recognized as disadvantaged in American society: "[Because] so many of the people who are infected with HIV are from... the more disenfranchised segments of society... you know, [injection drug users], gay men, African-American women... other communities of color. So... they tend to be not... the WASP."

Multiple participants mentioned stigma, shame, and marginalization in ways that contributed additional considerations to this theme. For example, while speaking to the issue of stigma, Douglass related his views on judgment and discrimination toward HIV-positive individuals by other gay men, a group that has historically experienced antigay

prejudice from the larger society. Relating his views of the present-day epidemic to his own lived experience as a gay man who survived the epidemic's earliest years, he observed:

I think that the judgment, including myself... there should be no reason somebody gets HIV anymore, especially if you're gay. Not now! It just shouldn't be. And so there's a judgmental piece of it that I have to deal with. It's almost like having dealt with coming out and internalized homophobia. It's very complicated.

Theme 7: Service needs

From the earliest stages of strategic planning in 2013, MAP's Board members and staff raised a number of concerns with key trends in the broader population of PLWH, which pointed to a changing or emerging set of constituent needs that the organization had not historically positioned itself to address. Chief among these concerns were medical needs, referring to the specific physical health of PLWH and associated populations, and psychosocial needs, taken here to include a range of conditions including mental health, substance abuse, and emotional support. Other ancillary needs such as housing, transportation, and financial assistance were not mentioned directly enough to warrant inclusion with these themes, although MAP continues to offer these services.

Medical needs. As noted previously, historic medical advances in the 1990s had begun to shift HIV's medical prognosis away from likely death to long-term and increasingly manageable. With this movement away from consumers experiencing HIV as a more acute condition, the need for supportive services with substantial levels of personal involvement between provider and client were presumed to be less intensive as

well. Having worked with clients since this earlier time, staff member Ava observed, “I think with the changes in the epidemic, we’re just not gonna have people with the intensive needs because of the... really the chronic disease nature of the thing. So in that regard, we might be moving toward more of an MS, cancer kind of thing where you’re dealing with chronic issues for years and years and years and years, that need just minimal information and guidance until you reach an acute phase.”

Acuteness, however, should not be confused with a lack of urgency with respect to keeping individuals engaged with treatment. As Board member Craig noted,

It's so very critical that you get everything right, because if you don't have something right, you're really disrupting not just the overall quality of life, but... I'm thinking from the healthcare standpoint. So, if you don't get a patient to maybe their doctor's office soon enough, and they maybe miss a couple days on their meds, diabetes medicine... We may increase your dosage a little bit. HIV meds, if you mess up here or there, you could disrupt the long-term survival, the morbidity or mortality of the patient if they get a resistant infection because this one thing wasn't there.

Thus, the variety of contingencies in a patient’s daily living pattern, which may disrupt one’s utilization of medical care and pharmaceutical treatment, would need ongoing consideration from providers to ensure that the virus does not progress to a more acute phase and/or bring about more severe coinfections with other illnesses, such as such as Hepatitis C and sexually transmitted infections.

Psychosocial needs. Planning documents also identified specific unmet service needs associated with aging and HIV, dental care, health insurance, mental health, and case management, while noting that services needs of PLWH with incomes above federal poverty guidelines remained unknown (and could represent a potential new market for

some of MAP's services). Interview participants offered their considerations for how services should be tailored to the lived experiences of MAP's HIV-affected constituencies, with stigma again mentioned among a number of concerns. Dominic, for example, emphasized the need for providers to pay close attention to each consumer's immediate circumstances: "[There] has to be support there. There has to be some hand holding. And that's okay, and that's a part of the gig, with HIV or with chemical health. You have to meet them where they're at."

To that end, staff member Gabriel raised the issue of facilitating a peer to peer relationship between providers and consumers, whereby PLWH can benefit from working with staff who possess an intimate understanding of the individual's circumstances:

You know, I think it's great that so many people in the organization care and are empathetic and sympathetic. But until you've woken up at 2 o'clock in the morning with night sweats, you know, you don't know what that's like. And if that's what's preventing you from taking your medication... let's try to work through this together, and what did I do to get past that, and what can you do with the information I gave you? Let's come up with a game plan to do that.

With respect to addressing these needs within MAP's new strategic plan, Gabriel viewed the circumstances as an opportunity to leverage members' ties to the community to engage potential new consumers:

We can speak better to, you know, some of the challenges that, if you're wanting to get ahold of someone, we can [say], 'You know, this is what I went through in order to stay in care. What can we do to help you maintain your care or get into care?' So, we could be the conduit to get people in through outreach.

Yet, Gabriel noted that opportunities for PLWH to gain visible employment in the organization had remained slim, thus limiting staff's ability to utilize such intimate firsthand knowledge across its consumers' various needs. Noting a downward trend in openly HIV-positive employees at MAP, he noted:

And you know, when I started here... I think that the staff numbered sixty-two. At that point, there were seven people who were openly HIV-positive in the organization. That number has dwindled to four, and the staff has not diminished that much. I think we have fifty-two or fifty-three staff people, and right now there are four people who identify or have identified at certain levels as HIV-positive. And two of those... are hired by virtue of... HIV status. So... it's an interesting... quandary.

Organization History and Service Values

As detailed below in Table 9, considerations of the organization's history and service values stood out in a number of strategic planning documents and meeting observations, although the bulk of relevant information came from participant interviews, when members were asked to describe MAP's defining qualities and how the proposed changes might impact the organization. Two overarching themes emerged with respect to the organization's history and service values: Defining Service Characteristics and Workplace Culture.

Table 9: Summary of data sources for Research Question 4

Theme	Number of Documents (n = 40)	Number of Meeting Observations (n = 10)	Number of Interviews (n = 26)
Defining service characteristics	8	1	22
Workplace culture	5	5	24

Theme 8: Defining service characteristics

Whereas the technological considerations described above shed light on *what* MAP does (and how those functions might be leveraged into future revenue opportunities), the elements detailed below illustrate *how* the organization carries out its work and the institutional memory that informs members' approaches. Thus, within the larger category of defining service characteristics, two subthemes arose concerning the emphasis MAP places on its services and the longevity as a service provider.

Emphasis. Across multiple documents and participant interviews, members described the priorities MAP places on the delivery of its services, including: services that are unique from other health and human service organizations; services that are diverse and varied based on PLWH needs; services that emphasize a trusting relationship between consumer and provider; services that publicly advocate for the needs of its consumers; and services that are tailored to address the needs and affirm the identities of MAP's LGBT consumers. From early 2013 onward, strategic planning documents that largely focused on clarifying MAP's targeted marketplace and most feasible service

model continued to check and recheck potential changes against the organization's identity as a community-based ASO, founded by and still recognized as serving members of the LGBT community. Where these service characteristics merited mention in documentation from this phase, participant interviews offer key examples of how these elements are recognized in context of members' ongoing work.

With respect to the diversity and uniqueness of its services, early planning documents indicate that Board and staff shared a view of MAP as "a large organization with a broad range of services" that are "well known and/or unique including syringe exchange, prevention, and case management" as well as "leadership in advocacy." Board member Craig stressed the importance of MAP's comprehensive service offerings:

I would say maybe multifaceted, just because I've learned too that Minnesota AIDS Project— and this is the part that I really loved about it when I started getting involved— it wasn't one little thing, it's not... We do housing. We do food assistance. It's everything. It's this comprehensive... just this conglomerate of all the needs of this specific community under one roof, or as much as we can fit under one roof. I really feel its main strength lies in its ability to provide so many services.

As an example of this comprehensiveness, multiple interviewees described how MAP's social services included an emphasis beyond medical issues to include meeting consumers' psychosocial and basic needs. As Nathaniel related:

An easy example... in the case management system, there are case managers that are technically the same type that MAP's are in various clinics. On the AIDSLine side, if we're making a referral for a client to get into case management services, if it seems like their medical stuff is kind of semi-stable and their needs are more around social service needs, basic needs, housing, things like that, we will not refer to a clinic program, because the clinic programs don't have the capacity and the skill level at this point to work on some of those issues... as opposed to our case management here; we can still do pretty intensive work around housing and stuff like that.

In addition to emphasizing a comprehensive or holistic range of services, members also described how the intimate nature of HIV infection- primarily transmitted in the U.S. through unprotected sexual intercourse or sharing syringes- influenced the relationship between service provider and consumer. For example, staff member Amelia noted, “I think, well certainly... because it’s HIV, we deal very straightforwardly with sexual, sex and sexuality and sexual identity and... all of those issues that I think other organizations... don’t even want to touch.” With respect to substance use and HIV risk, staff member Dominic added a similar sentiment:

There’s no other place that I know of where you can go into and talk about drug use... and not be judged or told what to do on some level. And our clients really appreciate that. I mean the feedback is, “I really appreciate that.”

Members’ emphasis on establishing trust between the consumer and provider touched closely on these intimate facets of HIV transmission, the lifelong nature of infection, and the aforementioned stigma. Echoing this sentiment, staff member Paige observed, “[The] thing that has struck me about working in HIV services is just how personal it is and how fast you get to that... place of trust, and I think that is... unique really to HIV service organizations.”

Multiple planning documents cited MAP’s reputation as a leading public advocate for PLWH as a critical service emphasis. As the organization’s leadership finalized its vision in mid-2013, the stated intentions specifically included a continuation of MAP’s emphasis on voicing public policy concerns with legislators and the general public.

Numerous interviewees affirmed this emphasis, with Board member Wyatt describing the

organization as “extremely strong in advocacy.” More specifically, he noted, “I think frankly MAP is the go-to place for HIV and AIDS policy. You ask most people what you think of when you think HIV and AIDS policy, what organization, it’ll be MAP.”

MAP’s identification with the LGBT community arose in multiple planning documents and across numerous participant interviews. Because of the organization’s founding by gay activists and the continuing overrepresentation of men who have sex with men in local and national epidemiology, LGBT-related concerns are addressed in subsequent thematic findings such as longevity and identification with HIV-affected constituencies. However, the emphasis on meeting the needs of LGBT-identified consumers and diverging opinions concerning the extent to which MAP should expand its emphasis with this population stood out as especially critical to understanding the ways in which members defined the organization’s work.

Staff’s review of local and national research pointed toward the need for services to address LGBT health disparities, provider discrimination based on sexual orientation and gender identity, and cultural competency training around issues of human sexuality. One option presented during the initial strategic planning retreat (described as *Scenario 3* under Technological Considerations above) would see MAP develop into a community-based medical center that would expand to serve a broader segment of the LGBT community, which some Board and staff found concerning in that it might undermine the organization’s efforts to attract non-LGBT consumers. Evidence of this concern also came to light in focus groups with volunteers and program participants, where some

members described MAP as having an emphasis on LGBT-specific programming to the exclusion of non-LGBT women of color.

Participant interviews reflected a similar lack of consensus concerning MAP's emphasis on LGBT-centered programming, with some describing it as a historic strength, especially with respect to advocacy and prevention efforts, and in the case of Board member Craig even likening the organization to a community or family: "I know MAP has always been very focused on just trying to get everybody involved. It's not just the community affected, but also the supporters of that community." At the same time, Board member Naomi questioned whether MAP's emphasis had kept up with the community's changing needs, observing, "Stereotypes are stereotypes for a reason, and we are an old white man's organization."

Longevity. Planning documents and member interviews cited MAP's thirty years of experience, often in tandem with the service emphases mentioned above, as defining characteristics of the organization. Constituent focus groups described the organization as having been there "in the beginning" and remaining active in its purpose ever since, which members recognized for both its strengths and limitations. For example, Board member Wyatt described the organization as "embodying the history of the epidemic" and "extremely embedded in the community," while staff member Nathaniel, with quiet laughter, characterized MAP as "[an] organization with a whole lot of history... good and bad baggage that goes with having all that history." In addition to "baggage," members also speculated that MAP's longevity and its position as the largest local ASO may have

contributed to a sense of complacency in the years leading up to the current systemic change process.

Staff who experienced the earlier years of the epidemic, when HIV-positive patients were presumed to grow sick and die quickly, noted how changes in the prognosis of the disease had served to deepen relationships with some consumers over time. Staff member Ava, reflecting on the long-term nature of contact between providers and consumers, noted the closeness that had grown out of these connections: “[There’s] long-term relationships because people are living longer.” Constituent focus groups also mentioned this connection to earlier years, as older participants compared MAP’s current service offerings to those from ten to twenty years ago, which often relied heavily on volunteers from the community to distribute risk reduction materials or speak on the organization’s behalf.

Accompanying this recognition of MAP’s history as a source of knowledge and expertise were concerns about identifying with the past in a manner that could diminish the organization’s current and future relevance to consumers. For example, consumer focus group members questioned the continued use of “AIDS” in MAP’s name, which was described as reinforcing “stigma and misunderstanding about what HIV/AIDS means, is a dated concept.” As noted above, MAP’s longstanding work with LGBT constituencies drew mixed sentiments from members, including some who viewed it as a fundamental strength while others questioned whether MAP could effectively attract non-LGBT constituencies. One example of this unease between past and future was raised during a September 2013 meeting with staff concerning the newly approved strategic

plan, when a member asked about the continued prominence of a large, rainbow-colored LGBT pride flag hanging in the lobby. While noting the importance of recognizing MAP's origins, some staff questioned whether its centrality, combined with the absence of banners or artifacts signifying a welcome to other minority populations, would instead communicate an exclusionary message that could undermine its efforts to reach a broader circle of HIV-affected constituencies.

Theme 9: Workplace culture

A number of factors within the organization came to light that, in contrast to service characteristics pertained more closely to interactions and expectations held between the members who collectively comprise the makeup of the organization. From these factors, two subthemes emerged concerning unsettled points of view concerning MAP's present identity and perceptions of professionalization that might occur in the future.

Unsettled. When prompted during participant interviews, members also expressed their opinions concerning how the technological changes under consideration might influence the culture of the organization in the future. In response, members described their perceptions of MAP's culture in a variety of ways, although some stark contrasts emerged between members who viewed it positively and those who questioned whether a "culture" really existed within the organization. On one hand, Ava commented, "It's a very... comfortable workplace. It's a place I think that's supportive to employees. There's not a lot of internal politics in my experience with MAP." Her colleague Dominic, however, expressed a sharply different viewpoint: "Well, we have to create a

culture first. [There] are departments and there are cultures and there are cliques within that, but there is no overarching culture at MAP. I mean, unless you want to consider an airport concourse ‘culture.’”

In light of these differences, interviewees’ perceptions of MAP’s culture in the context of systemic change illuminated ways in which the organization’s identity continued to be questioned or reconsidered. For example, Board member Wyatt wondered if the organization had operated in more of a reactive “crisis mode,” responding to external forces such as changes in funding instead of anticipating how to best operate in the future:

We’re kind of still reacting to the form of the crisis. This [change process] is going to be a lot more of looking ahead, to the continuity of the future of HIV, until there’s a cure, you know. And then also, rather than living grant to grant and having our services completely morph based on what grants are available, I mean, we’re expanding now in the African American community because there’s a grant there. You know, and so we’re reacting simply to where the cash goes.

Participant interviews cited MAP’s tenuous financial circumstances—tied heavily to government contracts while discretionary income declined—in ways that indicated both a technological barrier (as noted above) and a reflection on concerns about the organization’s identity. In multiple planning documents and interviews, staff noted pressures such as substandard pay, lack of benefits such as contributing to a retirement plan or tuition assistance, and loss of talented staff for higher paying jobs. Yet, staff also expressed concerns with introducing a clinic and pharmacy to MAP, which included the potential loss of its distinction as a community-based organization, the perceived medicalization of its staff, and favoritism or hierarchical deference toward certain

credentialed workers. One example, cited by staff member Nathaniel, involved the team approach used by its social service workers to address consumers' multifaceted needs:

[The] professionals in MAP are all pretty equal at the professional level, so there isn't some of the politics and... conflict that can happen when you have a truly multidisciplinary team, i.e., a medical doctor who's telling a social worker what they should be doing with a client, or a social worker trying to have a medical doctor hear what they're saying. It's one thing to feel... that conflict and tension externally. It would really add a new dynamic of how to manage through that if it that were an internal element.

Professionalism. Participant interviews brought to light contrasting opinions concerning the potential for changes to the organization's identity, with two key concerns involving workers' attire (i.e., clothing that resembles a clinic staff versus casual dress) and holding members accountable for their job performances. For staff member Ted, the issue of professional attire was related directly to funding and revenue: "Well I mean, I think, grass root organizations... you get the picture of grunge and Birkenstocks, but we aren't. We're... that might be somewhere in the organization. I think some people... still hold that close and that's okay. But when it comes to how money is brought into the organization, it's... wing tips and suits." Yet, his colleague Amelia echoed the sentiments of other workers that an informal dress code was critical in some instances for establishing trust and rapport with populations that have historically avoided more formal, clinic-based services: "[We] have a group of clients that really need some of these sort of informal services in order to engage in care. And I think it's going to be much, much harder to pay for [these services]."

Other staff favored allowing workers to dress as they see fit, or in the case of Levi, speculated that the addition of clinic-based services would do little to change this facet of the organization's identity:

Will [senior management] still allow them to still come dressed as they do? I don't know, I mean, hopefully because... it's a fun culture and I think people really appreciate that, and if adding a clinic-pharmacy means folks have to dress like I do every day to work, then I think it might change the [culture], but I doubt it. [That's] just part of who MAP is, and our client base, I think, appreciates that. I mean, it's different than walking into the county office. So I don't know, I would have a hard time seeing MAP... becoming a shirt and tie type of an office, even if we had a clinic-pharmacy.

Longtime staff member Felicity, however, countered with her desire to see the organization shift toward a more standard dress code across departments:

My own sense and frankly my own hope is that it will encourage more professionalization within the staff. And, I think sometimes, and this is a personal observation, things are a little too... casual here, in terms of... just how the staff presents itself and... I think, you know, again there's been such a... tension between people seeing the people who, some of the people who work at MAP, this is part of our community. And then there's the other, more professional service end of it.

With this anticipation and speculation about changes to the organization's culture, concerns about members' accountability to MAP's mission arose in ways that differed between Board members and some members of senior management. At the Board level, members discussed the issue at a strategic planning implementation committee meeting in early 2014, when the question of varying levels of staff buy-in for the plan was raised. In the context of concern that individual workers may express tacit or passive resistance to the plan, participants related their observations to the absence of a dedicated human resources staff, a technological barrier cited above which, in the context of organizational

culture, represented an additional burden on managers to develop and maintain performance standards tailored to each unique program, without consistent guidance from the organization itself. While the treatment cascade offered MAP an opportunity to link its service achievements directly to an overarching, measurable outcome (i.e., suppression of viral load in the community through retention in medical treatment), members pondered how best to determine the extent to which workers were able to relate the accomplishment of their core job functions to this guiding concept.

In multiple interviews, Board and staff related these tensions around accountability to MAP's identity as a nonprofit organization that emphasizes the health of the greater community over generating profitable revenues. At the Board level, Naomi commented:

No secret, I mean, I appreciate that nonprofits run without making a profit— I get it. However... nonprofits are a business, and I believe nonprofits should be run how for-profit businesses are in terms of employee expectations, performance reviews... if you're not able to do your job, what do we do to move you into a position that's better suited, or move you out of the organization? I have no problem with that at all levels. I think that can be really scary for staff to think about the possibility of eliminating their job. Or, being asked to do something that they don't consider to be in their wheelhouse. "You know, I'm really comfortable with what I do, I'm really good at what I do, or I think I'm really good at what I do. I don't want to be pushed or stretched."

Having overseen the growth of the aforementioned teaching and education program, the income for which comes from fees and CEUs, staff member Sophie offered a firsthand observation of these challenges within MAP's existing culture:

Well, I already can see how it impacts [culture]. I find myself having to explain our model and having people say, "Well that can't be right!" We produce a product, a service for the better good of the community. If we don't bring in the money, we can't do the good work. So our first goal is always to bring in money

to support the program so we can keep doing the good work, and I think it's the opposite for other people.

As a counterpoint, however, some participants raised concerns about a lack of adequate training on vital workplace components, such as business plan development and technology utilization. Staff member Amelia emphasized that MAP's leadership needed to make sure that workers were adequately educated and trained on their changing responsibilities:

We want... managers maybe to have better financial skills than we do. Well, then we better invest in that process, or we're not gonna get there. Sometimes we say, hey, write a business plan on this. We've never told somebody how to write a business plan, or what's the purpose of a business plan; it's just a phrase for a lot of people. I think it's going to be that business models are going to become more important. We don't have business people here. And so we need to have... people who can do both the human service piece and the business piece. We need to combine that.

ASO Members' Systemic Change Experiences (Part II)

As noted at the beginning of this chapter, one theme pertaining to members' experiences with systemic change, Appraisal of the Change Process, addressed members' perceptions of how systemic change should be carried out, as well as their reflections after specific changes had been introduced within the organization. As these considerations followed most of the findings presented above, the theme is therefore presented at chapter's end so that members' responses may be considered in chronological context. Table 10 summarizes the data sources pertaining to this theme.

Table 10: Summary of data sources for Research Question 1 (Part II)

Theme	Number of Documents (n = 40)	Number of Meeting Observations (n = 10)	Number of Interviews (n = 26)
Appraisal of the change process	7	9	26

Theme 10: Appraisal of the change process

Members' appraisal of the change process itself fell into two main thematic subcategories: opinions on how changes should be facilitated, and appraisals of changes that had occurred.

How changes should be facilitated. The notion of uncertainty, implicit throughout MAP's formulation of its rationale for change, emerged more fully in members' perspectives concerning how the organization should proceed. Across the entire change process, the competing notions expediency/urgency and caution persisted in organizational documents, implementation meetings, and participant interviews. On one hand, the lack of certainty concerning future revenue streams in the post-ACA healthcare environment led stakeholders (both internal and external) to assert that MAP needed to act swiftly, position itself ahead of other local HIV service providers, and offer itself as an example and a technical assistance provider to other organizations. The sentiment stood out especially in leaders' conversations with heads of other local ASOs, who offered encouragement and a desire to see the Minnesota AIDS Project clarify its

new service priorities so that they could align their organizations' efforts to work together.

At the same time, Board and staff members cautioned MAP's leadership to proceed with diligence, consider all possible alternatives, and consult with stakeholders to determine the most prudent course for proceeding. In multiple meetings, staff and Board expressed hesitation or skepticism toward moves that could potentially alienate providers that had historically been partners to MAP, draw direct competition for business from these providers, or alienate existing consumers by pursuing mergers and consolidating services with other local ASOs. Linking this emphasis on diligence to the need for organizational leaders with change management skills, Audrey commented,

Even the prospect of going as big as some of the ideas that they have, that is gonna be, I'm guessing that will be frightening for a number of people. Are we gonna become this big, bad monolith thing, and what happens to this real, down to earth, one on one stuff that we do, that we think makes a difference everyday? And, it does, but all they're gonna see is the change as a big monster, right? So you have to have leadership in place that can help set that vision and lead them through, and I think, making sure they have that training and you have the right leaders with the right buy-in.

Coupled with concerns about regulatory compliance with respect to a number of specific changes (e.g., mental health services, pharmacy, billing insurance), staff members like Amelia also cited misgivings about MAP's financial state and the feasibility of taking on new initiatives without a clear understanding of its partners in the work: "I'm just not sure that the finances have caught up with the need for change. And, I'm not, the other piece again is, I don't know what, I think without doing it collaboratively, I don't think we can start something brand new." Recognizing this

tension between emphasizing action and caution, Ted stressed the need for “reflective work,” engaging in careful planning and consultation with staff and potential partners before committing to undertake any specific high-risk initiatives. Doing so, he posited, “...will help us in the long run to be more... of reflective leaders than reactive leaders.”

Changes that have already occurred. Turning to members’ appraisal of MAP’s change process as it was carried out, a number of participants shared perspectives that sometimes corroborated but also differed from each other in critical ways. Interview participants characterized their enthusiasm for the proposed changes on an informal scale ranging from Hot (Very Positive) to Cold (Very Negative). Of the twenty respondents, seven (35%) described themselves as “Hot,” eleven (55%) selected “Warm,” one characterized himself as “somewhat confident,” and one stated that he did not have sufficient information on the changes to make a rating.

Echoing the above-cited sentiments that change needed to be carried out either urgently or cautiously, some members described MAP’s strategic plan implementation as “aggressive,” while others questioned the extent to which any changes had occurred or characterized the process as “fits and starts.” At the Board level, Naomi described how enthusiasm for new ideas could sometimes wane when checked against the reality of all the details to be considered, such as compliance rules or finances, while Audrey, acknowledging a gap in clarity between MAP’s aspirations and its implementation plans, cited the transition away from a grassroots identity to “something else,” to which she wondered, “My first question was, what of these ideals are you going to leave behind?”

And, how ready is anybody to do that?” Commenting on what he had learned from the drawn out nature of the process, Craig noted:

I know it's necessary to hammer out all those bits and details and... nitpick certain phrases like, what's our mission statement? Because everybody's got to agree. But to me it almost seemed cumbersome because I'm not used to having, I would just think, one person can come up with a good draft, and then we can work with it from there. But having to include everybody's opinion into one, dare I say socialist idea of, like, let's all throw in for this! It's been difficult for me to follow through, to be perfectly honest. It seemed very complex to me.

With respect to staff's perspectives toward the implementation process, Nathaniel described a sense of anticipation: “And I can only imagine, I've learned a lot about program design and implementation in my years, but I know nothing about bringing medical services into a nonprofit (laughs). There's excitement around. I think there's understanding of how the healthcare landscape is shifting, and how a move like that could really help keep the agency viable and sustainable in the future.” Yet, Nathaniel also noted lingering concerns about the loss of MAP's social service “heart,” the accompanying shift to a medical focus, and perceptions of his own role in the organization's future:

[There] are times too where I question some of it, where I think... this will be an interesting journey. And you know, there may be points in this journey where... there are times when I question the change... when I do stop to ask myself, am I really questioning what's good for MAP, or is it just not the fit for me?

The question of staff's involvement in the change process had been raised, questioned, and repeated in numerous settings, dating back to the very beginning of strategic planning. Leadership had sought the perspectives of its workforce on multiple occasions in 2013, including an electronic survey and focus groups, and feedback from

interview participants generally affirmed that prior to implementation, communication between leadership and staff had been consistent and clear. During the implementation phase, however, this dynamic would change in a way that members again described as “fits and starts.” Even while Board members and leadership wondered about how to gauge staff’s commitment to the strategic plan in a 2014 committee meeting, interview participants spoke of the need for more consistent communication and clarity between decision makers and staff. Coupled with key staff departures, sometimes on short notice and with little explanation, members cited feelings of insecurity toward their own positions in the organization, to which Leo commented:

We just need to be more open and communicative about what changes we’re making in the agency when we are making them. If we are changing the structure of specific parts of the agency and that means specific positions are being shifted or eliminated or whatever, just be open about it so people know. [People] think, if they’re not telling us something, it must be bad. And so just communication in general must be improved, [within the] agency.

During the interview phase of this study, participant identification and selection continued up to a point when no new information was learned (i.e., theoretical). This stage became apparent when multiple informants at the non-managerial staff level expressed their lack of knowledge or familiarity with the details of MAP’s strategic planning implementation process, its progress, or its relevance to the consumers with whom they worked. At least two participants had commented on the need for greater specificity, noting that the strategic plan had emphasized broad outcomes without clear connections to each program currently operating within MAP. Dominic, commenting on a perceived lack of engagement and specificity, lamented:

If someone engaged me, I feel like I don't have... an opinion because I don't really know exactly what the hell is going on. I'm there enough. I should know. I've asked, what's coming around? What's happening? I've heard things, but no one's given me [information] and said, "This is our plan." I feel like we do good work, but as far as a comprehensive plan of what we're going to move to, that has never been presented.

Similarly, some interview participants expressed concern with whether MAP had done enough work to solicit the input of its consumers. Although invited to participate in focus groups during the planning phase, MAP's volunteers and program participants were ostensibly left out of any feedback or planning meetings once the plan had been approved in August 2013. With data saturation occurring at a point when MAP's workers- presumed to work most closely with its consumers- could not identify changes brought about by the strategic plan, the opportunity to engage service recipients waned. To that end, staff member Gabriel, who had expressed enthusiasm for the changes as he understood them, urged a reengagement with MAP's constituents so that the organization could reestablish its ties to the community it served:

I believe that they need to make the community as a whole aware of what's going on. This is what we're doing now. And you know, maybe having— once more of the changes are instituted— having an open house, inviting the community in to see, you know, this is your agency. This is what we've done, and this is what we're gonna continue doing and... these are some of the things that we've never done in the past and we're excited about it. Come and see us and see what's going on, and opening up the doors and letting the fresh air in.

Reflecting on these gaps in communication, Board and staff leaders recognized points in the process where messaging with MAP's workers, mentioned early in strategic planning as a strength, had declined. Amber noted, "I think, you know, when you're moving fast, it's like you go through almost a year of strategic planning, and you actually

get approval and everybody's on board for the plan, and it's kind of go time, right? And so, just somewhere along the way it seems like we just had some gaps in communication, that we just weren't closing the loop. And so moving forward, we'll be way more thoughtful about that and trying to make sure everybody's engaged and informed as we move through the next cycle."

Board and staff both cited one new initiative as potentially helpful, the practice of having staff from a specific department attend the Board's monthly meetings and provide an overview of their work. Yet, follow-up interviews with a subsample of participants revealed a period of numerous staff departures and a restructuring of the organization's departments that left key staff informants feeling less optimistic and more skeptical of MAP's current leadership. While in principle still agreeing with the strategic plan's broad outline, staff interview participants questioned the logic and truthfulness of certain actors within leadership, lamented a number of instances when their expertise had not been shared or had been mischaracterized to Board leadership, and expressed a desire for the Board to become more actively aware of workers' concerns.

Describing the recent restructuring, which had included the departure of one especially long serving staff member, Felicity questioned her earlier enthusiasm for the change process, observing instead, "I feel right now that we are so undercut and adrift that I'm just not sure what would make a difference." Nathaniel, who in his earlier interview had described questioning his future role in the organization, viewed the current circumstances as an opportunity to reemphasize collaboration across multiple levels of the organization:

At this point, one of the things I think would be really helpful would be for the Board to get connected in a way that it hasn't been in a long time, so there can be maybe a working committee that is... multiple levels. So, decision-makers on the Board along with our executive level of leadership, along with people at director-management level, and maybe even line staff, to help make sure again that all of the communication is flowing back and forth, that all of the correct factors are being considered. I think that people are feeling that... to make sure everybody is on the same journey together.

This "journey," as Nathaniel had characterized it, would continue without the involvement of numerous staff members. In the month following the conclusion of data collection, staff continued to depart from the organization, including two more members of the senior leadership team. Of the thirteen employees interviewed for this study, five had left the organization by the end of 2014, representing slightly less than 40% of this subgroup within the interview sample. Email communication and one in-person meeting with Board informants confirmed that MAP remained committed to advancing the goals of its strategic plan; however, it would need to do so with an almost entirely different senior management team.

Coda

Taken as a whole, the themes related in this chapter depict a process riddled with uncertainty, where choices that had been presumed to expand the organization's capacities, such as introducing a medical clinic and pharmacy services, were complicated by the local policy context, persistent internal barriers, and a gradual worsening of relationships, leading to an increase in departures among senior leadership and staff. In the months to follow, MAP's Board and interim leaders aimed to resolve a number of these nagging issues by selling its property and using the assets to stabilize the

organization's finances before hiring new executive leadership. Still, the prospects for growth were hampered by a continued decline in government grant revenues, punctuated by the loss of direct federal funding for one of its signature HIV prevention programs. Broader implications for organizational theory and community-based efforts to suppress HIV will be addressed in the chapter to follow. However, the story of how this organization experienced systemic change, as witnessed over 13 months of data collection, concludes with arguably greater uncertainty than it began, owing to the ways in which internal factors, such as finance and staff dissatisfaction, compounded the aforementioned external pressures relating to policy context and changing public perceptions.

Chapter 6: Discussion

This case study examined how members of the Minnesota AIDS Project, a nonprofit, community-based HIV/AIDS service organization, experienced systemic change in response to Affordable Care Act legislation. Evidence from documents, meeting observations, and semi-structured interviews revealed ten unique themes corresponding to members' systemic change experiences, the technological changes considered, members' knowledge of or identification with MAP's HIV-affected constituencies, and members' identification with the organization's history and service values.

Members of the organization experienced systemic change as a moment of reckoning with key external factors, including potential changes in the larger system of publicly-funded HIV healthcare policy and shifting public perceptions toward HIV and services for its most affected constituencies. Universally, participants viewed systemic change as necessary for MAP's survival, while some also considered the move essential for reasserting MAP's position as a leader in the local HIV service sector. The competing tensions of quick, decisive action and careful, cautious deliberation appeared at numerous junctures, as did concerns about openness and inclusion of diverse opinions from staff, consumers, and the community at large. Ultimately, although a majority of interview participants offered enthusiasm for the proposed changes, members also expressed waning confidence in leaders' decision making and communication, and staff departures became more commonplace as the study reached its conclusion.

The adoption of a central, measurable outcome – Gardner’s treatment cascade – offered opportunities for members to reframe their thinking around MAP’s service objectives while considering the challenges and opportunities for gathering evidence to evaluate goal fulfillment and estimate the value of its activities. Members’ considerations of technological opportunities to pursue identified some key organizational strengths on which to build, yet their aspirations were tempered to some degree by persistent barriers present in both the surrounding environment and within the organization, including limited referral resources, competition from well-established clinics, deficits in computing technologies, and lack of staffing in critical areas such as finance and human resources.

Multiple individuals related their knowledge of and/or identification with HIV-affected constituencies to personal experiences and affiliations with communities disproportionately affected by the disease. They largely agreed that stigma and marginalization continue to adversely influence consumers’ utilization of MAP’s services, which may also be complicated by the presence of complicated medical and psychosocial needs. With respect to the organization’s history and service values, members cited its emphasis on nonjudgmental services tailored to the needs and identities of MAP’s consumers, as well as its longevity as the state’s longest-serving ASO. Less settled, however, were participants’ opinions concerning workplace culture, perceptions of professionalism, apparent closeness to LGBT communities, and how to emphasize accountability across different staffing and managerial levels.

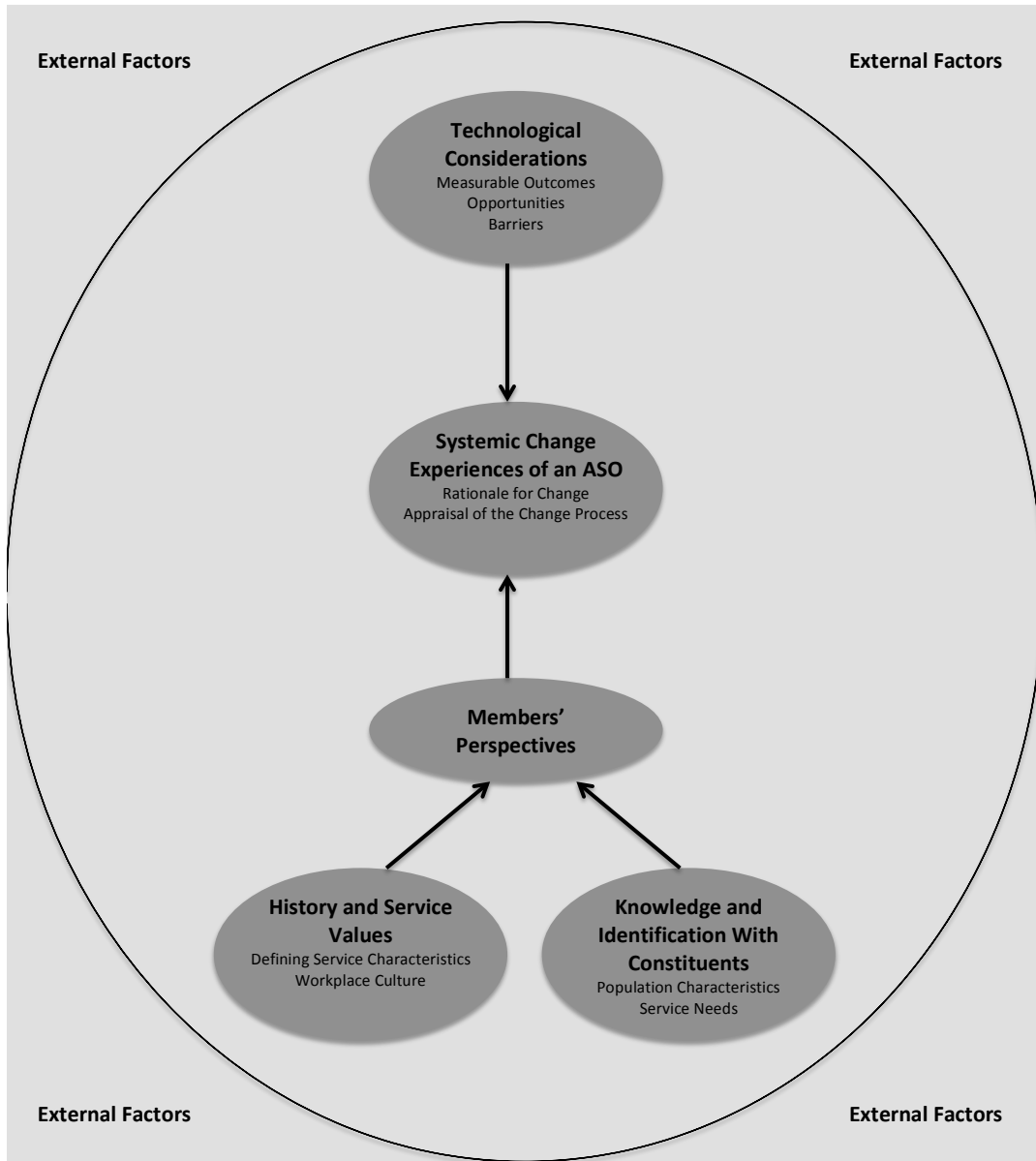
This research approach proved especially useful for gaining knowledge from informants who represented or worked closely with populations that are disproportionately overrepresented in domestic HIV cases (CDC, 2010) and which have experienced persistent disparities with respect to health outcomes (Greenwood et al., 2005; Stall et al., 2003), poverty (Albelda, Badgett, Schneebaum, & Gates, 2009), and violence and discrimination (Herek, 1991; Herek, 2009; Tilcsik, 2011). While the single-subject case study did not allow for drawing conclusions about the broader experiences of ASOs in the current policy environment, the themes identified in this research can be especially useful for guiding future studies concerning the influence of ACA legislation on HIV/AIDS service delivery as part of the larger U.S. health care system. This chapter will consider key implications from these findings, with specific attention to theoretical considerations, applicability and transferability within the community-based HIV service sector, and implications for the social work research and practice.

Theoretical Implications

Based on study findings, Figure 3 below offers a revised model accounting for factors influencing the systemic change process of a nonprofit HIV/AIDS service organization. This depiction organizes themes identified in the data to reflect their apparent relationship with each other in the context of this study's single case. External factors, represented here by a single ring encompassing all the other elements, were a pervasive influence that touched all other facets of MAP's systemic change experiences. In this model, technological considerations and members' perspectives influenced both

the rationale for change and their appraisal of the change process, which together comprise the organization's systemic change experiences. The ways in which these elements informed the process, however, differed both in character and extent. For example, the rationale for change reflects members' perspectives relating both to their knowledge of consumers' needs and their considerations for the organization's market position as a leading provider of services and advocacy among local ASOs. When presented with a "sun setting" option during strategic planning, Board and staff agreed that MAP's absence could potentially do harm to its constituents, convey a message that HIV is no longer a public health threat, and destabilize the local HIV service sector.

Figure 3: Factors influencing the systemic change process of a nonprofit HIV/AIDS service organization (revised)



Appraisal of the change process, which included members' opinions on how this transformation should be conducted and their reflections on how it was carried out, included their considerations of the technological opportunities and barriers facing the organization - framed in part by the revenue opportunities which appeared to be available - and the adoption of Gardner and colleagues' treatment cascade as a central measure of these services' effectiveness and value. At the same time, these appraisals included members' desire to involve a larger cross-section of the organization's workers, its service consumers, and the broader community of HIV-affected constituencies in conversations about MAP's future aspirations. As some members came to view the change process as worrisome or disappointing, they indicated a few specific concerns with technological considerations (such as projections for utilization of pharmacy and mental health services), while also expressing misgivings toward changes in MAP's workplace culture and leadership's communication around the restructuring process.

Organizational Theory

Findings from this study highlighted a number of issues relevant to organizational theory, organizational change, complexity, and the evolutionary processes outlined in Chapter 3. The passages below examine theoretical insights that arose during analysis with respect to organizational jurisdiction, qualifications within the ASO workforce, and locus of authority as it relates to both external forces and internal considerations. The influence of trauma on members' perspectives, a consideration that came to light during the analysis of thematic findings, is also explored below.

Organizational jurisdiction. To revisit bureaucratic theory, Weber (1947) specifies the principle of fixed jurisdiction as one of the recognizable characteristics of a defined organizational structure. Given the shifting environmental conditions in which community-based HIV/AIDS services find themselves, study results indicate that defining this jurisdiction may prove increasingly difficult for an ASO that does not offer or maintain a formal link to clinic-based medical care. With respect to the Minnesota AIDS Project, members indicated their uncertainty or lack of consensus around a number of jurisdictional issues, including its location and geographic focus, its decision to retain a strictly HIV-centered mission, its identity as a provider within the local LGBT community, and its adoption of a central metric (i.e., the treatment cascade) that emphasizes medical rather than social service outcomes.

Some of this jurisdictional uncertainty may stem from the local environment, where members cited state policy that favored broad-based funding of HIV social services rather than encouraging consolidation, as had occurred among neighboring states, and the presence of numerous HIV medical specialists that expressed a strong endorsement of MAP's social services but also indicated mixed interest in co-locating a medical clinic at the organization's office site. To that end, while the National HIV/AIDS Strategy offers several broad policy goals for drawing down and eventually ending the domestic epidemic, the pathway toward these achievements may vary by each state and municipality's policy context, the availability of supportive services to meet PLWHs' diverse needs, and an organization's capacity for managing the changes necessary to survive. Thus, for a comparable organization considering a systemic change strategy as

MAP did, a thorough assessment of external factors (addressed more specifically in passages below) may be warranted.

Qualified workers. Weber's bureaucratic theory also defines an organization by its provision for the ongoing fulfillment of duties and hiring of qualified individuals. Members of the organization raised multiple concerns about placing a higher value on the expertise of workers with certain qualifications (i.e., medical credentials) over others, such as social service backgrounds or lived experiences. For example, workers like Nathaniel raised questions about how staff's expertise would be valued in clinic settings where physicians' opinions have traditionally held sway over social service staff's, while Gabriel emphasized the value of having workers with lived experiences in HIV-affected communities, who possessed the ability to relate with and assist consumers as peers. Yet, he noted, the number of openly HIV-positive workers in the organization had declined during his years as an employee.

These conversations illustrate the breadth of qualifications that an ASO may still need to encompass in its workforce, ranging from precise medical knowledge of viral progression and pharmaceutical regimens to the daily experiences of living with HIV, mental health and substance abuse disorders, discrimination, poverty, and stigma. Given the stark reality of funding limitations facing an ASO, along with trends dating back to the late 1980s of ASOs offering services through an increasingly professionalized workforce (Andriote, 2011; Gillett, 2011), the perception of what qualifies an individual to work for an ASO may continue to shift toward formal education and technological skill, as verified by specific professional credentials that may be unattainable for

populations persistently linked to marginalization and poverty, and away from lived experiences that can be offered as examples for HIV-affected service consumers.

For an ASO that is seeking to incorporate funding streams other than government grants, which MAP's members universally endorsed, the incorporation of clinical services that require highly credentialed workers may offer opportunities, in the form of higher revenues with which to bolster infrastructure and expand services, and drawbacks in terms of positioning the organization to be less intimately connected to its constituent communities. Interview participants such as Board member Craig, who defined MAP in part by its comprehensiveness and inclusiveness, may view the present moment as one to more closely embrace an all-encompassing, egalitarian ethos as an enduring trait of the organization's identity. On the other hand, his fellow Board member Audrey characterized the moment as akin to moving from a startup business to a corporate entity, which would force the organization's members to reconcile their aspirations with facets of MAP's identity that they would need to jettison. Given the degree to which this ASO's members cited its closeness to the community it serves as an asset for leveraging consumers' utilization of various supportive services, the question of how to maintain this proximity as changes proceed may continue to require members' careful consideration.

Locus of authority. At several points during MAP's strategic planning implementation, questions of power and authority arose in ways that indicated a complicated relationship between the organization's leaders and its workforce. Although Weber's bureaucratic theory offers some guidance for understanding the presumed

relationship between individuals who direct the organization's efforts and those who carry out the work, Parsons offers a useful depiction of the bureaucracy's role in controlling internal operations while negotiating relationships with external forces. At multiple junctures of this study, the need to simultaneously manage these different functions appeared to exert its strain on MAP's leadership and workforce, which faced the impetus to seek new business opportunities and revenue-enhancing partners while needing to fulfill existing obligations such as financial stewardship and property management.

Hasenfeld (2009), examining Walmsley and Zald's political economy theory (1976) in the context of human service organization, highlights the critical issues of resource dependence and adaptive strategies for survival. To the extent that MAP's strategic planning process reflected a response to changing and uncertain external factors, its ability to pursue and fully adopt a number of strategies that could aid its efforts to secure a stable market share was constrained at least in part by adaptive strategies made in the past. Specifically, members cited MAP's limited financial infrastructure and lack of human resources staff, areas where senior leaders had either absorbed the work into their own responsibilities or secured short-term help from contractors, as internal barriers to change. Uncertainty over actions to take with MAP's property, both a previously-acquired asset and a substantial expense, also arose at different junctures of the study. This tenuous balance between internal oversight and the pursuit of external resources and partnerships became especially apparent as implementation of the plan proceeded and

members began to express frustration with leaders' lack of communication with workers, increasing staff turnover, and unexpected restructuring plans.

To an extent, Hasenfeld's depiction of human relations theory and its applicability to the human services may offer guidance for managing systemic change in community-based ASOs. Multiple staff interviewees expressed a desire for leadership to more closely tend to workers' needs, including improved compensation, further training around job responsibilities, and creating opportunities for advancement within the organization. At the same time, members' desire for broad-based participation in strategic planning, including a larger cross-section of MAP's staff and constituent communities, offered some indication that total quality management (Martin, 1993), with its emphasis on shared power and continual learning, may merit further consideration with respect to the change processes of a community-based ASO.

Trauma considerations. From its outset, this study maintained that MAP, as a representative case for community-based ASOs, offered an example of organizational complexity in that ASOs had historically signified more than the sum of their numerous parts to their HIV-affected constituencies. Echoing Andriote's (2011) observations that ASOs have experienced change at numerous points in their collective history, a number of interview participants characterized MAP as having adapted to shifting external circumstances throughout its existence. In this sense, the adoption of an evolutionary mindset, as suggested by Patton (2011), may offer researchers the benefit of studying change with an eye toward interactions between organizational actors, potential conflicts, the delineation of organizational goals, and the selection of certain pathways for

achieving these goals. However, to fully understand the developmental trajectory of community-based HIV/AIDS services, the question of unresolved trauma among organizational actors bears consideration as a potentially unexplored phenomenon that may influence an ASO's evolutionary course.

Almost half of this study's interview participants described relationships with MAP spanning at least 10 years, with some detailing involvement in HIV-related work (either paid or volunteer) dating back to the 1980s. Members who experienced the early domestic epidemic recounted experiences of loss, continuing to feel anger, having an "axe to grind," and remembering what AIDS came to signify "for the community." One interview participant wondered how he hadn't become infected during that period in his life, while another recalled his experiences waking up with night sweats. With respect to the organization, staff member Nathaniel described MAP as having a lot of history, "good and bad," while Board member Owen expressed his desire to see it move beyond a state of perpetual crisis.

In his grounded theory examination of urban gay men's experiences with midlife, clinical social work researcher James Lampe (2010) uncovered several instances of undiagnosed Posttraumatic Stress Disorder (PTSD) among his interview participants, all of whom had lived in major U.S. cities during the earliest and most devastating years of the epidemic. Several of his participants indicated that during study interviews, for the first time they were able to cohesively organize their thoughts to describe the impact of witnessing so many friends and loved ones deteriorate and die at uncharacteristically young ages. In this study, Board member Douglass echoed similar sentiments when

mentioning that he had not spoken of his feelings on this topic prior to his interview. This act of making sense of one's traumatic experience, sharing with others the recollection of a stressful event in context, suggests a process of attribution or meaning making, which in theory represents a critical step toward fully reckoning with its manifested effects (Kleber, Brom, & Defares, 1992). While this study does not presume to clinically diagnose members of this small participant sample with PTSD, the question of whether a shared experience of unresolved trauma may influence the developmental course of a community-based organization merits attention that was not considered at the commencement of this investigation.

Myriad sources of literature address trauma at the individual level; this discussion is concerned not with exploring these various theoretical perspectives but instead considering the ways in which patterns of behaviors and decision-making may emerge in an organizational setting, where a substantial portion of its members share memories of a traumatic event or defined period of time. Searches for literature addressing the potential influence of trauma in organizational development yielded no prior studies of this phenomenon. However, theoretical perspectives on historical trauma, examined by Sotero (2006) in the context of public health research and practice, may prove useful for making sense of the experiences of community-based ASOs. Synthesizing the domains of psychosocial theory, political/economic theory, and social/ecological theory, Sotero posits that historical trauma theory operates on four explicit assumptions:

- 1) mass trauma is deliberately and systematically inflicted upon a target population by a subjugating, dominant population;
- 2) trauma is not limited to a single catastrophic event, but continues over an extended period of time;

- 3) traumatic events reverberate throughout the population, creating a universal experience of trauma; and
- 4) the magnitude of the trauma experience derails the population from its natural, projected historical course resulting in a legacy of physical, psychological, social and economic disparities that persists across generations. (pp. 94 – 95)

Most frequently used to help make sense of experiences shared by different ethnic populations - e.g., Jewish Holocaust survivors, Native Americans, African Americans, Mexican Americans, Palestinians, and other populations that have experienced systemic displacement, marginalization, and/or genocide – historical trauma includes a key emphasis that the memory of these distressing experiences becomes encoded and transmitted to subsequent generations within the population (Sotero, 2006; Estrada, 2009).

With respect to the above assumptions and their applicability to domestic HIV and community-based ASOs, several key comparisons highlight historical trauma's possible relevance to the subject of this study. First, with respect to the deliberate and systematic inflicting of mass trauma on a target population, the documented history of systemic failure in the U.S. government's initial response to HIV and the willingness of public officials to withhold resources due to political considerations (Shilts, 1987) may contribute to survivors' continued feelings of subjugation, mistrust, and suspicion toward top-down systemic change. Second, the early AIDS crisis encompassed a period of approximately 15 uninterrupted years, during which thousands of U.S. citizens died and ASOs came into existence to attend to their unmet human service needs. Third, with respect to the epidemic's reverberations through subsequent generations, domestic HIV has maintained persistent overrepresentation among gay and bisexual men across age

cohorts for over three decades, as noted in earlier chapters. Even when considering historic breakthroughs in pharmaceutical treatments, preventive options, and life expectancies, numerous study participants noted the continued presence of stigma and shame as barriers for individuals seeking testing and treatment, irrespective of generational affiliation. Fourth, the historical work of Shilts, Gillett, and others document the ways in which organized societal backlash, scientifically unfounded fears, and pre-existing prejudices toward homosexuality, sex work, and recreational drug use effectively encoded anti-HIV discrimination in various public and organizational policies, such as banning gay men from donating blood, restricting travel to the U.S. by HIV-positive individuals, and enacting state-level criminal laws punishing the transmission of HIV.

The consequences of a traumatic experience can manifest themselves in a variety of ways, depending on persons' individual characteristics, lived experiences, and social networks (Kleber, Brom, & Defares, 1992). Some participants in Lampe's clinical research likened the early years of HIV to a Holocaust and recalled feelings of bombardment as in combat, while also describing how, when new medications began to dramatically reverse individuals' prognoses, they felt a shared impulse to move on, not look back, and try to resume a normal life. Organizational actors in an ASO such as MAP may share similar recollections, as some interview participants in this study seemed to indicate. Members may also, as in the case of this study, represent some of the longest serving actors in the organization, who by virtue of their many years' experience and expertise be called upon to help guide the organization through another transitional phase. The presence of unresolved trauma may heighten members' feelings of anxiety,

identification with the suffering experienced by earlier generations of PLWH, and distress toward certain microaggressions, i.e., chronic and often ongoing events that subtly demean or negate a person's identity, experiences, or feelings as a member of an oppressed minority (Center for Excellence in Children's Mental Health, 2010).

Younger generations of workers, who as noted in previous chapters may view the ASO as a professional destination, may come to experience this trauma vicariously through their interactions with long-term HIV survivors and workers with lengthy experience, through direct or indirect exposure to HIV risk and its associated stigma within their peer groups, the maintaining of certain customs or rituals within the organization, or the adoption of institutional suspicion toward larger entities such as government funders. Members who desire to move away from this conflicted past, a phenomenon recognized by Lampe among his study participants, may be met with resistance by others who fear that doing so will effectively erase the organization's past and thus consign those members' experiences to a forgotten history.

Sotero's work emphasizes the need for research to more closely link historical trauma to a population's aggregate health outcomes; at the organizational level, these implications may suggest that exploratory research would help to clarify the extent to which shared trauma can exist and become encoded in the development of an organization's culture and operational practices. Beyond the field of HIV, such research may offer benefits for understanding the distinct experiences of agencies and services founded by members of populations who experience a shared trauma, such as refugee

resettlement and relief and assistance for survivors of abuse, in tandem with a shared desire to alleviate conditions for others who have survived similar experiences.

Implications for a Community-Based HIV/AIDS Service Organization

The passages to follow address implications derived largely from technological considerations detailed in Chapter 5, with special emphasis on Gardner's treatment cascade and identifying conceivable links between the components of a "full service" ASO (as members described the Minnesota AIDS Project) with the larger medical goals of retention in care, pharmaceutical adherence, and suppression of HIV at a community or population level.

Applications of the Treatment Cascade

Since 2011, the treatment cascade's focus on heightened detection, linkage to care, retention in care, and adherence to antiretroviral therapy to estimate a population's viral suppression has provoked conversations among public health and medical researchers that in some ways parallel the conversations of MAP stakeholders in this study, with emphasis especially on identifying conditions that contribute to deficits in any of the cascade's essential stages. For example, Hull, Wu, and Montaner's (2012) review of current and recent "test and treat" and "seek, test, treat, and retain" strategies argues for increased attention on factors contributing to deficits along all points of the cascade, which, they argue, should be tailored to respond to local circumstances and populations while addressing unmet needs, including substance abuse and mental health treatment,

homelessness, and access to nutritious food. Lourenço and Colleagues' (2014) analysis of attrition across stages of the cascade supports this call for adaptive strategies that account for heterogeneity among HIV-affected populations, as they uncovered higher rates of dropout among individuals under 30, females, and persons who inject drugs in a cohort of British Columbia PLWH.

Eberhart and Colleagues (2015) offer a salient examination of factors associated with the cascade's key outcomes by focusing on geographic "hotspots," i.e., areas with poor levels of retention in care or viral suppression, and identifying factors associated with these conditions, which include varying levels of economic deprivation, female sex, distance from medical centers or pharmacies, and access to public transportation. Although the model was developed to specifically depict geographic areas in Philadelphia, its methodological approach, using a retrospective cohort of newly diagnosed individuals and multivariate logistic regression models, provides strong support for the viability of developing a testable model for reducing HIV incidence through anti-retroviral therapy.

These researchers' findings may be especially helpful for guiding the efforts of public health officials and members of organizations like MAP, whose deliberations included questions both of which services to prioritize and where to locate them. At the same time, the literature to date, with its apparent focus on factors contributing to deficits along the treatment cascade, offer only a limited depiction of conditions that may contribute to the achievement of viral suppression within a defined geographic area or population. The context of this qualitative study's results, however, may offer insights

toward conceptually reframing the evaluation of an ASO's social service outcomes toward identifying factors contributing to the attainment of viral suppression of HIV, the efficacy of which could be evaluated at the jurisdictional level.

For example, on key indicators of the treatment cascade, Minnesota significantly outpaces national rates with respect to engagement or linkage with medical care (87% to 40%) and approximated viral suppression (63% to 37%) (AIDS.gov, 2015; Minnesota Department of Health, 2015). In 2011, the state ranked 29th of 50 for new HIV diagnoses (CDC, 2013), a number that has consistently averaged approximately 320 new cases per year since 2004 (MDH, 2015). Additionally, this study's findings revealed a context where, bucking the trend of consolidation in other states, Minnesota has maintained a policy emphasis on funding a number of community-based organizations to provide supportive services to PLWH. This current alignment may afford opportunities to singularly identify environmental factors contributing to a city or state's viral suppression at the geographic, population, or organizational level that would otherwise be obscured in the context of a consolidated service model, situated in a controlled, clinical setting.

While community-based research of this nature would potentially require a commitment of substantial resources and logistical coordination, it should be noted that organizations may already rely, as MAP did in 2013, on data from existing needs assessments conducted by departments of health and human services locally and in other states. A shift in focus from identifying the unmet service needs of PLWH to clarifying the contributions that community-based social services make toward achieving PLWHs' sustained engagement with medical care may prove advantageous both for pinpointing

gaps in a jurisdiction's continuum of care services and measuring the extent to which each supportive service contributes to the treatment cascade's ultimate goal of viral suppression within a defined geographic area or population.

Implications for Social Work Practice and Research

Results from this study build on a body of social work research that has raised timely and pertinent issues for the HIV provider workforce as disease prognosis and treatment have changed over several years. A number of implications for research and practice, including challenges and opportunities for social workers in HIV/AIDS-related service settings, became apparent from this study's findings. Self-identified social workers in this study offered perspectives from numerous levels within the organization, including senior leadership, middle management, and direct engagement with clients. In documents, meetings, and interviews, members called upon and advocated for the inclusion of evidence from a variety of sources, including policy guidelines, social service partners, peer-reviewed research literature, members of MAP's workforce, and its HIV-affected constituencies. Reflecting the social work profession's emphasis on interdisciplinary collaboration, some members shared their desire for striking a balance between quality of life outcomes and achieving the medical objectives of Gardner's treatment cascade.

At an earlier turning point in the epidemic, Strug, Grube, and Beckerman (2002) foresaw a role for social workers' expertise in advancing primary and secondary HIV prevention, psychosocial supports for PLWH and their loved ones, and collaborative,

interdisciplinary research on emerging best practices. Members' reflections on MAP's organizational change process did little to discount the continued need for these forms of engagement; they did, however, illuminate new opportunities for professional self-advocacy, as participants reckoned with a potential culture change that would more closely align MAP's operations with a "medical" service model. Some interview participants characterized MAP's strategic plan as a shift from its "social service" identity to that of a "public health" organization. With this change, however, other members expressed concern about social workers' potential loss of influence in decision-making in a more hierarchical, physician-led model. Social workers in these settings may face the challenge of voicing their critical role in achieving the medical goals around which these service outcomes coalesce. To that end, findings from this study also echo Strug, Grube, and Beckerman's call for social workers' involvement in interdisciplinary research, which in the current era may illuminate and clarify the optimal direct practice strategies for achieving the treatment cascade's medical-oriented outcomes. Both as a matter of evaluating practice and extending the profession's knowledge base and influence, adding to this evidence base will be critical for helping organizations such as MAP to identify and address contextual factors that either promote or inhibit the National HIV/AIDS Strategy's progress toward containing and ultimately ending the domestic epidemic.

Members placed a high value on MAP's longstanding public advocacy and education efforts while describing external factors they characterized as contributing to funding uncertainty, declines in HIV/AIDS philanthropy, and changing public

perceptions of the disease and community-based ASOs' relevance. Participants' attention to concerns such as persistent stigma, marginalization, and health disparities among HIV-affected constituencies echoed the social work profession's historic emphasis on justice, equity, and elimination of poverty while suggesting a need to reengage MAP's community of supporters around its present-day efforts and needs. Further, where research findings have pointed toward a number of structural and psychosocial barriers to services for HIV-affected constituencies (e.g., Auerbach & Beckerman, 2010; Cavaleri et al., 2010; Lourenço et al., 2014; Eberhart et al., 2015), social workers possess an opportunity to translate this literature into reengagement with the general public. By aligning its advocacy more visibly to the efforts of several social movements, including those addressing poverty, income inequality, racial justice, LGBT inequality, and gender equity, an ASO such as MAP - founded by grassroots social justice movements - may reassert an especially critical, evidence-informed voice for linking the elimination of structural inequalities to eradication of domestic HIV.

Chapter 7: Conclusion

During a period when researchers, policymakers, and organizational leaders have sought to broadly make sense of the Affordable Care Act's ramifications for HIV healthcare and human services, this study offers a unique contribution to the field by examining the depth and complexity of a single case, the Minnesota AIDS Project. In their efforts to define MAP's continued relevance to the field, members of the organization shared their planning process, their internal deliberations and within-group interactions, personal reflections, and appraisals of the plan's implementation as it occurred throughout 2013 and 2014. From these results, social work researchers may gain critical insights concerning factors to consider with respect to systemic change, community-based health and human services, and grassroots social movements with longstanding interests in the organizations they have created.

Findings from a single-subject case study cannot be generalized beyond their immediate context; however, these results may offer valuable information for organizational actors in comparable settings, which may include community-based ASOs with service portfolios and histories similar to MAP's, and organizations in jurisdictions similar to the state of Minnesota, where the trend of HIV service consolidation has not occurred. Furthermore, several opportunities for future research emerged from this study's implications. With respect to organizational theory, this ASO revealed an opportunity to examine the extent to which the presence of shared, unresolved historical trauma may influence the growth and transformation of organizations with comparable histories and circumstances. Study implications also offered insights for reframing the

achievement of suppressed HIV at the community level to clarify the role that community-based service providers contribute toward the central objectives of Gardner's treatment cascade.

Finally, the study revealed numerous ways that social workers in this case have used their training and experience to inform MAP's change process at multiple levels of the organization. Building on a body of work dating back to the domestic epidemic's earliest years, members of the profession in this sample highlighted the continuing need for social workers' expertise with respect to professional self-advocacy, reengagement with policymakers, supporters, and the public at large, and collaborative, interdisciplinary research situated in the environments where HIV-affected communities work to manage their health and wellbeing. From these findings, future studies concerning community-based models of HIV care and supportive services may gain critical insights both for best practices in the field and for developing research approaches that examine and account for depth and complexity in the experiences of the organization's member constituencies.

References

- Albelda, R., Badgett, M., Schneebaum, A., & Gates, G. (2009). Poverty in the lesbian, gay, and bisexual community. Retrieved from: <http://escholarship.org/uc/item/2509p8r5>
- Andriote, J-M. (2011). Five crises: A brief history of ASOs. *The Gay & Lesbian Review Worldwide*, 18(3), 21 – 23.
- Auerbach, C., & Beckerman, N. L. (2010). HIV/AIDS prevention in New York City: Identifying sociocultural needs of the community. *Social work in health care*, 49(2), 109-133.
- Badgett, M. V. L. (1995). The wage effects of sexual orientation discrimination. *Industrial and Labor Relations Review*, 48(4) , 726-739.
- Bolman, L.G., & Deal, T. (2008). *Reframing organizations: Artistry, choice, and leadership*. San Francisco, CA: Jossey - Bass.
- Cavaleri, M. A., Kalogerogiannis, K., Mckay, M. M., Vitale, L., Levi, E., Jones, S., ... & Flynn, E. (2010). Barriers to HIV care: an exploration of the complexities that influence engagement in and utilization of treatment. *Social work in health care*, 49(10), 934-945.
- Center for Excellence in Children's Mental Health (2010). Historical trauma and microaggressions: A framework for culturally-based practice. Retrieved from <http://www.extension.umn.edu/family/cyfc/our-programs/ereview/docs/cmhereviewOct10.pdf>
- Centers for Disease Control & Prevention [CDC]. (1992). *Content of AIDS-related written materials, pictorials, audiovisuals, questionnaires, survey instruments, and educational sessions in Centers for Disease Control and Prevention (CDC) assistance programs*. Retrieved on February 20, 2013 from: <http://www.cdc.gov/od/pgo/forms/hiv.htm>
- Centers for Disease Control & Prevention [CDC]. (2003). *HIV Prevention Community Planning Guide*. Retrieved from: <http://www.cdc.gov/hiv/topics/cba/resources/guidelines/hiv-cp/pdf/hiv-cp.pdf>
- Centers for Disease Control & Prevention [CDC]. (2006). *MMWR: Chronicling HIV and AIDS from the Beginning*. Retrieved from: <http://www.cdc.gov/hiv/resources/other/PDF/MMWR%2025%20Year.pdf>
- Centers for Disease Control and Prevention. (2010). Prevalence and Awareness of HIV Infection Among Men Who Have Sex With Men - 21 Cities, United States, 2008. *Morbidity and Mortality Weekly Report*. Vol. 59. No. 37. September 24, 2010.

- Centers for Disease Control and Prevention (2014). Pre-exposure prophylaxis for HIV prevention. Retrieved from: <http://www.cdc.gov/hiv/prevention/research/prep/>
- Centers for Disease Control and Prevention. (2015). HIV in the United States: At a glance. Retrieved from: <http://www.cdc.gov/hiv/statistics/basics/ataglance.html>
- Centers for Disease Control and Prevention. (2013). DHAP HIV funding awards by state and dependent area (fiscal year 2012). Retrieved from: <http://www.cdc.gov/hiv/policies/funding/states12/index.html>
- Centers for Disease Control and Prevention. (2012). HIV in the United States: The stages of care. Retrieved from: <http://www.cdc.gov/nchhstp/newsroom/docs/2012/Stages-of-CareFactSheet-508.pdf>
- Centers for Disease Control and Prevention. (2013). Minnesota – State health profile. Retrieved from: http://www.cdc.gov/nchhstp/stateprofiles/pdf/Minnesota_profile.pdf
- Cohen, M. S., Chen, Y. Q., McCauley, M., Gamble, T., Hosseinipour, M. C., Kumarasamy, N., . . . Pilotto, J. H. S. (2011). Prevention of HIV-1 infection with early antiretroviral therapy. *New England Journal of Medicine*, 365(6), 493-505.
- Corbin, J., & Strauss, A. (2008) *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, CA: Sage.
- Creswell, J. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Crowley, J.S., & Kates, J. (2012). *The Affordable Care Act, the Supreme Court, and HIV/AIDS: What are the implications?* Retrieved from: <http://www.kff.org/hivaids/8363.cfm>
- Crutchfield, L.R., & Grant, H.M. (2012). *Forces for good: The six practices of high-impact nonprofits*. San Francisco, CA: Jossey-Bass.
- Dodd, S.J., & Meezan, W. (2003). Matching AIDS service organizations' philosophy of service provision with a compatible style of program evaluation. In Meezan, W., & Martin, J. (Eds.) *Handbook of research with lesbian, gay, bisexual and transgender populations* (pp. 352 - 371). New York: Routledge.
- Earnshaw, V. A., & Chaudoir, S. R. (2009). From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures. *AIDS and Behavior*, 13(6), 1160-1177.

- Earnshaw, V. A., Smith, L. R., Chaudoir, S. R., Amico, K. R., & Copenhaver, M. M. (2013). HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. *AIDS and Behavior, 17*(5), 1785-1795.
- Eberhart, M. G., Yehia, B. R., Hillier, A., Voytek, C. D., Fiore, D. J., Blank, M., ... & Brady, K. A. (2015). Individual and community factors associated with geographic clusters of poor HIV care retention and poor viral suppression. *JAIDS Journal of Acquired Immune Deficiency Syndromes, 69*, S37-S43.
- Eoyang, G.H. (2004). *Complex adaptive systems (CAS)*. Monograph produced for The Kellogg Foundation. Retrieved from: <http://www.kapiti.co.nz/bobwill/CASmaterial.pdf>
- Estrada, A. L. (2009). Mexican Americans and historical trauma theory: A theoretical perspective. *Journal of Ethnicity in Substance Abuse, 8*(3), 330-340.
- Ferris, K., Pike, E., & Schaefer, N. (2007) *The financial health of AIDS service organizations in the United States, 2001-2007: Raising questions about a model in transition*. Retrieved from: <http://www.kmferris.com/publication/Ferris2007.pdf>
- Gardner, E. M., McLees, M. P., Steiner, J. F., del Rio, C., & Burman, W. J. (2011). The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clinical infectious diseases, 52*(6), 793-800.
- Gardner, E. M., & Young, B. (2014). The HIV care cascade through time. *The Lancet infectious diseases, 14*(1), 5-6. Gillett, J. (2011). *A grassroots history of HIV/AIDS in North America*. Spokane, WA: Marquette Books, LLC.
- Greenwood, G., Paul, J., Pollack, L., Binson, D., Catania, J., Chang, J., Humfleet, G., Stall, R., Tobacco use and cessation among a household- based sample of urban men who have sex with men (MSM) in the US. *American Journal of Public Health, 2005, 95*(1): 145-152.
- Gronbjerg, K.A. (1991). Nonprofit human service organizations: Funding strategies and patterns of adaptation. In Hasenfeld, Y. (Ed.). (1992). *Human services as complex organizations*. Newbury Park: Sage.
- Gusmano, M. K., Fairbrother, G., & Park, H. (2002). Exploring the limits of the safety net: Community health centers and care for the uninsured. *Health Affairs, 21*(6), 188-194.
- Hasenfeld, Y. (2009). Theoretical approaches to human service organizations. In Hasenfeld, Y. (Ed.). (2009). *Human services as complex organizations*. Newbury Park: Sage.

- Herek, G. M. (1991). Stigma, prejudice, and violence against lesbians and gay men. In John C. Gonsiorek & James D. Weinrich (Eds.) (1991), *Homosexuality: Research implications for public policy* (pp. 60-80). Newbury Park, CA: Sage.
- Herek, G. M. (2009). Hate crimes and stigma-related experiences among sexual minority adults in the United States: Prevalence estimates from a national probability sample. *Journal of Interpersonal Violence, 24*(1), 54-74.
- HIV Health Reform. (2015). About. Retrieved from: <http://www.hivhealthreform.org/about-hivhealthreform-org/>
- Hull, M. W., Wu, Z., & Montaner, J. S. (2012). Optimizing the engagement of care cascade: a critical step to maximize the impact of HIV treatment as prevention. *Current Opinion in HIV and AIDS, 7*(6), 579-586.
- Jacobs, R. J., & Kane, M. N. (2010). HIV-related stigma in midlife and older women. *Social work in health care, 49*(1), 68-89.
- Jefferson, D. (2006). How AIDS changed America. In *Newsweek*, May 15, 36-41. Retrieved from: <http://www.thedailybeast.com/newsweek/2006/05/14/how-aids-changed-america.html>
- Kaiser Family Foundation (2011). *Summary of new health reform law*. Retrieved from: <http://www.kff.org/healthreform/upload/8061.pdf>
- Katz, D. and Kahn, R. (1978). *The social psychology of organizations*. New York: Wiley.
- Kilmarx, P. H., & Mermin, J. (2012). Prevention with people with HIV in the United States: The nexus of HIV prevention and treatment. *JAIDS Journal of Acquired Immune Deficiency Syndromes, 60*(3), 219-220.
- Kleber, R. J., Brom, D., & Defares, P. B. (1992). *Coping with trauma: Theory, prevention and treatment*. Swets & Zeitlinger Publishers.
- Koh, H. K., & Sebelius, K. G. (2010). Promoting prevention through the affordable care act. *New England Journal of Medicine, 363*(14), 1296-1299.
- Lampe, J.N. (2010) *An exploration of the impact of the AIDS epidemic on gay men in midlife*. Doctoral Dissertation. The Institute for Clinical Social Work (Chicago, IL).
- Lincoln, Y.S. & Guba, E.G. (1985) *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

- Lourenço, L., Colley, G., Nosyk, B., Shopin, D., Montaner, J. S., Lima, V. D., & STOP HIV/AIDS Study Group. (2014). High Levels of Heterogeneity in the HIV Cascade of Care across Different Population Subgroups in British Columbia, Canada. *PloS one*, 9(12), e115277.
- Marks, G., Crepaz, N., & Janssen, R. S. (2006). Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. *AIDS*, 20(10), 1447-1450.
- Martin, E. G., & Schackman, B. R. (2012). What does US health reform mean for HIV clinical care? *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 60(1), 72.
- Martin, L. L. (1993). *Total quality management in human service organizations*. Thousand Oaks, CA: Sage.
- Minnesota AIDS Project [MAP]. (2012 - a). Critical issues for Minnesota's HIV/AIDS service field: An impact initiative policy paper. Provided to the author via email on November 9, 2012.
- Minnesota AIDS Project [MAP]. (2014). *2011 annual report*. Retrieved from: <http://mnaidproject.org/pdf/annual-reports/2013-annual-report.pdf>
- Minnesota AIDS Project [MAP]. (2015). Services. Retrieved from: <http://mnaidproject.org/services/index.php>
- Minnesota AIDS Project [MAP]. (2015a). About us. Retrieved from: <http://mnaidproject.org/about-us/index.php>
- Minnesota Department of Health. (2015). Minnesota treatment cascade for people living with HIV/AIDS – April 2015. Retrieved from: <http://www.health.state.mn.us/divs/idepc/diseases/hiv/hivtreatmentcascade.html>
- Minnesota Department of Health. (2015). New HIV infections in 2014. Retrieved from: <http://www.health.state.mn.us/divs/idepc/diseases/hiv/stats/2014/index.html#newsli des>
- Office of National AIDS Policy [ONAP]. (2010). National HIV/AIDS strategy for the United States. Retrieved from: <http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf>
- Parsons, T., & Jones, I. (1960). *Structure and process in modern societies*. New York: Free Press.
- Pascoe, E. A., & Smart Richman, L. (2009). Perceived discrimination and health: A meta-analytic review. *Psychological Bulletin*, 135(4), 531.

- Patton, M.Q. (1978). *Utilization-focused evaluation*. Beverly Hills, CA: Sage.
- Patton, M.Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Patton, M.Q. (2011). *Developmental evaluation: Applying complexity concepts to enhance innovation and use*. New York: Guilford.
- Richert, C. (2013). Affordable Care Act has unique proving ground in Minnesota. Minnesota Public Radio News. Retrieved on from <http://minnesota.publicradio.org/display/web/2013/07/09/health/affordable-care-act-minnesota-proving-ground>
- Ross, E. (1993). Preventing burnout among social workers employed in the field of AIDS/HIV. *Social work in health care*, 18(2), 91-108.
- Rutledge, S. E., Whyte, J., Abell, N., Brown, K. M., & Cesnales, N. I. (2011). Measuring stigma among health care and social service providers: The HIV/AIDS provider stigma inventory. *AIDS patient care and STDs*, 25(11), 673-682.
- Ryan, C., Huebner, D., Diaz, R. M., & Sanchez, J. (2009). Family rejection as a predictor of negative health outcomes in white and Latino lesbian, gay, and bisexual young adults. *Pediatrics*, 123(1), 346-352.
- Sabin-Farrell, R., & Turpin, G. (2003). Vicarious traumatization: implications for the mental health of health workers?. *Clinical psychology review*, 23(3), 449-480.
- Sherer, R. (2013). Generic antiretrovirals and the uncertain future of HIV care in the United States. *Annals of Internal Medicine*, 158(2), 133-134.
- Shilts, R. (1987). *And the band played on: Politics, people, and the AIDS epidemic*. New York: St. Martin's.
- Sommers, B. D., & Epstein, A. M. (2010). Medicaid expansion—the soft underbelly of health care reform? *New England Journal of Medicine*, 363(22), 2085-2087.
- Sotero, M. (2006). A conceptual model of historical trauma: Implications for public health practice and research. *Journal of Health Disparities Research and Practice*, 1(1), 93-108.
- Stall, R., Mills, T., Williamson, J., Hart, T., Greenwood, G., Paul, J., Pollack, L., Binson, D., Osmond, D., Catania, J.; Co-occurring psychosocial health problems among urban men who have sex with men are associated with increased vulnerability to the HIV/AIDS epidemic. *American Journal of Public Health*, 93(6):939-942.
- Strug, D. L., Grube, B. A., & Beckerman, N. L. (2002). Challenges and changing roles in

- HIV/AIDS social work: Implications for training and education. *Social work in health care*, 35(4), 1-19.
- Tilcsik, A. (2011). Pride and prejudice: Employment discrimination against openly gay men in the United States. *American Journal of Sociology*, 117(2), 586-626.
- Video LAN Organization (2015). VLC media player. Retrieved from <http://www.videolan.org/vlc/index.html>
- U.S. Department of Health & Human Services. (2012). *Individuals and the Affordable Care Act*. Retrieved from: <http://www.healthcare.gov/news/factsheets/2011/08/individuals.html>
- U.S. Department of Health & Human Services (2012). *Lesbian, gay, bisexual, and transgender health*. Retrieved from: <http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25>
- U.S. Department of Health & Human Services (2015). HIV/AIDS care continuum. Retrieved from: <https://www.aids.gov/federal-resources/policies/care-continuum/>
- U.S. Department of Health and Human Services: Health Resources and Services Administration (2015). 340B drug pricing program. Retrieved from: <http://www.hrsa.gov/opa/>
- Weber, M. (1947[1924]). *The theory of social and economic organization*. Translated by A. M. Henderson & T. Parsons. New York: MacMillan.
- Wheeler, D. P. (2011). Advancing HIV/AIDS domestic agenda: Social work and community health workers unite. *Health and Social Work*, 36(2), 157.
- Yin, R. K. (2008). *Case study research: Design and methods*. Thousand Oaks, CA: Sage.

**Appendix A:
University of Minnesota
Institutional Review Board Application**

**SOCIAL & BEHAVIORAL SCIENCES
APPLICATION FORM**

Version 5.8

February 2013, check <http://www.irb.umn.edu> for the latest version

IRB Use Only
IRB Study #

1. Project Identifiers

1.1 Project Title (Project title must match grant title. If different, also provide grant title):

Systemic Change in Nonprofit HIV/AIDS Organizations: Examining the Influence of Affordable Care Act Legislation On Services for HIV-Affected Populations

1.2 Person preparing this document

Name: Michael G. Lee	Phone number: 612-822-2828
Email: leex5298@umn.edu	Fax:

- Please note that if you intend to perform work on this project, then you will also need to be listed as principal investigator, co-investigator, or staff.

1.3 Principal Investigator (PI)

Name (Last name, First name MI): Lee, Michael G.	Highest Earned Degree: M.S.W.
Mailing Address: 87 Peters Hall 1404 Gortner Avenue St. Paul, MN 55108	Phone Number: 612-822-2828
	Pager or Cell Phone Number: 612-822-2828
	Fax:
U of M Employee/Student ID: 4303609	Email: leex5298@umn.edu

U of M x.500 ID (ex. smith001): leex5298		University Department (if applicable): School of Social Work
Occupational Position: <input type="checkbox"/> Faculty <input type="checkbox"/> Staff <input checked="" type="checkbox"/> Student <input type="checkbox"/> Fairview Researcher <input type="checkbox"/> Gillette Researcher <input type="checkbox"/> Other:		
Human Subjects Training <input checked="" type="checkbox"/> CITI, <input type="checkbox"/> Investigator 101 (until 2008), <input type="checkbox"/> NIH training (EXCEPT for 5/8/06 to 2/29/08), <input type="checkbox"/> UM/RCR (between 1994-2003) <input type="checkbox"/> Other - Indicate training received, when and from which institution:		HIPAA Training (Required if Data Contains PHI): <input type="checkbox"/> HIPAA
<p>As Principal Investigator of this study, I assure the IRB that the following statements are true:</p> <p>The information provided in this form is correct. I have evaluated this protocol and determined that I have the resources necessary to protect participants, such as adequate funding, appropriately trained staff, and necessary facilities and equipment. I will seek and obtain prior written approval from the IRB for any substantive modifications in the proposal, including changes in procedures, co-investigators, funding agencies, etc. I will promptly report any unexpected or otherwise significant adverse events or unanticipated problems or incidents that may occur in the course of this study. I will report in writing any significant new findings which develop during the course of this study which may affect the risks and benefits to participation. I will not begin my research until I have received written notification of final IRB approval. I will comply with all IRB requests to report on the status of the study. I will maintain records of this research according to IRB guidelines. The grant that I have submitted to my funding agency which is submitted with this IRB submission accurately and completely reflects what is contained in this application. If these conditions are not met, I understand that approval of this research could be suspended or terminated.</p>		
leex5298	12 April 2013	Doctoral Student
x.500 of PI	Date	Title of PI

Training Links:

Accepted Human subjects and HIPAA training: <http://www.irb.umn.edu/training.html#.UIWvTFE5g4c>- "UM/RCR" includes all human subjects protection training offered in-person or online at the University of Minnesota from 1994-2003.

- The online NIH tutorial offered during the period May 8, 2006-February 29, 2008 is NOT acceptable to meet this requirement.

- If you completed a version of this training not included on the list provided, provide details as indicated

1.4 Co-Investigator(s)

Co-Investigators responsible for, or working on, this project should be listed below. Include any individual who will have responsibility for the consent process, direct data collection from subjects, or follow-up.

Name (Last name, First name MI):	Highest Earned Degree:

Mailing Address:	Phone Number:
	Pager or Cell Phone Number:
	Fax:
U of M Employee/Student ID:	Email:
U of M x.500 ID (ex. smith001):	University Department (if applicable):
Occupational Position: <input type="checkbox"/> Faculty <input type="checkbox"/> Staff <input type="checkbox"/> Student <input type="checkbox"/> Fairview Researcher <input type="checkbox"/> Gillette Researcher <input type="checkbox"/> Other:	
Human Subjects Training <input type="checkbox"/> CITI , <input type="checkbox"/> Investigator 101 (until 2008), <input type="checkbox"/> NIH training (EXCEPT for 5/8/06 to 2/29/08), <input type="checkbox"/> UM/RCR (between 1994-2003) <input type="checkbox"/> Other - Indicate training received, when and from which institution:	HIPAA Training (Required if Data Contains PHI): <input type="checkbox"/> HIPAA
x.500 of Co-PI	Date
	Title of Co-PI

Name (Last name, First name MI):	Highest Earned Degree:
Mailing Address:	Phone Number:
	Pager or Cell Phone Number:
	Fax:

U of M Employee/Student ID:		Email:
U of M x.500 ID (ex. smith001):		University Department (if applicable):
Occupational Position: <input type="checkbox"/> Faculty <input type="checkbox"/> Staff <input type="checkbox"/> Student <input type="checkbox"/> Fairview Researcher <input type="checkbox"/> Gillette Researcher <input type="checkbox"/> Other:		
Human Subjects Training <input type="checkbox"/> CITI , <input type="checkbox"/> Investigator 101 (until 2008), <input type="checkbox"/> NIH training (EXCEPT for 5/8/06 to 2/29/08), <input type="checkbox"/> UM/RCR (between 1994-2003) <input type="checkbox"/> Other - Indicate training received, when and from which institution:		HIPAA Training (Required if Data Contains PHI): <input type="checkbox"/> HIPAA
x.500 of Co-PI	Date	Title of Co-PI

Research Staff

Personnel you wish to be included in correspondence related to this study e.g. study coordinators

Name (Last name, First name MI):	Highest Earned Degree:
Mailing Address:	Phone Number:
	Pager or Cell Phone Number:
	Fax:
U of M Employee/Student ID:	Email:
U of M x.500 ID (ex. smith001):	University Department (if applicable):
Occupational Position: <input type="checkbox"/> Faculty <input type="checkbox"/> Staff <input type="checkbox"/> Student <input type="checkbox"/> Fairview Researcher <input type="checkbox"/> Gillette Researcher <input type="checkbox"/> Other:	
Human Subjects Training <input type="checkbox"/> CITI , <input type="checkbox"/> Investigator 101 (until 2008), <input type="checkbox"/> NIH training (EXCEPT for 5/8/06 to 2/29/08), <input type="checkbox"/> UM/RCR (between 1994-2003) <input type="checkbox"/> Other - Indicate training received, when and from which institution:	HIPAA Training (Required if Data Contains PHI): <input type="checkbox"/> HIPAA

Name (Last name, First name MI):	Highest Earned Degree:
Mailing Address:	Phone Number:
	Pager or Cell Phone Number:

	Fax:
U of M Employee/Student ID:	Email:
U of M x.500 ID (ex. smith001):	University Department (if applicable):
Occupational Position: <input type="checkbox"/> Faculty <input type="checkbox"/> Staff <input type="checkbox"/> Student <input type="checkbox"/> Fairview Researcher <input type="checkbox"/> Gillette Researcher <input type="checkbox"/> Other:	
Human Subjects Training <input type="checkbox"/> CITI, <input type="checkbox"/> Investigator 101 (until 2008), <input type="checkbox"/> NIH training (EXCEPT for 5/8/06 to 2/29/08), <input type="checkbox"/> UM/RCR (between 1994-2003) <input type="checkbox"/> Other - Indicate training received, when and from which institution:	HIPAA Training (Required if Data Contains PHI): <input type="checkbox"/> HIPAA

Need more space for Co-Investigators and Staff? Download an [extra personnel sheet](#) and include it with your application.

1.5 Student Research

If the PI of this research is a student, include Appendix J filled out by the advisor with this application form and include the advisor's x500 below.

Advisor Name (Last name, First name MI): Quam, Jean K.	Highest Earned Degree: Ph.D.
Mailing Address: 104 Burton Hall 178 Pillsbury Drive S.E. Minneapolis, MN 55455-0221	Phone Number: 612-626-5177
	Pager or Cell Phone Number:
	Fax: 612-626-7496
U of M Employee/Student ID: 2109762	Email: jquam@umn.edu
U of M x.500 ID (ex. smith001): jquam	University Department (if applicable): College of Education & Human Development
Occupational Position: <input checked="" type="checkbox"/> Faculty <input type="checkbox"/> Staff <input type="checkbox"/> Student <input type="checkbox"/> Fairview Researcher <input type="checkbox"/> Gillette Researcher <input type="checkbox"/> Other:	
Human Subjects Training <input checked="" type="checkbox"/> CITI, <input type="checkbox"/> Investigator 101 (until 2008), <input type="checkbox"/> NIH training (EXCEPT for 5/8/06 to 2/29/08), <input type="checkbox"/> UM/RCR (between 1994-2003) <input type="checkbox"/> Other - Indicate training received, when and from which institution:	HIPAA Training (Required if Data Contains PHI): <input type="checkbox"/> HIPAA
jquam	4/12/2013
x.500 of Advisor	Date

2. Funding

2.1 Is this research funded by an internal or external agency?

Yes.

Type of Funding Source: Federal Funds Foundation Business and Industry

Name of Funding Source:

[Include Appendix A](#)

No. Explain how costs of research will be covered:

Costs are expected to be minimal and will be covered by the PI.

3. Institutional Oversight

3.1 Is this research proposal being reviewed by any other institution or peer review committee?

- Yes. Attach copy of materials submitted for peer review.
 No.

If yes, Please select which other committee approvals are required for this research and provide documentation of their approval:

- Cancer Protocol Review Committee (CPRC)
 Cancer Protocol Review Committee/Non-Therapeutic Interventional Trials Review (CPRC/NTI)
 Conflict of Interest Review Committee
 Nursing Research Council
 Other IRB, please specify: _____
 Other, please specify: _____

Peer review Web sites:

- [Cancer Protocol Review Committee \(CPRC\)](#)
- [Cancer Protocol Review Committee/Non-Therapeutic Interventional Trials Review \(CPRC/NTI\)](#)
- [University Research Opportunity Program \(UROP\)](#)
- [Grant-In-Aid of Research, Artistry, and Scholarship Program \(GIA\)](#)

3.2 Does this research involve cancer prevention, treatment, survivorship, or supporting care?

No.

Yes.

If this research is cancer-related, including prevention, treatment, survivorship or supportive care, then documentation of approval from the Cancer Protocol Review Committee (CPRC) or CPRC/NTI (Non-Therapeutic Interventional) MUST be provided before final IRB approval can be granted. If this cancer-related research has been peer-reviewed by NIH, CPRC approval is still required.

4. Conflict of Interest

Federal Guidelines emphasize the importance of assuring there are no conflicts of interest in research projects that could affect the welfare of human subjects. Reporting of financial interests is required from all individuals responsible for the design, conduct or reporting of the research. If this study involves or presents a potential conflict of interest, additional information will need to be provided to the IRB. Examples of conflicts of interest may include, but are not limited to:

- A researcher participating in research on a technology, process or product owned by a business in which the researcher or family member holds a significant financial interest or a business interest
- A researcher participating in research on a technology, process or product developed by that researcher or family member
- A researcher or family member assuming an executive position in a business engaged in commercial or research activities related to the researcher's University responsibilities
- A researcher or family member serving on the Board of Directors of a business from which that member receives University-supervised Sponsored Research Support
- A researcher receiving consulting income from a business that funds his or her research
- A researcher receiving consulting income from a business that could benefit from the results of research sponsored by a federal agency (i.e. NIH)

"Family Member" means the covered individual's spouse or domestic partner, dependent children, and any other family member whom the covered individual reasonably knows may benefit personally from actions taken by the covered individual on behalf of the University.

"Business Interest" means holding any executive position in, or membership on a board of a business entity, whether or not such activities are compensated.

For additional details and definitions, please refer to the appropriate policy:

University of Minnesota Researchers, please refer to:

<http://www.policy.umn.edu/Policies/Operations/Compliance/CONFLICTINTEREST.html>

University of Minnesota Researchers involved in clinical health care in the Academic Health Center, also refer to:

http://www.policy.umn.edu/Policies/Operations/Compliance/CONFLICTINTEREST_APPA.html

Fairview Health System Researchers, please refer to:

<http://www.fairview.org/Research/index.htm>

Gillette Children's Specialty Healthcare Researchers, please refer to:

<http://www.gillettechildrens.org/>

4.1 Do any of the Investigators or personnel listed on this research project have a business interest or a financial interest of \$10,000 or more (\$5,000 or more if research is funded by a Public Health Service (PHS) agency or researcher is involved in clinical health care) associated with this study when aggregated for themselves and their family members?

No.

Yes.

If yes, identify the individual(s) and complete section 4.3:

4.2 Do any of the investigators or personnel (when aggregated for themselves and their family members) listed on this research have:

Ownership interests less than \$10,000 (\$5,000 if research is funded by PHS or researcher is involved in clinical health care) when the value of interest could be affected by the outcome of the research?

No. Yes.

Ownership interests exceeding 5% interest in any one single entity (or any equity interest in a non-publicly traded entity if research is funded by PHS or researcher is involved in clinical health care)?

No. Yes.

Compensation less than \$10,000 (\$5,000 if research is funded by PHS or researcher is involved in clinical health care) when the value of the compensation could be affected by the outcome of the research?

No. Yes.

If yes, identify the individual(s) and complete section 4.3:

4.3 Has the business or financial interest been reported?

N/A (No business or financial interest indicated in 4.1 or 4.2)

No.

If you are a University of Minnesota researcher, please report your business or financial interest online via the Report of External Professional Activities (REPA) at:

http://egms.umn.edu/quickhelp/EGMS_Instructions/prepa.html

If you are a Fairview Health System researcher, please complete the Fairview Health Services Conflict of Interest Disclosure forms at:

<http://www.fairview.org/Research/BusinessOperations/ConflictsofInterest/index.htm>

and submit the completed forms to the Fairview Office of Research.

If you are a Gillette Children's Specialty Healthcare researcher, please contact the Director of Research Administration, at 651-229-1745.

Yes.

If yes, have you been informed that a Conflict of Interest Review Committee is reviewing the information you reported on your REPA?
No.

Yes.

The IRB will verify that a management plan is in place with the Conflict of Interest (COI) Program. If the COI Program does not have an approved management plan in place for this research, they will contact the individual(s) listed in question 4.1 for additional information.

Final IRB approval cannot be granted until all potential conflict matters are settled. The IRB receives a recommendation from the Conflict of Interest Review Committee regarding disclosure to subjects and management of any identified conflict. The convened IRB determines what disclosure language should be in the consent form.

5. Compensation

5.1 Will you give subjects gifts, payments, compensation, reimbursement, services without charge or extra credit?

- Yes.
 No.

If yes, please explain:

6. Summary of Activities

Use lay language, do not refer to grant or abstract.

6.1 Describe the objective(s) of the proposed research including purpose, research question, hypothesis and relevant background information etc.

The purpose of this study is to examine how members of a nonprofit, community-based HIV/AIDS service organization (ASO) experience organizational change in response to the federal government's Patient Protection and Affordable Care Act (aka "Affordable Care Act" or ACA). The current investigation is a qualitative case study involving a single subject, the Minnesota AIDS Project (MAP) in Minneapolis, MN. The informants are employees and governing board members of the Minnesota AIDS Project, as well as unpaid volunteers and recipients of MAP's services.

Principal Questions. Because this study is concerned with organizational change within an HIV/AIDS service setting, this research design will address the following central question: How do the grassroots origins of an HIV/AIDS service organization influence its members' experiences with organizational change brought about by the Affordable Care Act?

Key sub-questions that will guide this investigation include the following:

- 1) What do constituent members (e.g. staff, service recipients, volunteers, donors, etc.) recognize as the organization's defining values?
- 2) How do members define individual and organizational effectiveness in this specific context?
- 3) What changes does the organization's management propose in response to ACA legislation?
- 4) What is the ultimate goal of the proposed changes, and what intermediary outcomes will indicate progress toward this goal?
- 5) How are these changes perceived by the constituent members who will be most directly affected?
- 6) To what extent do organization members' perceptions of these changes align with the organization's stated intentions?
- 7) Which theoretical constructs help to make sense of constituent members' responses to this

organizational change?

Propositions. Although qualitative research does not typically include hypothesis testing, this research design is guided by one central proposition and two key sub-propositions.

Central proposition: While HIV/AIDS organizations (ASOs) have endured several critical changes in mission and function since the 1980s, presently organizational survival among ASOs depends on the adoption and integration of top-down changes in federal health care policy.

Sub-proposition A: The extent to which ASO members perceive congruence between the change process, their technical responsibilities, and their personal and professional values may influence the organizational change experience in a number of ways.

Sub-proposition B: Members' perceptions of organizational change may vary due to a number of key factors including the magnitude of change experienced in individuals' roles within the organization; direct personal and/or professional experiences with sexual minority or drug-using populations; the amount of individual experience working in HIV/AIDS, sexual health, or chemical health services; and, differing perspectives on how to achieve optimal service outcomes.

6.2 Which methods will this study include? (check all that apply)

- Descriptive
- Ethnographic
- Experimental/Control Design
- Field work (*If checked, please include Appendix L*)
- Formative
- Longitudinal
- Oral history
- Phenomenological
- Qualitative
- Quantitative
- Other, specify : _____

6.3 Describe the research study design.

The present study will utilize the following approaches to collect and analyze data concerning the subject:

1) Analysis of organizational documents pertaining to MAP's current strategic planning process (e.g. by state and federal policy, best practices among similar organizations, published research, staff and/or consumer input, local needs assessments, etc.) New documents to be considered in this study will include the following: 1) the organization's new strategic plan; 2) documentation from its recent strategic planning process (e.g. supporting evidence, alternative approaches, noted concerns); 3) relevant constituent data (aggregated demographics, needs assessment findings, etc.); and, 4) meeting notes and official communications (e.g. memos, letters, and emails) with members concerning implementation of the strategic plan. Copies of periodical articles written about the organization during the study's timeframe may also be examined for relevance.

2) Observations of organization meetings that explicitly address the current change process.

The selection of organizational meetings to observe will be guided by information gleaned in documentary analysis, with permissions negotiated with relevant members of the management team prior to commencement. The investigator will aim to maintain the role of nonparticipant before, during, and after the conclusion of meetings. The investigator's familiarity as a previous employee of the organization may afford him the opportunity to adopt the stance of both insider (who possesses familiarity with the organization's history and objectives) and outsider (who has not worked alongside new employees or experienced recent operational changes). The researcher's familiarity with former colleagues may help to establish trust during field observations if he is recognized as a peer with credible knowledge of their experiences and perspectives. At the same time, the practice of self-observation ("reflexivity") will need to be adopted and maintained in order for the researcher to discern his perspective from those observed in participants during the process (Patton, 2002).

3) Semi-structured oral interviews with MAP employees, governing board members, volunteers, and service recipients. The investigator will systematically select informants based on findings gleaned from documentary analysis and field notes. The following stakeholders will be considered potential sources, including but not limited to: 1) Employees who experience substantial changes in their technical responsibilities due to ACA-related obligations. 2) Employees with lengthier records of employment, who may have experienced numerous changes in HIV/AIDS services over time. 3) Employees who closely work or identify with LGBT and/or drug-using populations; 4) Members of MAP's governing board who participated in drafting its new strategic plan. And, 5) Volunteers and service recipients identified by staff informants, who are considered "rich" cases by virtue of their voluntary involvement in organizational functions.

6.4 Describe the tasks subjects will be asked to perform. Attach surveys, instruments, interview questions, focus group questions etc. Describe the frequency and duration of procedures, psychological tests, educational tests, and experiments; including screening, intervention, follow-up etc. (If you intend to pilot a process before recruiting for the main study please explain.)

All informants will be asked to complete a Demographic Information Form (see Appendix #) when they complete the informed consent process. Information to be collected will include name, email address, telephone number, date of birth, race/ethnicity, gender identity, sexual orientation, and length of involvement with the organization.

Interview procedures: The semi-structured interview guide will adhere closely to the central question of this study, which is, "How do the grassroots origins of an HIV/AIDS service organization influence its members' experiences with organizational change brought about by the federal government's Affordable Care Act?"

To sensitize interviewees to this key query, the open-ended questioning route will begin by addressing the following key topics:

- 1) How the individual member came to be involved in the organization.
- 2) How the interviewee describes its defining characteristics and values.
- 3) Which characteristics the interviewee perceives as distinguishing HIV/AIDS service organizations from other health and human services.
- 4) How the interviewee defines individual and organizational success within this context.

- 5) How the interviewee describes the current change process in their own words, both with respect to technical aspects (i.e. job functions and responsibilities) and cultural aspects (i.e. organizational climate and values).
- 6) Building on these responses, the interviewer will ask participants to describe their enthusiasm for the proposed changes on a 4-point scale: Hot (Very positive), Warm (Somewhat positive), Lukewarm (Somewhat negative), and Cold (Very negative).
- 7) Using this information, the interviewer will verbally review the participant's prior responses and ask him or her to identify which of these factors have the strongest influence on this estimation.
- 8) To conclude the interview, the researcher will summarize each participant's responses and ask him or her to identify any unaddressed factors they believe are valuable to consider, and what types of support do they feel are needed from in order to for the change process to be successful.
- 9) Debriefing procedures will include follow-up contact via email to share initial analyses ("member checking") as well as to encourage the solicitation of additional suitable informants.
- 10) As data collection and analyses proceed, the investigator will determine which cases should be considered for follow-up interviews, during which participants will be encouraged to reflect on their previous comments in light of their subsequent experiences with the subject matter.
- The use of probes and follow-up questions throughout this sequence (e.g. "How did that come to happen? Could you say some more about that?" etc.) will help the researcher to gain further details from each participant while clarifying potential misunderstandings in the data (Patton, 2002).

6.4a List here any procedures that would be performed for these subjects if there were no research involved (i.e. procedures performed for diagnostic or treatment purposes)

The organization's implementation of a new strategic plan will occur regardless of whether participants enroll in this study. Findings from each stage of analysis will enable the investigator to logically sequence the subsequent steps for data collection and analysis, so that further document reviews, observation sessions, and participant interviews occur as parallel processes to the organization's implementation of the strategic plan.

6.5 How many months do you anticipate this research study will last from the time final approval is granted?

12

7. Participant Population

7.1 Expected number of participants: 40

20 of Male

20 of Female

7.2 Expected Age Range

Check all that apply:

- 0-7 (Include parental consent form)
- 8-17 (Include child's assent form and parental consent form)
- 18-64
- 65 and older

Exact ages to be included: 18 - 64

7.3 Inclusion/Exclusion of Children in this Research

If this study proposes to *include* children, this inclusion must meet one of the following criterion for risk/benefit assessment according to the federal regulations ([45CFR56, subpart D](#)).

Check the one appropriate box:

- (404) Minimal Risk
- (405) Greater than minimal risk, but holds prospect of direct benefit to subjects
- (406) Greater than minimal risk, no prospect of direct benefit to subjects, but likely to yield generalizable knowledge about the subject's disorder or condition.

Explain how this criterion is met for this study:

If this study would *exclude* children, [NIH guidelines](#) advise that the exclusion be justified, so that potential for benefit is not unduly denied. Indicate whether there is potential for direct benefit to subjects in this study and if so, provide justification for excluding children. Note that if inclusion of children is justified, but children are not seen in the PI's practice, the sponsor must address plans to include children in the future or at other institutions.

- No direct benefit to participation (exclusion of children permissible)
- Potential for direct benefit exists.

Provide justification for exclusion of children:

Because the primary focus of this study concerns constituent members of an HIV/AIDS service organization, the population is expected to include primarily adult workers, governing board members, volunteers, and service recipients. While the organization does not specifically exclude children from its services, they represent a small minority of its constituent population. Because this study examines how the grass roots origins of an HIV/AIDS service organization may influence its current experiences with organizational change, children would likely not possess the length of experience necessary to be considered information-rich cases.

7.4 Other Protected Populations to be Targeted or Included in this Research. Check all that apply:

Protected by Federal Regulations

Pregnant Woman/Fetuses/IVF

Refer to guidance at <http://www.research.umn.edu/irb/guidance/women.html> and [45CFR46 subpart B](#)

Prisoners

[Include Appendix C](#) and Refer to and [45 CFR 46 subpart C](#) on the populations protected by Federal Regulations

Protected by Federal Guidelines

Include Appendix I

Mentally/Emotionally/Developmentally Disabled/Impaired Decision Making Capacity

Minority Group(s) and Non-English Speakers

Gender Imbalance—all or more of one gender

7.5 Inclusion and Exclusion of Subjects in this Research Study

Describe criteria for inclusion and exclusion of subjects in this study

Inclusion Criteria:

The following stakeholders will be considered potential sources: 1) Employees who experience substantial changes in their technical responsibilities due to ACA-related obligations. 2) Employees with lengthier records of employment, who may have experienced numerous changes in HIV/AIDS services over time. 3) Employees who closely work or identify with LGBT and/or drug-using populations; 4) Members of MAP's governing board who participated in drafting its new strategic plan. And, 5) Volunteers and service recipients identified by staff informants, who are considered "rich" cases by virtue of their voluntary involvement in organizational functions. Because the organization's service area is bounded geographically, its members are expected to be located within or adjacent to the state of Minnesota.

Exclusion Criteria:

Participants will not be included if they cannot verify a relationship with the organization that meets the above criteria.

7.6 Location of subjects during research activity or location of records to be accessed for research:

Check all that apply:

University of Minnesota Medical Center, Fairview

Fairview Southdale

Fairview Ridges

Other Fairview Facility, specify: _____

Gillette Children's Hospital

Other Hospitals, specify: _____

Community Clinic, specify: _____

Elementary/Secondary Schools (*include Appendix M*), specify: _____

- Community Center, specify: Minnesota AIDS Project, 1400 Park Avenue, Minneapolis, MN 55404
- University Campus (non-clinical), specify: _____
- University Campus (clinical), specify: _____
- Prisons/Halfway houses (*include Appendix C*), specify: _____
- Nursing Home(s), specify: _____
- Subject's Home, specify: _____
- International Location: _____ (*include Appendix K*)
- Other special institutions, specify: _____

7.7 Describe the rationale for using each location checked above. Include IRB approvals or letters of cooperation from other agencies or sites, if applicable.

The primary site for field observations and interviews will be the Minnesota AIDS Project office building in Minneapolis. The building possesses multiple meeting spaces that can accommodate both individual interviews and meetings of up to 60 people, with flexible scheduling options based on time of day and staff's needs. For constituents who are uncomfortable meeting on site, the researcher will offer the following alternatives: 1) face-to-face interviewing at a location mutually agreeable to both parties; 2) audio-recorded telephone interviewing; or, 3) video-recorded interviewing via computer or mobile device using Adobe Connect, an Internet meeting software available to researchers at the University of Minnesota.

8. Recruitment

8.1 Describe the recruitment process to be used for each group of subjects:

Attach a copy of any and all recruitment materials to be used e.g. advertisements, bulletin board notices, e-mails, letters, phone scripts, or URLs.

Staff and board informants: Initially, the Minnesota AIDS Project will send an email to its employees and governing board members explaining the study and introducing the principal investigator. Second, the investigator and MAP's Executive Director will explain the study in person at the organization's monthly governing board meeting, as well as its monthly all-staff meeting. At that time, the investigator will distribute a postcard asking employees to indicate their willingness to participate in the study and provide their name and preferred mode of contact (email or telephone). Materials will be provided for members who are absent from the meetings as well. Third, recruitment for members of the organization who are not employees will be embedded into the procedures described below.

Volunteers and service recipients: As part of the interview process, staff informants will be asked to share information about the study with additional potential participants. Employees who identify volunteers and/or service recipients to contact will be provided with a standard email or telephone message to send to the individual, informing him or her of the study and asking for permission to share their contact information with the investigator. If the individual agrees, the researcher will follow up by sending the above-mentioned informational email

describing the study and arranging time to meet and administer informed consent. Finally, in order to examine experiences with organizational change over a period of time, all interview participants will be asked about their willingness to engage in a future follow-up conversation, both to revisit their previous responses and to reflect on their subsequent experiences with the change process.

8.2 Explain who will approach potential subjects to take part in the research study and what will be done to protect individuals' privacy in this process:

Initial contact of subjects identified through records search must be made by the official holder of the record, i.e. primary physician, therapist, public school official.

The P.I. will recruit sequentially based on initial findings from documentary analyses and observations, beginning first with employees and governing board members and extending eventually to volunteers and service recipients. This strategy represents a form of operational construct sampling, which is appropriate for studying "real-world" examples of the construct of interest to the investigator (Patton, 2002). Because implementation of new organizational policy may occur sequentially across different departments, this purposeful sampling approach will allow the investigator to trace members' experiences logically from program to program. The following procedures are intended to ensure that participants are systematically informed about the purpose and timing of the study.

Participants will sign an informed consent agreement to be interviewed, observed, and quoted (see Appendix #). Included in the consent procedures will be language specifying the individual participant's right to review the transcript and delete portions they do not wish to be quoted. Meeting participants who do not consent to being included in the study will be excluded from the researcher's analysis of field notes. Informants quoted in this study will be identified by generic titles instead of names. When possible, gender-neutral language will be used to reduce the possibility of recognition. However, due to the small number of potential participants, the investigator will caution all informants that the identities of those who are quoted, even with generic identifiers, might be recognizable to individuals familiar with the organization.

8.3 Are subjects chosen from records?

Yes. Who gave approval for use of the records: The selection of strategic planning documents will be negotiated with the organization's senior management team prior to commencement of this study.

No.

If yes, are records "private" medical or student records?

Yes. Provide the protocol, consent forms, letters, etc. for securing consent of the subjects of the records. Written documentation for the cooperation/permission from the holder or custodian of the records should be attached.

No.

8.4 University of Minnesota policy prohibits researchers from accepting gifts for research activities. Is the study sponsor offering any incentive connected with subject enrollment or completion of the research study (i.e. finders fees, recruitment bonus, etc.) that will be paid directly to the research staff?

- Yes.
 No.

If yes above, please affirm that you have declined acceptance of gifts in the box below.
Code of Conduct - http://www1.umn.edu/regents/policies/academic/Code_of_Conduct.pdf

9. Risks and Benefits

9.1 Does the research involve any of these possible risks or harms to subjects?

Check all that apply:

- Use of a deceptive technique. (Include Appendix N)
 Use of private records (educational or medical records)
 Manipulation of psychological or social variables such as sensory deprivation, social isolation, psychological stresses
 Any probing for personal or sensitive information in surveys or interviews
 Presentation of materials which subjects might consider sensitive, offensive, threatening or degrading
 Possible invasion of privacy of subject or family
 Social or economic risk
 Other risks, specify: _____

9.2 Describe the nature and degree of the risk or harm checked above. The described risks/harms must be disclosed in the consent form.

The nature of a member's involvement in an HIV/AIDS organization may stem from personal circumstances including identification with sexual minority or drug-using populations, close personal relationships with HIV-positive persons, or having an HIV diagnosis. Some participants may feel that disclosing their perceptions of the organization's current circumstances may put them at risk for exposure and possible sanction, including termination of employment or social services.

9.3 Explain what steps will be taken to minimize risks or harms and to protect subjects' welfare. If the research will include protected populations (see question 7.4) please identify each group and answer this question for each group.

As outlined above, the informed consent procedures will include steps for ensuring that

identifying information is changed, and participants have opportunities to review their interview transcripts and delete portions they do not wish to be quoted.

9.4 Describe the anticipated benefits of this research for individual subjects in each subject group. If none, state “None.”

(Hint: For instance, if the intervention proves effective, subjects in active arms will benefit but controls will not.)

None

9.5 Describe the anticipated benefits of this research for society, and explain how the benefits outweigh the risks.

The risks associated with this study are relatively minimal. Given the system-wide significance of current health policy reforms, this study is timely and relevant for examining organizational change within this specific setting at the present time. The findings of the study will contribute to the following bodies of knowledge: organizational policy and practice in the health and human services; HIV/AIDS service provision; public health; and, social services that have arisen from gay, lesbian, bisexual, and transgender (GLBT) social movements.

10. Confidentiality of Data

See [Protecting Private Data Guideline](#) from the Office of Information Technology (OIT) for information about protecting the privacy of research data.

10.1 Will you record any direct identifiers, names, social security numbers, addresses, telephone numbers, etc?

- Yes.
 No.

If yes, explain why it is necessary to record findings using these identifiers. Describe the coding system you will use to protect against disclosure of these identifiers.

As interview data are transcribed and coded, interviewees will be assigned a sequential numeric indicator (P1, P2, P3, etc.) that will be consistently used to refer to the individual in the analysis. For the final write-up, the PI will generate a list of generic identifiers to associate with each coded individual, to ensure that quoted material cannot be attribute to any individual associated with the organization.

10.2 Will you retain a link between study code numbers and direct identifiers after the data collection is complete?

- Yes.
 No.

If yes, explain why this is necessary and state how long you will keep this link.

10.3 Will you provide the link or identifier to anyone outside the research team?

- Yes.
 No.

If yes, explain why and to whom:

10.4 Where, how long, and in what format (such as paper, digital or electronic media, video, audio, or photographic) will data be kept? In addition, describe what security provisions will be taken to protect this data (password protection, encryption, etc.).

Paper records (e.g. organizational documents, field notes, interview notes, signed consent forms) will be kept in a locked file located in the PI's office on the University of Minnesota.

Electronic data (e.g. interview recordings, transcripts, data analyses) will be saved to the PI's computer, which will be password protected, encrypted, and backed up with an external hard drive.

The researcher will retain access to these data for no more than 18 months following the conclusion of this study.

10.5 Will you place a copy of the consent form or other research study information in the subjects' record such as medical, personal or educational record? (This information should be explained on the consent form.)

- Yes.
 No.

If yes, explain why this is necessary:

10.6 Federal Certificates of Confidentiality

If the data collected contains information about illegal behavior, visit the NIH Certificates of Confidentiality Kiosk (<http://grants1.nih.gov/grants/policy/coc/>) for information about obtaining a Federal Certificate of Confidentiality.

Will you obtain a Federal Certificate of Confidentiality for this research?

- Yes. Submit documentation of application (and a copy of the Certificate of Confidentiality award if granted) with this application form.
 No.

11. Use of Protected Health Information (PHI): HIPAA Requirements

11.1 As part of this study, do you:

- a. **Collect protected health information (PHI)* from subjects in the course of providing treatment/experimental care; or**
- b. **Have access to PHI* in the subjects' records?**

Please read the definition of PHI below before answering.

*PHI is defined under HIPAA as health information transmitted or maintained in any form or medium that:

1. identifies or could be used to identify an individual;
2. is created or received by a healthcare provider, health plan, employer or healthcare clearinghouse; and
3. relates to the past, present or future physical or mental health or condition of an individual; the provision of health care to an individual; or the past, present or future payment for the provision of healthcare to an individual.

The following records ARE EXEMPTED from the definition of PHI even though they may contain health-related information: student records maintained by an educational institution and employment records maintained by an employer related to employment status. If your study uses these kinds of records, it is not subject to HIPAA. However, existing IRB rules on informed consent and confidentiality still apply.

Health-related information is considered PHI if (any of the following are true):

1. the researcher obtains it directly from a provider, health plan, health clearinghouse or employer (other than records relating solely to employment status);
2. the records were created by any of the entities in "1" and the researcher obtains the records from an intermediate source which is NOT a school record or an employer record related solely to employment status; OR
3. the researcher obtains it directly from the study subject in the course of providing treatment to the subject.

Health-related information is not considered PHI if the researcher obtains it from:

1. student records maintained by a school;
2. employee records maintained by an employer related to employment status; OR
3. the research subject directly, if the research does NOT involve treatment.

Yes. If yes to a or b above, complete Appendix H to show how you will satisfy HIPAA requirements for authorization to use PHI in research.

No. If no, continue to section 12.

12. Expedited Review Eligibility

Federal criteria for risk assessment make some studies eligible for Expedited Review (see 45 CFR 46.110 and 21 CFR 56.110). Expedited review categories can be found at <http://www.irb.umn.edu/expedited.html>. Studies eligible for Expedited Review must meet the federal definition of minimal risk, which is as follows: "the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests". Expedited Review eligibility decisions are made by the IRB following receipt of the application.

12.1 What is the level of risk to subjects in this research study?

- Not greater than minimal risk.** Justify minimal risk in accord with the federal definition and indicate which expedited review category (1-9) applies to this research:

This research design meets the criteria for Category 7. The probability of harm or discomfort that a research participant would experience will be minimal. Regardless of whether a participant enrolls in this study, the individual will have access to the same information and resources to support his or her experiences working for or with the Minnesota AIDS Project.

- Greater than minimal risk (full committee review)**

13. Informed Consent Process

13.1 Recognizing that consent itself is a *process* of communication, build on your responses to questions 8.1 and 8.2 and describe what will be said to the subjects to introduce the research. Do not say "see consent form". Write the explanation in lay language. If you are using telephone surveys, telephone scripts are required.

The following procedures are intended to ensure that participants are systematically informed about the purpose and timing of the study.

Staff and board informants: Initially, the Minnesota AIDS Project will send an email to its employees and governing board members explaining the study and introducing the principal investigator. Second, the investigator and MAP's Executive Director will explain the study in person at the organization's monthly governing board meeting, as well as its monthly all-staff meeting. At that time, the investigator will distribute a postcard asking employees to indicate their willingness to participate in the study and provide their name and preferred mode of contact (email or telephone). Materials will be provided for members who are absent from the meetings as well.

Only members who indicate willingness to participate in the study will be contacted for interviews. Meeting participants who do not consent to being observed will be excluded from the researcher's analysis of field notes. Informed consent will be administered with each eligible participant at the point of first contact (i.e. prior to observing a specific meeting or before conducting each new interview).

Finally, recruitment for members of the organization who are not employees will be embedded into the procedures described below.

Volunteers and service recipients: As part of the interview process, staff informants will be asked to share information about the study with additional potential participants. Employees who identify volunteers and/or service recipients to contact will be provided with a standard email or telephone message to send to the individual, informing him or her of the study and asking for permission to share their contact information with the investigator. If the individual agrees, the researcher will follow up by sending the above-mentioned informational email describing the study and arranging time to meet and administer informed consent. Finally, in order to examine experiences with organizational change over a period of time, all interview participants will be asked about their willingness to engage in a future follow-up conversation, both to revisit their previous responses and to reflect on their subsequent experiences with the change process.

13.2 In relation to the actual data gathering, when will consent be discussed and documentation obtained? (e.g., mailing out materials, delivery of consent form, meetings) Be specific.

Informed consent will be administered with each eligible participant at the point of first contact (i.e. prior to observing a specific meeting or before conducting each new interview).

13.3 Will there be any waiting period between informing the prospective participant and obtaining the consent? Please explain.

Consistent with the principle of theoretical saturation, data collection and analysis will be conducted concurrently, with the final participant sample determined by the point at which the researcher encounters redundancy, i.e. the point at which no new themes are found in the data. Because implementation of new organizational policy may occur sequentially across different departments, this purposeful sampling approach will allow the investigator to trace members' experiences logically from program to program.

The procedures for introducing the study to MAP's entire staff will allow for prolonged engagement that can help the PI establish trust with participants. Findings from initial documentary analyses will enable the investigator to logically sequence the subsequent steps for data collection and analysis, so that further document reviews, observation sessions, and participant interviews occur as parallel processes to the organization's implementation of the strategic plan. The investigator will systematically select interview participants based on findings gleaned from documentary analysis and field notes.

13.4 Will the investigator(s) be securing all of the informed consent?

- Yes.
 No.

If no, please name the specific individuals who will obtain informed consent and include their job title/credentials and a brief description of your plans to train these individuals to obtain informed consent and answer subjects' questions.

13.5 How will you determine who will give consent?

i.e. subject, parent, guardian, Legally Authorized Representative. If someone other than the subject will give consent, provide justification and a plan for obtaining surrogate consent.

Consent will always be given by the research participants.

13.6 Describe the steps taken to minimize the possibility of coercion or undue influence.

All communication with potential participants, including introductory email messages and presentations to staff and board, will emphasize the voluntary nature of this study. Participants will be reminded that they are free to withdraw at any point in the study. Interview participants will be offered the opportunity to review transcripts of their comments and delete portions that they do not wish to be quoted.

13.7 If subjects are minors, will they still be involved in this study when they reach the age of majority (18)?

N/A – No Minor Subjects

No.

Yes. If yes, outline your plan to re-consent these subjects at the age of majority:

Subject Comprehension

It is the responsibility of the investigator to assess comprehension of the consent process and only enroll subjects who can demonstrate informed understanding of the research study ([45 CFR 46.116](#))

The federal regulations require that consent be in language understandable to the subject. If subjects do not comprehend English, translated consent forms are required or the use of short forms with an oral explanation can be accepted. (see the [Consent Process & Forms](#) section of our Web site)

13.8 What questions will you ask to assess the subjects' understanding of the risks and benefits of participation? (Questions should be open-ended and go beyond requiring only a yes/no response.)

The investigator will ask the following questions when offering informed consent:

What concerns you regarding participation in this study?

What experiences have you had in the past that have negatively or positively impacted your participation in outcome studies?

What questions do you have for me at this time about the University of Minnesota study?

Documentation of Consent

13.9 Prepare and attach a consent form for IRB review.

Please see the [sample consent form](#) and follow it carefully. Do not submit sponsor prepared forms without editing the form to include University of Minnesota IRB standard language and all essential elements of informed consent.

Under specific conditions, when justifiable, documentation of informed consent can be waived or altered. These limited conditions are described in [45 CFR 46.116](#) and [45 CFR 46.117](#). If you believe that this research qualifies according to the regulations, include [Appendix W](#).

Resources for preparing informed consent forms:

- [Informed Consent Online Tutorial](http://www.research.umn.edu/consent/) – <http://www.research.umn.edu/consent/>
- [Informed Consent section of the Human Subjects Guide](http://www.research.umn.edu/irb/guidance/guide4.html) - <http://www.research.umn.edu/irb/guidance/guide4.html>

You have reached the end of this form. Please make sure that you have responded to every question on this application (even if your response is “not applicable”).

**Appendix J
Student as Principal Investigator Worksheet**

Use this worksheet in collaboration with your Academic or Project Advisor to demonstrate research preparedness of the Student investigator.

To be completed by the Academic Advisor

1. Student academic level: (check all that apply)

- Undergraduate
 Graduate: Masters candidate PhD. candidate

2. Explain how the scope of the proposed project, including anticipated risks and benefits, is appropriate to student research?

the risks to subjects and the agency are very minimal if they exist at all. Significant benefits could result for the agency as to future planning and program delivery.

3. Explain what experience, training or special preparation, the student researcher brings to the project from relevant coursework or professional exposure:

Michael Lee is a professional social worker who has over ten years of experience in practice. He has completed all research requirements for his doctorate in social work. He and I have jointly worked on research projects and I can personally attest to his research expertise.

As Academic or project advisor for the named student investigator, I assume the roles and responsibilities required to oversee the conduct of this research, prevent harms to subjects and foster benefits to the subjects. I will report any changes in the project, adverse events, or incidents to the IRB which may affect the conduct of this project.

Jean K. Quam

Name of Academic Advisor (Printed)

jquam

4/12/2013

Academic Advisor x500

Date

Advisors shoulder the responsibility for students engaged in independent research and should be copied on all correspondence.

***University of Minnesota
Review Board***

Institutional

By completing this form, I certify that the student researcher is knowledgeable about the regulations and policies governing research with human subjects and has sufficient training and experience to conduct this particular study in accordance with the research protocol.

Additionally:

By completing this form, I hereby confirm that I have thoroughly reviewed this IRB application and verify that it is complete and the research is appropriate for student research in topic and design.

I agree to meet with the student researcher on a regular basis to monitor study progress. I will arrange for communication during the course of the study if the procedures are carried out in a location away from the University or when regular channels of communication as not feasible.

I assure that the student researcher will promptly report unanticipated problems to the IRB and will adhere to all requirements for continuing review.

If I will be unavailable (e.g. sabbatical leave, vacation or resignation), I will arrange for an alternate faculty advisor to assume responsibility during my absence, and I will advise the IRB, in writing, of such changes.

If the student leaves the university, I will provide all the necessary documents for terminating the study or continuing review.

**jqum
x500 of Faculty Advisor**

**4/12/2013
Date**

**Appendix L
Field Work**

Research “in the field”, phenomenological, and ethnographic research proposals do not fit a traditional research design or IRB review model. However, the same principals for protection of subjects’/participants’ rights and welfare apply in these studies.

For more assistance with these issues see:

[American Psychological Association \(APA\) Ethical Code of Conduct 2002](#)

[American Sociological Association's Code of Ethics](#)

[American Anthropological Association Code of Ethics](#)

1. Describe research locale:

The primary site for field observations will be organizational meetings held at the Minnesota AIDS Project office building in Minneapolis. The selection of organizational meetings to observe will be guided by information gleaned in documentary analysis, with permissions negotiated with relevant members of the management team prior to commencement.

2. Describe how you chose this particular setting:

This selection is consistent with approaches commonly used in single-subject case studies involving organizations or programs. Direct observations in this setting will help to guide an examination of the context in which organizational change will occur.

3. Who is responsible for giving consent in this research setting/culture?

Individual members of the organization will be invited to give consent at the commencement of the study.

4. How will people in this setting let you know if they don't want to be in the research project or they don't want to talk with you?

Initially, the Minnesota AIDS Project will send an email to its employees and governing board members explaining the study and introducing the principal investigator. Second, the investigator and MAP's Executive Director will explain the study in person at the organization's monthly governing board meeting, as well as its monthly all-staff meeting. At that time, the investigator will distribute a postcard asking members to indicate their willingness to participate in the study and provide their name and preferred mode of contact (email or telephone). Individuals who indicate they are not interested in participating will be excluded from the researcher's analyses of field observations.

5. How will you handle situations in which group consent is provided but individuals do not want to participate and vice versa?

Permissions negotiated with relevant members of MAP's management team prior to the commencement of the observations. As clarified above, individuals who indicate they are not interested in participating will be excluded from the researcher's analyses of field observations.

6. How will you assess response to your research project? How do people feel about your writing about them, publishing, taking photos, etc.?

As part of introducing the study to MAP's employees and Board members, the PI will emphasize that as part of the consent process, participants retain the right to omit any statements they make from the final report. The investigator will remind participants of this stipulation prior to observing their meetings.

7. Will you consult with the people from whom you collected data before you publish? Explain.

Because this study involves prolonged contact between the PI and members of the organization, the PI will have multiple opportunities to consult with participants over the course of data collection. The PI will attempt to follow up with individuals as a matter of routine member checking, in order to strengthen the truth validity of his findings.

Note: If this is international research, Appendix K should also be included.

**Appendix B:
Letter of Assent**



MINNESOTA AIDS PROJECT
1400 Park Avenue
Minneapolis, MN 55404

612.341.2060
1.800.243.7321

MNAIDSPROJECT.ORG
fax 612.341.4057

April 15, 2013

To: Institutional Review Board, University of Minnesota

From: Bill Tiedemann, M.S.W., Executive Director

As Executive Director for the Minnesota AIDS Project, I am writing my letter to indicate my assent for the study you are currently reviewing. If you have any questions about the Minnesota AIDS Project's strategic plan implementation as it relates to this study, please contact me at (612) 341-2060, or at Bill.Tiedemann@mnaidsproject.org.

Sincerely

A handwritten signature in black ink, appearing to read "Bill Tiedemann", with a long horizontal flourish extending to the right.

Bill Tiedemann
Executive Director

LETTER OF UNDERSTANDING

THIS LETTER OF UNDERSTANDING is made and entered into effective as of 7 August, 2013 by and between the Minnesota AIDS Project ("MAP") and Michael G. Lee ("Michael Lee").

WHEREAS, MAP agrees to serve as sole research site for Michael Lee's dissertation study, "Systemic Change in Nonprofit HIV/AIDS Organizations: Examining the Adoption of Affordable Care Act Legislation in Services for HIV-Affected Populations." The proposal for this study has been reviewed by Michael Lee's faculty committee at the University of Minnesota, and was determined by the University's Institutional Review Board ("IRB") to not require IRB approval.

WHEREAS, Michael Lee agrees to hereby assign to MAP the right to full and accurate attribution as the sole source of data in any and all such Deliverables, and will acknowledge MAP in all publications with the following statement: "The author wishes to acknowledge the Minnesota AIDS Project of Minneapolis, MN, which served as the sole research site and provided the data for this study."

NOW THEREFORE, in consideration of the foregoing recitals, the mutual covenants and promises herein, and for other good and valuable consideration, the receipt and sufficiency of which are hereby acknowledged, the parties agree as follows:

1. MAP may provide the following to Michael Lee in connection with Michael Lee's dissertation research hereunder:

(i) Documents for analysis pertaining to the following topics:

- (I) MAP's new strategic plan
- (II) MAP's recent strategic planning process (e.g. supporting evidence, alternative approaches, noted concerns)
- (III) Relevant constituent data (aggregated demographics, needs assessment findings, etc.)
- (IV) Meeting notes and official communications with members concerning implementation of the strategic plan
- (V) Periodical articles written about the organization during the study's timeframe

(ii) Observation of organizational meetings pertaining to the implementation of MAP's new strategic plan

(iii) Time and meeting space to conduct semi-structured interviews with the following stakeholders:

- (I) Employees of MAP
- (II) Members of MAP's Board of Directors
- (III) Volunteers and service recipients identified by MAP's staff

2. Michael Lee agrees to conduct his research in a systematic and impartial manner.

3. Michael Lee agrees to keep all information associated with MAP's strategic planning process confidential. "Confidential Information" means any information that has value to MAP and is not generally know to the public, including but not limited to, business information, financial information, marketing plans, employee information, and client information whether

disclosed in writing, electronically or orally, and any compilation or combination of the foregoing. Notwithstanding the foregoing, information of MAP shall not be considered "Confidential Information" if it: (i) is or becomes public knowledge through no act or omission of Michael Lee; (ii) was already known by the receiving party at the time of the disclosure; or (iii) was lawfully obtained by the receiving party.

4. For the purpose of his dissertation research, Michael Lee shall not have access to any patient or client information during his research. Michael Lee shall actively avoid his exposure to any patient or client information. If Michael Lee at any time is exposed to any patient or client information, he shall keep such information confidential. This agreement is not construed to negate any prior agreements held between Michael Lee and MAP for research unrelated to the current study.

5. Michael Lee shall only use Confidential Information as necessary to perform the research for his dissertation study, "Systemic Change in Nonprofit HIV/AIDS Organizations: Examining the Adoption of Affordable Care Act Legislation in Services for HIV-Affected Populations."

6. Confidential Information shall be maintained in confidence and shall not be disclosed to any third party without the express written consent of the Executive Director of the MAP.

7. Michael Lee shall use not less than the degree of care used to prevent disclosure of his own confidential information to prevent disclosure of MAP's Confidential Information. In no event, however, shall less than a reasonable degree of care be used. Michael Lee shall take all actions reasonably necessary to assure that anyone working with him comply with the terms of this Agreement, including, but not limited to, any faculty or employees of the University of Minnesota. Michael Lee shall indemnify MAP for any and all acts and omissions of his agents, affiliated entities, or faculty and employees of University of Minnesota that, if performed by Michael Lee, would be a violation of this Agreement.

8. Any Confidential Information that is in writing, on a computer disk, or in any other form capable of being returned, shall be returned to MAP immediately upon request or termination of the agreement, whichever occurs first.

9. If a breach of this Agreement by Michael Lee occurs or is threatened, MAP shall be entitled to seek and obtain: (i) injunctive relief restraining Michael Lee from using or disclosing, in whole or in part, directly or indirectly, any Confidential Information of MAP; and (ii) recovery for damages, losses, and expenses of any nature, including without limitation, attorneys' fees arising out of, resulting from, or otherwise relating to such breach or threatened breach.

10. Michael Lee's obligations under this Agreement as to nondisclosure and non-use of Confidential Information of MAP shall survive the expiration or termination of this Agreement.

11. All information which is accessed or acquired by Michael Lee from MAP is and shall be the sole property of the MAP.

12. Any and all work product of Michael Lee created, conceived, or arising from Michael Lee's analysis of the data outlined above, including but not limited to, all reports, recommendations, public presentations, or published articles shall be the sole and exclusive property of Michael Lee.

13. The failure of either party to enforce any term of this Agreement will not operate as a

waiver of the party's right to enforce that or any other term of this Agreement at other times or in other circumstances.

14. Nothing contained in this Agreement shall constitute or be construed to be a limitation or restriction upon the parties' ability to use or disclose its own Confidential Information.

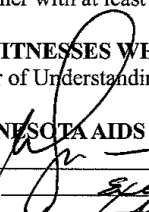
15. No amendments to or modification of this Agreement shall be effective unless reduced to writing and executed by the parties.

16. This Agreement shall be governed by and construed in accordance with the laws of the State of Minnesota without reference to its conflicts of law principles. The parties consent and agree to the exclusive jurisdiction of the state and federal courts located in Hennepin County, Minnesota and waive any argument that such forums are inconvenient.

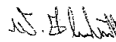
17. Either party hereto may terminate the relationship agreed upon hereunder by providing the other with at least ten days prior written notice of termination.

IN WITNESSES WHEREOF, Michael Lee and the Minnesota AIDS Project have agreed to this Letter of Understanding as of the date set forth below.

MINNESOTA AIDS PROJECT

By: 
Title: Executive Director
Date: August 7, 2013

MICHAEL G. LEE

By: 
Title: Principal Investigator
Date: 6 August 2013

**Appendix C:
Solicitation Materials**

**Solicitation Letter 1:
Email to MAP Employees**

To: All MAP Employees
From: Bill Tiedemann (MAP Executive Director)

Subject: University of Minnesota Study

Dear MAP Staff:

I am writing to let you know about a research study that will be conducted here at the Minnesota AIDS Project over the coming months. As you know, we have been developing a new strategic plan that will aim to bring our services into alignment with the Affordable Care Act legislation. As we move ahead with implementation of the strategic plan, a Doctoral candidate from the University of Minnesota School of Social Work will be examining the organizational change process as it is experienced by members of the organization, including and especially its employees. The study is expected to begin in June, and conclude at the end of this year.

The principal investigator for this study is Michael Lee, who is known to many of you from his years working at MAP both in PrideAlive and as Volunteer Coordinator. He will be joining our next all-staff meeting on [DATE] to introduce the study in greater detail. At that time, he will offer each of you the opportunity to indicate your interest in participating in the study. You will also have a chance to decline if you prefer not to participate. If you consent to participate, the interview may take about an hour of your time. He may also invite you to participate in a follow-up interview at a future date.

Although I encourage you to participate, you are not required to be a part of this study. Your participation will not influence any other aspect of your work or your standing in the organization. Additionally, Michael will not share any identifying information with me, or anyone else.

As I mentioned, Michael will be coming to our next all-staff meeting to describe the study in detail. But, if you have questions in the meantime, you may email him at leex5298@umn.edu.

Bill Tiedemann

**Solicitation Letter 2:
Email to MAP Board**

To: MAP Board Members
From: Bill Tiedemann (MAP Executive Director)

Subject: University of Minnesota Study

Dear MAP Board:

I am writing to let you know about a research study that will be conducted here at the Minnesota AIDS Project over the coming months. As you know, we have been developing a new strategic plan that will aim to bring our services into alignment with the Affordable Care Act legislation. As we move ahead with implementation of the strategic plan, a Doctoral candidate from the University of Minnesota School of Social Work will be examining the organizational change process as it is experienced by members of the organization, including its Board members. The study is expected to begin in June, and conclude at the end of this year.

The principal investigator for this study is Michael Lee, who is known to some of you from his years working at MAP both in PrideAlive and as Volunteer Coordinator. He will be joining our next Board meeting on [DATE] to introduce the study in greater detail. At that time, he will offer each of you the opportunity to indicate your interest in participating in the study. You will also have a chance to decline if you prefer not to participate. If you consent to participate, the interview may take about an hour of your time. He may also invite you to participate in a follow-up interview at a future date.

Although I encourage you to participate, you are not required to be a part of this study. Your participation will not influence any other aspect of your work or your standing with the organization. Additionally, Michael will not share any identifying information with me, or anyone else.

As I mentioned, Michael will be coming to our next Board meeting to describe the study in detail. But, if you have questions in the meantime, you may email him at leex5298@umn.edu.

Bill Tiedemann

**Solicitation Letter 3:
Email to Individual MAP Volunteers or Clients**

To: [MAP VOLUNTEER OR SERVICE RECIPIENT]

From: [STAFF INFORMANT]

Subject: University of Minnesota Study

Hello [NAME]:

I wanted to let you know about a research study that is being conducted here at the Minnesota AIDS Project. As you may know, we have been developing a new strategic plan. A University of Minnesota graduate student is examining how different members of the organization experience these changes, including [VOLUNTEERS/CLIENTS].

The researcher for this study is Michael Lee, who you may know from his years working at MAP both in PrideAlive and as Volunteer Coordinator. Michael asked if I knew any [VOLUNTEERS/CLIENTS] who might be interested in being interviewed, and I thought you might like to do so.

If you are interested, just send me a reply to let me know. If you say yes, I will share your email address with Michael, and he will contact you to arrange time to meet here at the MAP office. At that time, he will offer you more information about the study. If you consent to participate, the interview may take about an hour of your time.

Although I encourage you to participate, you are not required to be a part of this study. Your participation will not influence your relationship with MAP in any way. Additionally, Michael will not share any identifying information with me, or anyone else.

If you have questions before deciding, I'm happy to pass them along to Michael. Or, if you wish, you may email him directly at leex5298@umn.edu.

Thank you, [VOLUNTEER/CLIENT]!

[STAFF INFORMANT]

Solicitation Postcard for MAP Employees & Board
(To be distributed at introductory meeting)

University of Minnesota Study

Name:

Email Address:

Phone Number:

Preferred Way to Contact:

Relationship to the organization (e.g. staff position, Board role, etc.):

Please mark the response that best represents your wishes:

- I am interested in participating in the study.
- I am not sure if I am interested. Please contact me with additional information.
- I am not interested in participating and do not wish to be contacted.

Thank you for your response!

**Appendix D:
Informed Consent**

CONSENT FORM**Systemic Change in Nonprofit HIV/AIDS Organizations**

You are invited to be in a research study of the Minnesota AIDS Project's (MAP's) organizational change process. You were selected as a possible participant because you have been identified as an employee, board member, volunteer, or service recipient of the Minnesota AIDS Project. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by:

Michael Lee, Student Researcher, University of Minnesota School of Social Work

Background Information

The purpose of this study is to examine how members of a nonprofit, community-based HIV/AIDS service organization (ASO) experience organizational change in response to the federal government's Patient Protection and Affordable Care Act (aka "Affordable Care Act" or ACA).

Procedures:

If you agree to be in this study, we would ask you to do the following things:

- 1) Permit your social interactions and comments to be observed during organization meetings that address the implementation of MAP's new strategic plan.
- 2) Participate in semi-structured interviews with the researcher lasting approximately one hour, to discuss your experiences with the implementation process.
- 3) Permit your comments to be quoted in the final research report.

Risks and Benefits of being in the Study

The study has the following risks: You may experience discomfort when answering interview questions about your experiences and opinions toward changes in the organization. Due to the small number of potential participants, there is a chance that the identities of those who are quoted, even with generic identifiers, might be recognizable to people familiar with the organization.

The benefits to participation: There is no difference in benefits for people who enroll in the study compared with those who do not participate. It is anticipated that the findings of the study will contribute to the following bodies of knowledge: organizational policy and practice in the health and human services; HIV/AIDS service provision; public health; and, social services that have arisen from gay, lesbian, bisexual, and transgender (GLBT) social movements.

Compensation:

There is no additional compensation for participating in the study, and no penalty for withholding your consent.

Confidentiality:

The records of this study will be kept private. The researcher will keep confidential your identifying information such as name, address, date of birth, or physical characteristics. In any sort of report that might be published, the researcher will not include any information that will make it possible to

identify a participant. Any individual who is quoted will be identified by generic titles instead of names, and when possible, gender-neutral language will be used to reduce the possibility of recognition. You will have the right to review your interview transcript and delete portions that you do not wish to be quoted.

Research records will be stored securely at the University of Minnesota, and only the researcher will have access to the records.

Voluntary Nature of the Study:

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota or with the Minnesota AIDS Project. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions:

The researcher conducting this study is Michael Lee (student researcher). You may ask any questions you have now. If you have questions later, **you are encouraged** to contact him at the University of Minnesota School of Social Work, 612-822-2828, leex5298@umn.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), **you are encouraged** to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

You will be given a copy of this information to keep for your records.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

Signature of Participant: _____

Date: _____

Signature of Investigator: _____

Date: _____

**Appendix E:
Participant Demographics**

Systemic Change in Nonprofit HIV/AIDS Organizations**Demographic Information Form****(To be administered with informed consent)**

Thank you for agreeing to participate in this study. Please take a moment to answer the follow demographic questions.

Participant Code (to be completed by the researcher): _____

How old are you? _____

With what gender do you identify?

- Female
 Male
 Transgender
 Genderqueer
 Other (specify) _____
 Prefer not to say

How do you describe your sexual orientation?

- Bisexual
 Lesbian
 Gay
 Queer
 Straight
 Unsure
 Other (specify) _____
 Prefer not to say

How do you describe your race/ethnicity? (Mark all that apply)

- American Indian
 Black, African, or African American
 Mexican American or Chicano/Chicana
 Puerto Rican or other Latin American
 Asian American or Pacific Islander
 White
 Unsure
 Other (specify) _____
 Prefer not to say

How long have you been involved with the Minnesota AIDS Project? _____

Appendix F:
Data Collection Protocols

**Data Collection Protocol A:
Organizational Document Review**

Document Code
Document Name
Date Received
Date of Creation
Topics Addressed
Outcomes & Goals Identified
Action Steps Specified
Member(s) Involved
Researcher's Questions

Next Research Steps**Data Collection Protocol B:
Organizational Meeting Observations**

Meeting Code
Meeting Name
Date Attended
Meeting Participants
Describe the purpose of the meeting (e.g. operational goals, intermediate and/or long-term outcomes).
Describe the physical environment in which the meeting took place.
Describe the social environment (e.g. topics addressed, how members interact, placement into groups or subgroups, decisions on conduct the meeting)

Describe any historical perspectives that are shared, which indicate how programs have developed over time.

Describe any planned implementation activities or formal interactions. How is the activity organized from beginning, to midpoint, to closure?

Describe any informal interactions or unplanned activities when members are able to talk with each other about the organizational change process.

Researcher's Questions

Next Research Steps

A large, empty rectangular box with a thin black border, occupying the majority of the page below the section header. It is intended for the user to write their next research steps.

**Data Collection Protocol C:
Semi-Structured Interview Guide**

Participant Code
Interview Date
Interview Location
Q1. Tell me about how you came to be involved with MAP.
Q2. In your own words, how would you describe the characteristics that define MAP as an organization? Tell me what you know about its history, and how would you describe MAP's essential service values?
Q3. And, building on your last answer: What would you say are the characteristics that distinguish MAP as an HIV/AIDS service organization (ASO) from other health and human service organizations?

Q5. I want to focus now on the current strategic plan MAP is implementing.

How would you describe the current change process in your own words?

What would you say is the ultimate goal of the current change process?

What are some steps along the way that will be necessary for you and MAP to achieve this goal?

How do you see these changes impacting the technical aspects of (i.e. job functions and responsibilities) of your work?

How do you see the changes impacting the cultural aspects (i.e. climate and values) of the organization?

And, in what ways do you think that MAP's history as an ASO influences the way that these changes are being adopted?

Q6. Still thinking about the current change process, I'd like you to describe your enthusiasm for the proposed changes on a 4-point scale:

- Hot (Very positive)
- Warm (Somewhat positive)
- Lukewarm (Somewhat negative)
- Cold (Very negative)

Q7. Now I'm going to briefly review your responses to the questions leading up to that last one.

When you think about the rating you just selected, which of these factors had the strongest influence on your answer?

Q8. What types of support do you feel are needed—either from the organization or from elsewhere—to help this change process be successful?

Q8. We are almost finished with the interview, so I want to take a moment to again summarize what you've told me so far. Please stop me at any point if you feel the need to correct something I may have misheard or misunderstood.

Q9. And finally, I'd like to give you the chance to share any factors we haven't addressed, which you believe would be valuable to consider.

Final statement:

I want to thank you again for agreeing to be interviewed. When I have written up our conversation, I will email you a copy to share my initial analysis. You'll then have the opportunity to let me know whether my description is accurate, and if you would like me to leave any sections out of my report.

When I email you, I will also ask you if you know of other people—especially clients or volunteers—who could provide helpful information for this study. If you have anyone in mind, I can send you information to pass on to that person.

As my analysis continues, I may contact you again for a follow-up interview in order to learn more about your subsequent experiences. If you would prefer not to be interviewed again, you can let me know now, or when I email you my write-up.

Researcher's Questions**Next Research Steps**

**Data Collection Protocol D:
Semi-Structured Follow-Up Interview Guide**

Participant Code
Interview Date
Interview Location
Q1. Thank you for agreeing to this follow-up interview. You've read my write-up of our last conversation, and I want to just take a moment to re-state your responses.
Q2. Now I'd like you to share with me any important changes that have occurred since that time, either in your part of the organization or in other areas that you happened to notice.
Q3. Now I'd like you to think about your perception of MAP's implementation process since the last time we spoke. How would you describe MAP's progress toward the goals you identified in our last conversation? What factors do you believe have influenced this progress?

Q4. Sometimes when organizations go through this kind of long-term change process, there is a “learning curve” for people who participate in it. What would you say you have learned the most from this process so far?

Q5. Next, I want to repeat a question I asked you during our first interview. Considering what you have learned so far, what types of support do you feel are needed—either from the organization or from elsewhere—to help this change process be successful?

Q6. We are almost finished with the interview, so I want to take a moment to again summarize what you’ve told me so far. Please stop me at any point if you feel the need to correct something I may have misheard or misunderstood.

Q7. And finally, I’d like to give you the chance to share any factors we haven’t addressed, which you believe would be valuable to consider.

Final statement:

I want to thank you again for agreeing to be interviewed again. Just like last time, when I have written up our conversation, I will email you a copy of my initial analysis. You’ll then have the opportunity to let me know whether my description is accurate, and if you would like me to leave any sections out of my report.

Researcher’s Questions

Next Research Steps