Negotiated bodies: institution building and participatory policymaking in Mexico's public health sector

Katherine Truby
University at Albany, State University of New York, kmtruby@gmail.com

The University at Albany community has made this article openly available. Please share how this access benefits you.

Follow this and additional works at: https://scholarsarchive.library.albany.edu/legacy-etd

Part of the Political Science Commons, and the Public Policy Commons

Recommended Citation

This Dissertation is brought to you for free and open access by the The Graduate School at Scholars Archive. It has been accepted for inclusion in Legacy Theses & Dissertations (2009 - 2024) by an authorized administrator of Scholars Archive. Please see Terms of Use. For more information, please contact scholarsarchive@albany.edu.
Negotiated Bodies: Institution
Building and Participatory
Policymaking in Mexico’s Public
Health Sector

By

Katherine Truby

Copyright 2014
Acknowledgements

This dissertation would not have been possible without the invaluable contributions of many people. First and foremost, I am especially grateful to the members of my dissertation committee, Professors Meredith Weiss (Chair), Rey Koslowski, Holly Jarman, and Matt Ingram, for their thoughtful comments, immeasurable support of my work, and endless patience. I offer special gratitude to Meredith Weiss, who not only endured many drafts of this dissertation, but also offered critical support in the development of the research design, and in navigating international field research.

Beyond my dissertation committee, my research benefitted from the thoughtful comments, scholarly debate, and personal support offered by Drs. Susan Gauss and Laura Gonzalez-Murphy. I am further humbled by the support of the Rockefeller College community, including Dean David Rousseau, Barbara Mathews, and all other key support staff. The support and assistance of so many provided me the skills (and sanity) to complete the requirements for the PhD, including this dissertation.

The University at Albany, further, provided financial support towards the completion of this dissertation over several years. I am especially grateful to the following offices and programs for their support of my research: the University at Albany Initiatives for Women, the Graduate Student Association, the Graduate Student Employees Union, the Department of Political Science, and the Office of Graduate Studies.

I was deeply humbled by my field experience in Mexico City, with the willingness of my interviewees to discuss such important aspects of their lives with a researcher they did not know. This dissertation would not have been possible without the
contributions of my interviewees, who took time away from advocacy and policy work to answer my many questions, and provide critical insight into political processes in Mexico. Mexico City itself will always be a special place for my family and me.

I cannot imagine completing this dissertation without the love, support, and patience of such an extensive network of friends and family. I am lucky to have had the support and camaraderie of friends too numerous to name. Most importantly, I could not have achieved this milestone without the love, patience, and encouragement of my husband, Richard, and without the deadline set for me by my new son, Ezra.

Last, but not least, this project was inspired by the tireless work of advocates, whose labor has resulted in improved lives for the millions of people living with HIV/AIDS around the world. I am deeply thankful for their work, and in awe of their dedication.
Abstract

This dissertation examines the relationships between the state and civil society organizations within the context of HIV policy in Mexico. The Mexican context is important in this analysis: Mexico has relatively recently transitioned to a more democratic form of governance, including expanding institutional opportunities for civil society organizations to participate in processes of policy development and implementation. Further, Mexico has an HIV epidemic that is concentrated in the most at-risk communities. These communities typically face political and social exclusion. The extent to which civil society organizations advocating on behalf of these marginalized communities successfully negotiate the creation of new policy interventions and the creation of new public health infrastructure is an important indicator of how deeply democracy has developed in Mexico.

Through direct observation, document analysis, and interviews with government officials and civil society organizations, I find that the relationships between civil society organizations and the state in Mexico, rather than being static, are constantly negotiated. Using a process tracing method of analysis, I further find that civil society organizations wield more power than scholars previously afforded them. The analysis presented in this dissertation is organized around three key areas: identities, rights, and spaces. In negotiating identities, I engage constructivist theories of policy development to explain how the identities of at-risk communities affect both government policy and the relationships among civil society organizations. Because of divergent policy frames and
the structure of competitive financing mechanisms, a lack of collaboration among civil society organizations persists. In negotiating rights, I examine the international and national foundations for rights-based claims making in Mexico. As the Mexican government increasingly uses the rhetoric of rights in its public discourse with respect to health and HIV/AIDS, civil society organizations that mirror this discourse have a stronger position in negotiating their relationship to the state, and in advocating for policy changes. Finally, in negotiating spaces, I find that both the metaphorical and physical use of space shapes civil society organizations’ repertoire of strategies. This research contributes to the scholarly understandings of state-society relationships, policy development, and democratic inclusion and exclusion in middle-income settings.
Table of Contents:

Acknowledgements ............................................................................................................... III

Abstract ................................................................................................................................. V

Table of Contents .................................................................................................................. VII

List of Acronyms .................................................................................................................. VII

List of Tables ........................................................................................................................ XI

Chapter 1: Introduction ......................................................................................................... 1


Chapter 3: Civil Society, the State and HIV/AIDS in Mexico ............................................. 51

Chapter 4: Negotiating Identities ......................................................................................... 82

Chapter 5: Negotiating Rights ............................................................................................ 117

Chapter 6: Negotiating Spaces ............................................................................................ 160

Chapter 7: Conclusion ......................................................................................................... 188

Bibliography .......................................................................................................................... 196
Acronyms

A.C.: Asociación Cívica (Civic Association)

AIDS: Acquired Immune Deficiency Syndrome

ARV: Antiretroviral medication

CAPASITS: Centros Ambulatorios de Prevención y Atención en SIDA e ITS (Ambulatory Centers for the Prevention and Treatment of HIV/AIDS and Sexually Transmitted Infections)

CENSIDA: Centro Nacional para la Prevención y el Control del VIH/SIDA (the National Center for the Prevention and Control of HIV/AIDS)

CHECCOS: Comité Humanitario de Esfuerzo Compartido Contra el SIDA (Humanitarian Committee of Shared Effort Against AIDS)

CNDH: Comisión Nacional de Derechos Humano (the National Human Rights Commission)

COESIDA: Consejo Estatal para la Prevención y el Control del SIDA (State Council for the Prevention and Control of AIDS)

CONAPRED: Consejo Nacional para Prevenir la Discriminación (National Council to Prevent Discrimination)

CONASIDA: Consejo Nacional para la Prevención y el Control del SIDA (the National Council for the Prevention and Control of AIDS)

DIF: Desarrollo Integral de la Familia (National System for Integral Family Development)

DVVIMSS: Derechohabientes Viviendo con VIH del IMSS (Insured Workers with HIV of IMSS)

FRENPAVIH: Frente Nacional de Personas que viven con VIH/SIDA (National Front of People Living with HIV/AIDS)

HAART: Highly Active Antiretroviral Therapy

HIV: Human Immunodeficiency Virus

I.A.P.: Instituciones de Asistencia Privada (Private Assistance Institutions/Private Welfare Institutions)

VIII
ICNL: International Center for Not-for-Profit Law

IDU: injecting drug user

IMF: International Monetary Fund

IMSS: Instituto Mexicano del Seguro Social (Mexican Social Security Institution)

INSF: Instituto Nacional de Salud Pública (National Institute of Public Health)

ISSTE: Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado (Institute for Social Security and Services for State Workers)

MSM: men who have sex with men

NAFTA: North American Free Trade Agreement

OHCHR: Office of the High Commissioner for Human Rights

PAN: Partido de Acción Nacional (National Action Party)

PLWHA: People Living with HIV/AIDS

PRD: Partido de la Revolución Democrática (Party of the Democratic Revolution)

PRI: Partido de la Revolución Institucional (Institutional Revolutionary Party)

SEDESOL: Secretaría de Desarrollo Social (Secretariat of Social Development)

SEGOB: Secretaría de Gobernación (Interior Department)

SIPAM: Salud Integral Para La Mujer (Comprehensive Health Care for Women)

SNS: Sistema Nacional de Salud (National Health System)

SSA: Secretaría de Salud (Ministry/Minister of Health)

TRIPS: Agreement on trade-related aspects of intellectual property rights

WHO: World Health Organization

WTO: World Trade Organization

UN: United Nations
UNAIDS: Joint United Nations Programme on HIV/AIDS

UNFPA: United Nations Population Fund

List of Tables

Table 1: Percent HIV Cases by Transmission Category, 2000-2013………………..83
Table 2: HIV prevalence rate for young people (15-24 years) by gender, 2000-2013……………………………………………………………………………………84
Table 3: Social Construction of Target Populations………………………………87
Table 4: Percentage of HIV cases transmitted through injecting drug use, 2000-2013……………………………………………………………………………………104
Table 5: Number of Organizations/Percent of Total Organizations that self-reported working with a specified target population for 2011 CENSIDA registry………111
Table 6: Representation of Target Populations by Organizations Specifically Under Analysis ………………………………………………………………………………111
Chapter 1: Introduction

The 2008 International AIDS Conference (AIDS 2008) was perhaps the first time that international attention focused on the AIDS epidemic and country responses to the disease in Latin America. Held in Mexico City, the conference was preceded by large-scale community mobilizations aimed to call attention to issues of stigma and discrimination associated with HIV/AIDS, and the challenges associated with sufficient access to treatment for those suffering from the disease. Apart from community-based actions, inter-agency negotiations, focused on Mexico’s international image as a democratic state able to efficiently and progressively deal with the epidemic, contributed to a sense of excitement and hope for the many civil society groups participating in the conference. Through AIDS 2008, Mexico and its capital city served as the stage for best practices in a notably participatory fight against a preventable but spreading disease.

Luis E. Soto-Ramirez, a researcher in the department of infectious disease at one of Mexico’s national health research institutes, celebrated the International AIDS Society’s choice of Mexico City as the 2008 location: “Latin America and the Caribbean will … highlight extraordinary activism among communities, governments, religious organizations, and researchers. These groups are working together to thwart the epidemic through new programs, including group-specific education campaigns” (2008: 465). Soto-Ramirez’s comments reflect the optimism with which both government agencies and civil society organizations approached the 2008 conference: they were eager to share their best practices and successes, and to collaborate on challenges that remain. Despite the palpable excitement, in the weeks leading up to the conference, reports surfaced of large-scale failures within Mexico’s universal HIV treatment programs, persistent and
pervasive stigma and discrimination against those living with HIV/AIDS (or those at-risk of contracting the disease,) and conflict among civil society organizations. Great strides were made at the conference, including then-President of Mexico Felipe Calderon bowing to pressure from policy champions within government and civil society activists, using the words “gay” and “homosexual” for the first time in a public address in Mexico. However, in some ways, Mexico’s great international moment pointed towards more flaws than successes in the national system.¹

AIDS 2008 further provides an entry point into the story of HIV/AIDS and community advocacy in Mexico, the key topic under consideration in this dissertation. That Mexico City was chosen to host the 2008 Conference was certainly a signal from the international community about the importance of including Latin America and the Caribbean in dialogues about HIV/AIDS. But, the City’s selection was also a signal about how the International AIDS Society viewed Mexico: as a safe, stable democracy that would be an ideal site for a large-scale conference. For scholars and community activists who had long been tuned into HIV/AIDS in Mexico, hosting AIDS 2008 in Mexico City translated into international recognition of the tireless work of civil society organizations and government agencies in keeping disease prevalence low, and in continuously working to create a more accepting and inclusive political environment for some of the country’s most marginalized and vulnerable populations. The HIV/AIDS epidemic presents an ideal opportunity to examine how communities and governments develop, contest and strengthen their relationships over time through an analysis of a specific public health policy problem. Further, the fact that the trajectory of the epidemic in Mexico closely follows the trajectory of a long process of democratization provides a

¹ Interview with Jorge Saavedra, May 2012, Mexico City.
unique opportunity to understand how states and societies negotiate a new social contract throughout regime transition processes.

In considering the issue of HIV/AIDS policy in Mexico, this dissertation is organized around a number of compelling and timely questions: How do civil society organizations and states negotiate their new and developing relationships throughout the policymaking process, particularly in new or emergent democracies? To what extent do political institutions shape civil society organizations’ methods, tactics and perceptions about their internal efficacy in working with the government? And finally, might the relationships between states and civil society organizations be reciprocal and dynamic, rather than static and always dominated by the state? That is, do civil society organizations exert as much of a shaping influence on the state as the state exerts on civil society? I aim to provide answers to these questions in the chapters that follow, shedding light not only on how civil society organizations engage with the state, but also on the potential durability of democracy in challenging times.

There is a vast literature attesting to the critical function of civil society organizations in transitions to democracy and democratic consolidation in the developing world (O’Donnell and Schmitter 1986; Diamond 1994; Linz and Stepan 1996; Fox 1996; Cosgrove 2010). While a more thorough review of the relevant literature awaits in the next chapter, it is important to point out from the start that much of this literature is largely based on cross-national comparative case study analyses and indicates that civil society is important because it helps develop social or coalitional capital (Putnam 1995; Weiss 2005), and it can operate as an autonomous check on state power (Oxhorn 1005; Levitsky 2005). Largely missing from the literature are empirical analyses of the varied
ways in which civil society organizations specifically engage in policymaking processes in developing settings. Given the push by international development agencies to strengthen civil society over the last thirty years, we need more research directed at understanding how states and civil societies relate to one another in specifically policy-relevant ways.

Why HIV/AIDS? Why Mexico?

Part of the reason why the selection of Mexico City as the site of the 2008 AIDS Conference was an important moment in international health politics revolves around the relatively low rate of HIV/AIDS in Mexico. The Joint United Nations Program on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) indicate that the current national disease prevalence in Mexico is about 0.2-0.3 percent (UNAIDS 2013). This prevalence rate, while low when compared to rates in other regions of the world, is deceptive. While the overall rate is low, Mexico experiences a concentrated epidemic: within particular communities of at-risk individuals, the HIV rates are exponentially higher. For example, researchers at the Instituto Nacional de Salud Pública (INSP, National Institute of Public Health) found in 2013 that HIV prevalence rates among communities of men who have sex with men were approximately 16.9 percent, a rate much higher than people had originally thought (Bautista-Arredondo, et. al. 2013). The concentrated epidemic exposes the fact that HIV/AIDS continues to affect the most marginalized and vulnerable populations, rather than the general population. Policy interventions aimed at the general population are often more easily designed and

---

2 UNAIDS reported a 0.8 percent adult HIV prevalence rate globally in 2012. Mexico’s prevalence rate is one of the lowest in Latin America. For comparison, Argentina, Brazil and Chile have prevalence rates of 0.4 percent. For access to full prevalence data, please see AIDSinfo, a data tool produced by UNAIDS: http://www.unaids.org/en/dataanalysis/datatools/aidsinfo/
implemented than policy interventions that meet the needs of specific populations, particularly communities that engage in risky behaviors. In Mexico, according to Soto-Ramirez (2008), HIV/AIDS remains a “moral disease” from the perspective of many Mexicans (465).

Further, HIV/AIDS policy in Mexico provides a useful lens through which to examine the political dynamics of state-civil society relations. Mexico, in many ways, is a difficult case for successful institutional and policy changes resulting from civil society pressure. Despite twenty-five years of decentralization efforts in Mexico, governing power remains largely centralized in the offices of national government in Mexico City. The federal government, historically, has been reticent to share power generously with civil society (Foley and Edwards 1996). While this dynamic has shifted over the last ten years and scholars observe civil society groups directly contributing to the creation of new laws in Mexico (Gonzalez-Murphy 2013) and pay increased attention to subnational politics (Cornelius, Eisenstadt, and Hindley 1999), the relationship between the state and civil society organizations continues to develop within the context of a highly centralized political environment.

There is incredible pressure from the international community for states to both strengthen and engage with civil society, and to actively make policy to combat HIV/AIDS. While Mexico faces this international pressure, it concomitantly suffers from a middle-income country trap: it is in the unfortunate position of having an economy that is neither one of the most successful, nor one of the least successful. For this reason, AIDS budgeting has become increasingly challenging for the Mexican government.\(^3\) Particularly after the 2008 global financial collapse, many international donor agencies,

---

\(^3\) Interview with José Antonio Izazola, May 2012, Mexico City.
including the Global Fund to Fight AIDS, tuberculosis, and malaria, began pulling funds out of middle-income countries and refocusing efforts on the least-developed countries where agencies saw a greater return on their investment. The result is that Mexico receives very little foreign aid for health programs in general, and even less for HIV/AIDS programs specifically. José Antonio Izazola, former director of the Centro Nacional para la Prevención y el Control del VIH/SIDA (CENSIDA, the National Center for the Prevention and Control of HIV/AIDS), in speaking at the Latin American Roundtable of the 2012 International AIDS Conference, reported that ninety-nine percent of Mexico’s HIV/AIDS budget is funded through domestic revenue sources. Of this total budget, he estimated that ninety percent of the budget is spent on medication procurement, while the remaining ten percent of the budget attends to all other HIV/AIDS related issues. This is a complete shift from the early years of the epidemic, when most of the AIDS budget came from foreign sources. Mexico is not immune from the international pressure to manage its HIV/AIDS epidemic, but it is not a primary target for international funds.

In addition to the middle-income country trap, Mexico struggles, despite renewed commitments in 2008, to negotiate the cost of prescriptions drugs in the same manner as other countries. South Africa, India and Brazil defied patent laws and negotiated price points with pharmaceutical companies in an effort to stem rising HIV/AIDS prevalence.

4 Confidential phone interview with an individual working at a foreign agency in Mexico City, December 2012.
5 This is not to argue that Mexico has not received international funds for health and HIV/AIDS programs in the past. Most notable donors, like the United States Agency for International Development and the Global Fund, funded HIV/AIDS programs, and the World Bank funded efforts to decentralize the total health care system. However, compared to states in other regions, Mexico receives very little international funds directly. A key theme arising out of my interviews with civil society leaders and government personnel was that international programs are not only not funding new projects in Mexico, but they are also terminating current projects.
rates within their borders. Unlike South Africa, India, and Brazil, Mexico has made limited efforts to negotiate lower pricing. While government officials argued their ability to negotiate prices is constrained by obligations outlined in the North American Free Trade Agreement (NAFTA), the intellectual property provisions of NAFTA are no more constraining than the policies set forth in the agreement on trade-related intellectual property rights (TRIPS) of the World Trade Organization (WTO), to which South Africa, India, and Brazil are signatories (Shadlen 2009). Shadlen (2009) argues that differences in state-society relationships in Brazil and Mexico, alongside the absence of a strong domestic pharmaceutical industry in Mexico, account for the varied adherence to intellectual property rights regimes and the states’ overall ability to negotiate pharmaceutical prices.

This perceived intellectual property constraint is particularly salient given Mexico’s expanded guarantee of universal, free access to HIV/AIDS medicine for all who test positive for the disease. Again, Mexico is unlike South Africa, India, and Brazil in that it maintains its relatively low HIV prevalence rate on the national level. Because HIV/AIDS has not reached a crisis point for the general population, some civil society actors lack political opportunity structures (Tarrow 1994) or windows of opportunity (Kingdon 1994) to instigate policy and institutional changes. To a certain extent, the deck is stacked against significant civil society contributions to sweeping institutional changes in HIV/AIDS policies and institutions in Mexico; yet, civil society organizations have been instrumental in negotiating new policies and institutions to support HIV efforts and new relationships with government agencies to further their agenda. Because of this, now

---

6 The policy interventions in South Africa, India, and Brazil are considered vanguard in the international HIV/AIDS community, and thus worth noting as a point of comparison here.
7 Interview with Jorge Saavedra, Mexico City, May 2012.
is an opportune moment to examine civil society’s influence under these conditions: if civil society organizations are able to participate in policy processes in Mexico, then patterns established through this research could be applicable in countries were conditions are more amenable, or where epidemics have reached crisis points within the general population.

This points towards another key reason to examine HIV/AIDS in Mexico, specifically. While everyone is at risk of contracting HIV/AIDS, the disease affects the most marginalized populations. Therefore, these populations are the most in-need of protective policy measures. How public policies meet, or fail to meet, the needs of vulnerable populations is telling of how deeply democracy has developed. The extent to which civil society organizations channel and articulate the interests of these vulnerable groups, negotiate the identities of those in need of policy intervention, and develop and contest their relationships to the state provides important insight into the extent to which Mexican democracy is open, inclusive, and participatory. After all, when marginalized groups begin to participate in political processes, and see the fruits of their participation, it is more likely that they will continue to grow as active social and political actors (Piven and Cloward 1979). This is a policy area in which we may observe communities that traditionally experience social, economic, and political exclusion develop a better sense of self-efficacy with respect to their ability to influence public policy directly relevant to their lives.

A third reason why HIV/AIDS in Mexico deserves closer investigation in this dissertation is the extent to which the disease is representative of a public-private interface. The personal, private choices of individuals can have public consequences. In
Mexico, national identity and pride have historically been linked to the health of the nation (see chapter 3 for a more in-depth discussion of this theme). Beyond this, on the international level, HIV/AIDS is framed as a public health crisis, even more so than many other infectious diseases (Peterson 2002/3; McInnes and Rushton 2010; Brower and Chalk 2003). When considered concomitantly, HIV/AIDS as a result of private choices, yet constituting a public health emergency, creates a unique set of circumstances under which to consider the role that social and political actors play in determining the bounds of policy responses. How civil society organizations and state agents choose to frame the policy problems inevitably draws on the international construction of the disease as a crisis, and the public-private nature of HIV/AIDS.

Civil society organizations, particularly in the context of HIV/AIDS in Mexico, have been analyzed within the fields of anthropology, sociology and public health. But, the scholarly literature lacks an examination of the political phenomena that connect the state with civil society through a policy-centric analysis. As the international community increasingly turns to civil society as the panacea for weak or challenged democracy (Grindle 2007; Levy and Bruhn 2006; Howell and Pearce 2001), a timely analysis of how civil society organizations negotiate their relationship to the state through a specific policy sector is essential for conceptualizing a new way of thinking about the relationship between civil society, policy, and democracy. While much research focuses on the watershed moments of popular mobilization in democratic transitions, coalescing into the “contentious politics” paradigm (McAdam, Tarrow and Tilly 2001), this dissertation seeks to develop a better understanding of how civil society organizations maneuver at the interstices in newly democratizing contexts within the realm of normal politics.
Key Themes in this Dissertation

There are two key themes that emerge through this research: first, the state-civil society relationship is best understood as a process through which strategic negotiations reflect the uneven distribution of power among both governments and civil society organizations. While many scholars view democratic transitions as episodes with specific start and end points (O’Donnell and Schmitter 1986; Linz and Stepan 1996), I view Mexico’s trajectory towards a more democratic form of governance as a dialectical process without an end point. At the time of this writing, we are fourteen years removed from Mexico’s “transition” to democracy in 2000; however, as this research demonstrates, the relationships between the state and society(ies) are constantly (re)negotiated, even after formal moments of transitions are “complete.” For this reason, the research presented here focuses, to a certain extent, on three processes and their trajectories: the slow development of democracy in Mexico, the trajectory of an AIDS epidemic affected both by scientific advancement and new policy interventions, and, lastly, the continued negotiation of the relationship between civil society organizations and the state.

A second theme that emerges in this research is the marked divide between principle and practice in Mexico. While this presents another reason to observe Mexico’s transition to democracy as incomplete, still in process, or “unfinished” (Calleros Alcarón 2009), it also provides an entry point into analyzing state-civil society negotiations. The divergence between principles and practice in Mexico is clear both with respect to the nurturing and development of civil society writ large, but also, specific to the HIV/AIDS issue area, the promotion of health as a human right. This divide between principle and
practice creates both constraints and opportunities for civil society participation in policy processes. The divide between principle and practice provides opportunities for civil society organizations and the government to define identities, rights, and spaces in different ways, requiring different strategies of engagement and further state-society negotiation.

In the area of civil society, the Mexican government has invested significant resources in facilitating the involvement of civil society organizations in political processes, and to nurture the development of an active, yet conciliatory, civil society. To the extent that the government’s programs prioritize financing civil society organizations rather than focusing on creating substantive involvement in policymaking, many civil society organizations suffer in other crucial areas, like professionalization, technical capacity, and inter-organizational cooperation.\(^8\) In the area of HIV/AIDS, the government continues to frame health as a human right and to disparage discrimination on the basis of disease status because *dignity* is a human right, and it legally established universal access to HIV/AIDS treatment. But, in practice, discrimination persists, often on the part of civil servants, the right to health is often violated, and civil society organizations and the government define the policy problem and interpret the right to health in different ways. The difference between principle and practice in Mexico provides abundant opportunities and constraints for further negotiation of the state-civil society relationship.

*Methods*

\(^{8}\) While it is not necessarily the government’s responsibility to develop the capacity of civil society organizations, within the area of HIV/AIDS, the government has created programs aimed at capacity building and professionalization. Further, working with the government to nurture the technical capacity among organizations was a key component of the Global Fund’s Round 9 project in Mexico (interview with Melissa Melgar, July 2012, Washington, D.C.).
This dissertation addresses compelling questions about the nature of state-civil society relationships within the context of democratic transitions and policies of social importance. I examine these relationships through the lens of HIV/AIDS policy in Mexico, because of the nature of the disease and the extent to which Mexico’s new democracy seeks to accommodate civil society actors in the creation and implementation of new policies. Because I ask questions about the negotiation of relationships, about the everyday experiences of democracy, and the sense of effectiveness that organizations feel in their interactions with the state, I utilize a range of qualitative methods. To facilitate this research, I spent a total of twelve weeks in Mexico City, conducting semi-structured interviews, participant observation, and analyses of documents retrieved from both physical and digital archives. In addition to interviews, I examine newspaper articles, documents and memos from government agencies, the websites of civil society organizations, and reports from international development agencies as primary sources of evidence throughout this dissertation.

To systematically analyze multiple sources of qualitative data, I use process tracing, a method aimed at interrogating processes of policy development over time. This method facilitates an analysis of how particular conditions are “translated into outcomes” within the realm of HIV/AIDS policy in Mexico (Falleti 2006). By relying on the “timing and sequencing” of policy development as an analytical tool, I am able to consider the effects of feedback loops in the processes of democratization and disease response in Mexico (Pierson 2004: 11). Process tracing is a relevant methodological tool to examine policy development, as “self-reinforcing processes [and feedback loops] affecting a particular aspect of political and social life can transform the consequences of later stages
of the game” (Pierson 2004: 12). What will become clear throughout the analytical chapters of this dissertation is that timing and the sequence of events mattered quite a lot in the negotiation of the state-civil society relationship in Mexico.

According to the CENSIDA civil society registry, as of April 2011, there are a total of 321 civil society organizations registered as official HIV-related organizations across Mexico. Of the 321 organizations, 238 organizations had complete information, and only 122 of these 238 organizations self-reported that they focused primarily on HIV/AIDS. Utilizing the diverse case selection method (Seawright and Gerring 2008), I chose a small set of organizations from the 122 HIV-focused groups. Because this method calls for “maximum variance along relevant dimensions,” I selected civil society groups based on the target populations with which each organization worked (Seawright and Gerring 2008: 300). The primary effort in case selection was to include at least one organization for each of the targeted at-risk populations associated with HIV/AIDS. I also considered how regularly these organizations came up within news and scholarly reports about HIV/AIDS, and whether an organization maintained offices in Mexico City, the political center of the country. Through the registry process, civil society organizations self-report the target populations with which they work. In this way, I did not create my own categories of in-need populations; rather, I used those categories already determined to be germane by the Mexican government. In addition to the organizations I originally selected, I utilized a snowball sampling method, in which I asked participants to suggest other individuals they thought would be important to interview for this project. In the end, I closely analyzed eighteen civil society organizations in this dissertation. Beyond leaders of civil society organizations, I interviewed individuals from the main
government AIDS agency (CENSIDA), and the AIDS Program of Mexico City, along with the relevant national-level quasi-governmental agency el Consejo Nacional para Prevenir la Discriminación (CONAPRED, the National Council for the Prevention of Discrimination). In an effort to triangulate the patterns in data I recovered from these interviews, I also interviewed two individuals who worked in Mexico City for foreign development agencies. In total, I include the data from thirty (30) interviews with civil society leaders, government agents, and other experts in HIV/AIDS policy in Mexico.

During my time in Mexico City, I also collected data by observing the daily operations of a number of the most prominent civil society organizations included in this study. The kinds of operations I observed varied from service provision to individual patients, focus groups with women living with HIV/AIDS, strategy meetings for direct action campaigns, and the direct outreach of organizations during the 2012 Gay Pride Parade in Mexico City. To better understand the government’s perspective, I observed the operations of the first public AIDS clinic in Mexico, the Clínica Condesa. This included a tour of the facilities, meetings with civil society organizations using space within the Clinic, an interview with the director of the Mexico City AIDS program, and the opportunity to observe staff members of the Mexico City AIDS Program interacting and providing services directly to individuals living with or at-risk of contracting HIV/AIDS. All of these observations provided another lens through which to analyze state-civil society negotiations, and the lived, everyday experiences of citizens in need of interventions. Apart from the observations I conducted while in Mexico, I also attended the 2012 International AIDS Conference in Washington, D.C. At this conference, I was able to observe meetings of Mexican civil society organizations aimed at strategizing the
kinds of questions they would ask at the Latin American Roundtable on HIV/AIDS, and
the activities of Mexican civil society organizations in the Global Village.

Finally, in addition to interviews and direct observation, I analyzed documents
retrieved both from physical archives in Mexico City and in digital archives online. Many
of these documents came from the Archives of the Secretary of Health in Mexico City
and the libraries at the National Institute of Public Health in Cuernavaca, Mexico. I used
the digital archives of CENSIDA, CONAPRED, the Comisión Nacional de Derechos
Humano (CNDH, the National Human Rights Commission), the Ministry of Health, and
the Secretaria de Desarrollo Social (SEDESOL, the Secretariat of Social Development).
In addition to an analysis of government documents, aimed at developing an
understanding of the different responsibilities of various agencies in creating and
implementing HIV policy and in assessing how the Mexican government frames the
policy problem of HIV/AIDS, I also analyzed documents collected from the civil society
organizations under analysis in this dissertation. Many organizations provided me with
documents when we met, but I also accessed documents through their individual
websites, and through a Mexico City-based umbrella organization, Amigos Contra el
SIDA (Friends Against AIDS). In each case, I examined documents to ascertain the
overall framing of the HIV/AIDS issue area, and to develop the trajectory of AIDS policy
in Mexico. These three methods combined to provide a more complete analysis of the
negotiated relationships between civil society organizations and the state in Mexico.

This dissertation presents a qualitative analysis of 18 civil society organizations
(or cases) within the context of HIV policy and state-civil society negotiations in Mexico.
I attempt to explain how these particular kinds of organizations navigate the complicated
waters of policy advocacy and development in an ever-changing, newly democratic environment. As such, I do “not look for the net effect of a cause over a large number of cases, but rather how causes interact in the context of [these particular cases] to produce an outcome” (Bennett and Elman 2006: 458). While it may seem that “in a complex social world, cases are at some level unique,” this research is applicable to similar contexts (Bennett and Elman 2006: 458). The findings presented in the chapters that follow exhibit a bounded generalizability, in that convergence around the findings may be present in similar country contexts (middle income, newly democratic) and policy areas (social or health policy with a particularized target population.)

The analysis presented here contributes to current understandings of democratic consolidation by focusing on civil society’s role in the creation of new institutions and policies. By analyzing HIV/AIDS policies, I establish how state-civil society interaction in a policy area that bears on the most marginalized populations exposes how deeply democracy is experienced in newly democratic contexts. Not only does this research address the democratic inclusion or exclusion of the most marginalized populations, it also attends to how civil society organizations make use of the gaps between principles and practices to make claims and advocate for policy shifts in Mexico.

*Identities, Rights, and Spaces*

This dissertation is organized around three key thematic areas in which the above-described patterns manifest themselves. I analyze the state-civil society relationship through the lenses of identities, rights, and spaces, contributing to an overall illustration of the mechanisms guiding state-civil society negotiations. In the next chapter, I interrogate the construction of civil society with respect to democracy, policy advocacy,
and the dissertation’s three arenas, within the current academic literature, providing a theoretical foundation for the chapters that follow. Using the theory of structured mobilization, I argue that the negotiation of the state-civil society relationship is ultimately shaped by the way policy problems are defined, and, further, the state’s orientation on a given policy issue. Chapter 3 provides a historical overview of the “awakening” and further development of civil society in Mexico, alongside an analysis of the key milestones in the development of HIV/AIDS policy in Mexico (Walker 2013).

Chapters 4, 5, and 6 provide the analytical weight of this dissertation. Negotiating Identities (Chapter 4) leverages Ingram and Schneider’s (1993) social construction of the target population theory of policy development to better examine how the state and civil society organizations mutually construct the identity of the populations they view as most at-risk of contracting HIV/AIDS and, therefore, most in-need of policy interventions. What becomes increasingly clear is that, whereas Ingram and Schneider view policy elites as affected by social constructions but also nearly exclusively in control of policy design based on these constructions, I engage in an examination of how civil society organizations are equally subject to social constructions, not only in their advocacy on behalf of particular populations, but also in the way they relate to state agencies and one another. In this chapter, I provide an overview of general trends in HIV-related civil society organizations, in addition to relevant characteristics of the organizations specifically included in this dissertation. Finally, this chapter also provides important information about the obstacles and constraints civil society organizations face when they work on behalf of particularly negatively viewed populations.
Negotiating Rights (Chapter 5) examines how civil society organizations leverage, or fail to leverage, the construction of access to health and access to education as human rights in negotiating new policies. There are both international and national constructions of health and access to information about health as human rights. As the Mexican government increasingly uses the rhetoric of rights in its public discourse with respect to health in general, and HIV/AIDS in particular, civil society organizations that mirror this discourse seem to have a stronger position in negotiating their relationship to the state, and in advocating for policy changes. I examine two policy areas critical to HIV/AIDS: universal access to treatment for the disease and comprehensive sex education (universal access to information about one’s health.) In each area, I find different dynamics that structure the relationships between organizations and the state, allowing some organizations to seek out independent solutions to perceived problems, whereas other organizations must continue to work with the state. In this chapter, I focus on a select few organizations that are most active and most successful in negotiating both their relationship to the state, and the design of new policy interventions, within the context of health and human rights.

Finally, in Negotiating Space (Chapter 6,) I examine the varied ways in which both physical and metaphorical space contributes to the state-civil society negotiation and the strategies organizations use when advocating for policy change, or simply the implementation of existing policies. Negotiating Space turns a focused lens on the establishment of Clínica Especializada Condesa in Mexico City, the country’s first public AIDS clinic. Through negotiations about the use of this particular space, and the allotment of space within the clinic for certain civil society organizations rather than
others, I present an analysis of how space affects strategies and feelings of inclusion or exclusion. Further, I leverage Lune and Oberstein’s (2001) typology of HIV/AIDS civil society organizations. Lune and Oberstein (2001) identify three types of organizations characterized by the extent to which the organization works with the government: directly embedded, mediating, and outsider. I demonstrate that this typology is not static in nature, as it is originally described. Rather, the ways in which organizations acquire or lose spaces for action dictates, to a certain extent, their insider-outsider relationship to the government. For this chapter, I again focus on a select group of civil society organizations that were both active in Mexico City’s AIDS activist community, and had direct relationships with the Clínica Condesa.

Finally, in the concluding chapter, I provide an overview of the primary findings of this dissertation organized around the lenses of identities, rights, and spaces. These findings allow for a discussion of the significance of this research to a body of theoretical work on the quality of democratic regimes, but also the salience of this analysis to practitioners of development, global health policy, and those interested in leveraging the strengths of civil society organizations in policy development and implementation. In the last section, I highlight the boundaries of this research by outlining three key avenues for future research.
Chapter 2:
Citizens, Civil Society and Public Policy: A Review of the Literature

In political science literature, civil society is a contested concept that has been portrayed simultaneously as a harbinger of democracy, but also as an element that can undermine democratic principles and practices. In turning my analysis to a specific public policy problem, and its various components, in this dissertation, I provide a deeper understanding of how the negotiated relationships between the state and civil society organizations contribute to the durability of democracy in Mexico, a place where the official transition to democracy concluded in 2000, but that continues to experience the growing pains of a new political system. In this chapter, I review the literature on civil society and democracy more broadly, landing on a definition for civil society that seeks to capture the dynamic processes of citizen engagement, while also creating boundaries to avoid stretching the concept beyond its usefulness. I then examine how the academic literature conceives of civil society within the three arenas I explore in this dissertation: identities, rights, and spaces. In the concluding section, I counter the largely pessimistic literature on civil society in Mexico with an optimistic outlook: if we view the relationships between states and civil societies as dynamic negotiations, rather than static and dominated by state power, increasingly we can see the effects of a citizenry on the institutions of the state.

Civil Society, Policy Advocacy and Democracy:

While the scholarly literature largely contends that a healthy civil society is a prerequisite of democratic transitions, and a necessary component for democratic consolidation (Diamond 1994; Linz and Stepan 1996; Cosgrove 2010; Fox 1996;
O’Donnell and Schmitter 1986), there is a lack of empirical research that analyzes how civil society organizations actually engage the state. While much of the literature unpacks the ways in which civil society helps construct greater democratic participation, there is a dearth of theoretical and empirical work analyzing the role that civil society organizations play in the policy making process. Given that “civil society” is not a monolithic, homogeneous force, it is critical to ask at which points civil society organizations gain access to the state, and why some organizations attain greater access to the policy making process than others. State-civil society relations have “significant and potential impacts in terms of the efficiency and effectiveness of public service delivery, the quality and responsiveness of public policies, the degree of social exclusion, the expression of public values and the building of social capital,” but require still further systematic analysis of this undulating relationship throughout policy processes (Brinkerhoff and Brinkerhoff 2002: 13). By analyzing HIV/AIDS related policy processes in Mexico, we can elucidate more clearly how civil society organizations negotiate new policy initiatives with the state, particularly when the policy issue area directly impacts marginalized groups. Beyond new policy initiatives, though, these negotiations in the areas of identities, rights, and spaces, provide deeper insight into the mutually constitutive nature of the state: it is through negotiations, some placid and others more contentious, that social actors and the state influence the deepening of democratic participation, the effectiveness and inclusiveness of policy interventions, and ultimately the longevity of a given political system.

The importance of civil society in deepening the quality of democracy, though it should not be overstated, is quite clear in the current literature. Linz and Stepan (1996)
argue that a vibrant civil society “with the capacity to generate political alternatives and to monitor the government and state can help [democratic] transitions get started, help resist reversals, help push transitions to their completion, help consolidate and help deepen democracy” (9). Further, Baccaro and Papadakis (2008) advocate for participatory policymaking through the inclusion of civil society actors for the very reason that it “generates not just a richer texture of democracy but also more effective policies” (1). Larry Diamond (1994) enumerates ten critical democratic functions of civil society that enable democratic consolidation, with special emphasis on African, Southeast Asian and Latin American contexts. Some of these functions include: providing avenues for society to exercise some control over the state; encouraging and stimulating political participation in arenas separate from political parties; articulating and channeling interests in arenas separate from political parties; providing opportunities for individual political development and “training” future political leaders; and, civil society may “multiply the capacities of groups to improve their own welfare,” while also contributing to the responsiveness and openness of the state (Diamond 1994: 11). Finally, Cosgrove (2010) adds that civil society is critical to democracy because it provides an “associational space in which citizens can build coalitions, collaborate on projects or causes, and organize to achieve changes on issues of importance” (16).

Based on the extent to which scholars attribute increased democratization to robust civil societies, it remains a crucial concept in the analysis of political dynamics. Civil society can be broadly understood as the associational space between the state and the family, in which individuals act. It has historically been defined to “represent the so-called voluntary sector, or the realm of social organization that is self-generating and self-
supporting and that exists outside the state and the marketplace” (Encarnación 2000: 10). According to Oxhorn (2011), civil society is increasingly defined through a lens associated with liberal, more highly developed democracies, focusing on the intersections of individual rights and obligations. Civil society, thus, is dominantly “characterized as being coterminous with the spread of the market economy,” a viewpoint which can marginalize other perspectives that prioritize collective identities (Oxhorn 2011: 7). Because these definitions largely mirror the western experience, they might not translate as neatly to non-western, or developing contexts. In fact, governments in developing or transitioning societies are sometimes highly “suspicious of [civil society], particularly when they engage in actions that are perceived to challenge the state or constitute potential sources of countervailing political power” (Brinkerhoff and Brinkerhoff 2002: 10). Indeed, given the contentious nature of state-civil society relations during the transition period in Mexico, briefly discussed in the next chapter, the post-transition administrations might well be averse to engaging with autonomous non-state organizations.

For the purposes of this study, however, civil society must be understood as something more dynamic. While civil society is something distinct, its boundaries cannot be truncated by political activity. Within generally accepted definitions of civil society, there is an emphasis on complete autonomy from the state. Oxhorn (2011) argues that with particular notable exceptions (Migdal, Kohli and Shue 1994; Skocpol 1996), “protecting the necessary autonomy of civil society is generally seen to require a virtually impermeable barrier between the state and civil society” (9). While co-optation is a serious issue in terms of state-civil society relations, and will be discussed further below,
for this study I recognize the intersections of state and society wherein states create space for civil societies to operate, but argue that civil societies have reciprocal effects on states and institutions. Further, civil society is the “arena of the polity where self-organizing groups, movements and individuals, relatively autonomous from the state, attempt to articulate values, create associations and solidarities, and advance their interests”; however, civil society is also a contested space in which interests compete and intersect, and in which demands are made on governments (Linz and Stepan 7, emphasis added). The contentious nature of civil society becomes much clearer in the Mexican case when we consider how organizations negotiate the identities of populations in need of policy interventions. Civil society organizations not only negotiate with government agencies, advocating on behalf of particular populations for more direct policies and increased resources; rather, organizations also compete with one another for resources and to represent larger portions of populations in need. In this way, civil society can best be understood, not just as a space for political participation, but as a “process through which individuals negotiate, argue, struggle against or agree with each other and with the centers of political and economic authority” (Kaldor 2003: 385). When viewed through this lens, civil society provides a space for political participation, but should also be studied analytically as a process through which interests are contested, channeled and articulated.

That civil society is a necessary condition for democratization and democratic consolidation is not fully supported within the literature. The studies by Linz and Stepan (1996), O’Donnell and Schmitter (1986) and Van Cott (2005), cautiously trumpet the importance of civil society in transitions, but speculate that the functions of civil society,
namely interest channeling and representation, should dissipate as more institutionalized political parties become the primary reference points for citizen demands. While both civil society organizations and political parties can channel interests, they likely play distinct roles in policymaking processes. Encarnación (2006) questions whether civil society has a positive or negative effect on democracy. Noting the social capital building function of civil society, Encarnación admits “social capital is a double-edged sword; citizens can just as easily employ it to build democracy as to undermine it” (359). While particularistic interests can be problematic, most civil society analyses center on its capacity to serve as a check on state power, or in its social capital building function (Levitsky 2005). Particularly as scholars begin to accumulate empirical evidence of how civil societies’ competing interests affect democratic outcomes, we should turn our attention to how political institutions shape and are shaped by civil society activity. To date, there is no comprehensive theoretical understanding of government-civil society relations in developing contexts with emphasis on policy processes (Brinkerhoff and Brinkerhoff 2002; for a notable effort at developing comprehensive theories in the U.S. context, see Andrews and Edwards 2004).

Particularly in post-transition cases, the literature argues that civil society prominence might recede. As a whole, citizens may “feel less compelled to come together,” and the few groups that continue operations shift their focus to the “new challenges of democratization, including policy advocacy, governmental transparency, and civil and human rights” (Encarnación 2006: 361). While the civil society that remains focuses on new governance issues, they risk co-optation by new governments (Encarnación 2006; Oxhorn 1995). Given the importance of civil society and popular
mobilization in the democratic transition in Mexico (Gilbreth and Otero 2001), the potential that civil society might diminish once transitions are successful demands further investigation through policy-specific analysis. While citizen action may decline on the whole, civil society engagement might be policy-specific, varying within and between issue areas. For example, HIV/AIDS provides civil society groups with a non-oppositional way to access government processes. Historically, civil society organizations have played a complementary role to the state, by providing services to a targeted population (Rau 2006). In this way, these organizations fulfill a specialized function rather than serve as widespread opposition to new political regimes. Especially in post-transition settings, contentious, or transgressive, political action may decline, but specialized activity in specific sectors might continue to influence the quality of democracy under new regimes. As will be further discussed in chapter 6, civil society organizations in Mexico are less likely to engage in transgressive tactics when they are provided space to participate in HIV/AIDS related policy processes. Those organizations that are “left out” of processes resort to more aggressive strategies for contesting what they perceive as a lack of access to policy mechanisms. The extent to which civil society organizations are included in political processes and policy negotiations, then, matters when organizations determine the kinds of strategies they will employ in negotiations.

It should be noted that civil society itself is a contested concept. Some scholars, for instance, argue that notions of civil society that ignore market forces and business associations, particularly in the developing world, fall short of capturing the reality of civic organizing (Foley and Edwards 1996). Others argue that civil society interacts with the state and political institutions, noting that it is impossible to ignore the impact of the
nation-state when analyzing civil society activity (Radcliffe 2004). Beyond conceptual debates, some scholars turn a critical lens to civil society. For example, Mercer (2002) argues that some of the groups comprising civil society and nongovernmental organizations tend to be undemocratic: “characterized by authoritarian or charismatic personalized leaderships; competitive; riven along class, gender, religious, regional, spatial, and ethnic faultlines, and steered by either the state or donors, or both” (13; also Encarnación 2000). Particularly within the context of negotiated identities, we see in the case of HIV/AIDS in Mexico that civil society organizations are more likely to compete with one another for scarce resources than to collaborate on issues they have in common. Further, the role of financing has become so important among civil society organizations in Mexico that the individuals interviewed for this project viewed it as a primary obstacle to collaboration among organizations. Given the increased emphasis within the international donor community on the involvement of civil society organizations in development programs, and in health-related programs in particular, how civil society maneuvers, channels interests, and represents society at large is of increasing importance (Howell and Pearce 2001; Levy and Fukuyama 2010; Grindle 2007; Encarnación 2000).

In light of these definitional debates, it is important to recognize that civil society organizations function to channel and articulate interests and make demands on governments, but also provide services to communities. In Latin America broadly, social service provision has long been an important function of civil society groups that enables the building of coalitional capital and provides the foundation for savvy interaction with political institutional forces (Weiss 2005). This pattern is present in Mexico: all the

---

9 Many individuals indicated the lack of collaboration and cooperation among organizations as a primary obstacle to successful negotiation for new and expanded HIV/AIDS policies. Further, competition for scarce resources, both national and international, seemed to cause much of the lack of collaboration.
organizations under analysis in this project provide services directly to particular sets of target populations, beyond the policy advocacy that some of the groups perform. In his study of HIV-related civil society advocacy, Rau (2006) explains that, often times, “gaps in effective national policy and programmatic responses were filled by community and NGO initiatives” (286). He examines the inherent duality of civil society-state relationships, particularly in sub-Saharan Africa, noting that national authorities often use a vibrant and effective civil society as a justification for reduced support for the HIV-affected population (286). In a similar fashion, Gideon (1998) argues that service-providing civil society groups in Latin America have been “harnessed by the state and used as a tool to implement” economic development programs (304). Because of this, competition among civil society groups for access to the state, and for access to much needed resources and support, creates an environment in which groups whose “agenda pose[s] a threat to the state … find themselves outside the political arena” (Gideon 1998: 304). The service provision function of civil society organizations is, thus, contingent on the state.

Rau (2006) further recognizes the complexities of the relationships between national authorities and civil society organizations. The tension between states and organizations with respect to the HIV/AIDS epidemic can be categorized in terms of technical explanations and political explanations. Technical explanations include turf issues. Bureaucrats “fear losing their mystique of expertise and the power that goes with the control they have over budgets and planning” (Rau 2006: 289). This overall feeling that the government maintains a particular level of expertise above that of civil society organizations persisted in the comments of governmental officials with whom I spoke for
this project. For example, in speaking about the 2003 health care system reform, Jorge Saavedra, then director of the Centro Nacional para la Prevención y el Control del VIH/SIDA (CENSIDA, The National Center for the Prevention and Control of HIV/AIDS), argued that civil society groups were not brought to the table to discuss issues related to the financing of the program because that was not their area of expertise. The organizations have an advantage in pressuring legislators, and were asked to do this rather than participate in finance negotiations.\textsuperscript{10} Political explanations lend themselves to fears, on the parts of both national and international-level agencies, that successful civil society initiatives will contest the authority of the state and enable these groups to move into other areas of advocacy (Rau 2006: 291). Civil society scholars have repeatedly referenced the tension between the state and civil society, particularly with respect to the manner in which civil society organizations can contest the state, but also suggest that these organizations want to be included in the prevailing political structure. Rau (2006) explores a twist on this inherent tension, arguing a symbiosis between the state and civil society groups. Civil society groups fill policy gaps in national agendas, but national authorities often fear successful contestation of their authority and therefore sometimes fail to fully support civil society organizations.

In many cases, civil society can become institutionalized, which often happens in two key ways. First, governments invite successful leaders of civil society organizations into political bargaining or provide political appointments as a means of providing an outlet for the organizations’ complaints. While organizations may encounter newfound outlets for their frustrations, this form of institutionalization can also create an atmosphere in which only very narrowly defined interests make it to the negotiating table,

\textsuperscript{10} Interview, Mexico City, May 2012.
and many of the more contentious issues organizations originally connected with are left out of the discussion (Radcliffe 2004: 202). This represents a pattern of utility in which governments can co-opt the leaders of successful organizations or movements not only to limit the scope of their interests, but also to leverage the social capital fostered through civic organizing. While this can sometimes be the case, when civic leaders are invited into policy processes they are also able to bring their concerns to the table in an institutionalized and politically legitimate way. In Mexico, some scholars view civil society organizations in a more negative light (see, for example, Shefner 2008), finding that they become more or less co-opted and ineffective. Monteagudo (2011) argues, for example, that while civil society organizations, among other social actors, contributed to the efforts for democratization in Mexico, they did not have a lasting effect on the livelihoods and standards of living of the communities they represented in the process (153). Despite these critiques, the Mexican government appears to legitimately want civil society organizations to participate in policy processes.

A second way in which institutionalization is often felt, particularly in Latin America, is in the sense of social permanence that organizations have come to embody in particular communities (Oxhorn 1995). Because of the success of social organizing through the periods of dictatorship and democratic transition in Latin America, the idea that civil society organizations resist authoritarianism gained deep permanence in society. These same civil society organizations became permanent fixtures in society, providing for and advocating on behalf of communities during some of the more challenging authoritarian periods. In addition to service provision and advocacy, as will be elaborated below, these organizations also helped shape political identities and culture in post-
dictatorship settings. Take, for example, the unmistakable effects of the Madres de la Plaza de Mayo in creating public spaces for activism and delegitimizing the power of the military regime in Argentina (Radcliffe 2004: 202). One could argue that because of the visibility and success of groups like the Madres, civil society organizations have become widely and increasingly recognized and accepted as legitimate political entities throughout Latin America, but also specifically in Mexico (Radcliffe 2004).

Various scholars of civil society view the effects of institutionalization in both negative and positive terms. In Brazil, for example, the state passed legislation legitimizing the role of civil society in politics. Weyland (2005) argues that civil society has gained relatively influential access to the policymaking process, particularly resulting from the use of “popular amendments” and the creation and use of state-level advisory councils of civil society members (98). While scholars like Weyland see the institutionalization of civil society as a means of ensuring its durability, others, like Radcliffe (2004), Oxhorn (1995), and Dryzek (1996) question the intent behind the states’ efforts to institutionalize civil society participation. When new governments invite leaders of civil society groups to the bargaining table or appoint them to cabinet positions, they provide an outlet for the groups’ agenda; however, this also provides opportunities for the government to enlist the most vigorous leaders away from civil society and to shape these groups’ agendas (Radcliffe 2004: 202). The experience of co-optation varies among governments within and between regions. Governments in Latin America have routinely co-opted the leaders of successful social movements, as a means of limiting their efficacy in oppositional politics, and as a means of cashing in on the social capital often associated with civil society organizing (Radcliffe 2004).
Consequently, part of this research examines how institutionalization affects civil society, the methods organizations use to engage with the state, and how the state’s perception of civil society changes over time. A key pattern throughout the following chapters is that the Mexican government initiated several processes creating formal channels for civil society organizations to interact with state institutions. Through the civil society registry process, for example, organizations apply to become legally recognized civic associations, a status which garners certain privileges and obligations. Surprisingly, the individuals interviewed for this research were largely ambivalent about the registry, but not for the reasons other scholars suggest: no one expressed concerns that the process actually harmed them or their organization; rather, they noted that either they did not see much benefit to being registered or that being registered provided their organization with increased opportunities for a “seat at the negotiating table.”

Oxhorn (1995) argues that in developing states, civil society organizations often become the chief reference point for communities, while Dryzek (1996) contends that civil society can become the key point at which previously marginalized groups find inclusion in a state’s fledgling democracy. It is in this dynamic that scholars envision civil society activity as a response to state or market failures (Brinkerhoff and Brinkerhoff 2004). Especially in terms of service delivery, community organizations can sometimes be more reliable than the state (Paley 2001). According to Oxhorn (1995), because of the success and visibility of civil society organizations over the past fifty years, the state is no longer considered the “sole referent for the realization of popular sector demands” (285). While it is critical to maintain the state as a primary reference
point in political analyses, disambiguating the important dynamics of civil society organizations vis-à-vis the state should also be an integral part of the research agenda.

To develop a nuanced understanding of the nodes at which civil society organizations access political institutions, like the policy making process, it is critical to consider an atmosphere in which the state and civil society are connected in an important, yet flexible, relationship. The state may harness portions of civil society for its own purposes, as Gideon (1998), Rau (2006), and Iskander (2010) suggest or, as Diamond (1994) articulates in the democratic functions of civil society, it may provide an independent check on state power. Likely, the relationship is much more amorphous, as the state and civil society are constantly mutually constituted. Encarnación (2006) encourages scholars to fill literature gaps by considering the “decisive role that political institutions, from the state to the government to the party system, play in shaping the nature of civil society” (360). In this perspective, political institutions shape civil society: its relative strength or weakness and its potential to support or undermine democratic processes. As suggested by Migdal (2009), we should focus on the interconnected, flexible relationship between state and society for dynamic political explanation.

To further the research agenda suggested by Migdal (2009), the nature of civil society activity and the points at which these groups access the policymaking process could be examined through the lens of structured mobilization. A concept developed in sociology, structured mobilization is an appropriate theoretical tool to analyze when and how organizations access the policy making process. Structured mobilization builds on and combines the ideas of political opportunity structures (Tarrow 1994) and political culture (Lipset 1990). Moving beyond these core concepts, structured mobilization
indicates that civil society activity is molded by state institutions and state action in a given policy area (Bloemraad 2006: 102). The state’s orientation on a particular policy area, and how the state perceives and constructs policy problems, shapes the nature of civil society activity, mobilization and demand making in that policy area. In Mexico, as is further discussed in chapter 4, civil society organizations compete with one another to play a role in shaping state perceptions and the articulation of policy problems. Thus, while civil society organizations’ activities might be structured by state institutions, these same organizations also work to shape the state’s orientation on HIV-related policy issues. Equally important, structured mobilization allows an analysis of how civil society organizations’ perception of the state’s orientation affects the tactics and framings they use to engage with the state (Anner 2011).

Using the example of immigrant incorporation policy in Canada and the United States, Bloemraad (2006) argues that “differences in the two countries’ policies towards immigrants after they enter North America, in particular, the level of government support for immigrant settlement, including citizenship activities, and the official promotion of multiple identities and attachments as reflected in support for multiculturalism” allows for a more textured understanding of the political dynamics present in state-civil society interactions. By focusing on policy orientation, structured mobilization allows for a more “sticky” analysis of civil society activity and access to state institutions when the beneficiaries of such policies belong to marginalized groups (Bloemraad 2006). Because policies shift over time, structured mobilization enables us to point towards specific moments at which civil society is denied or extended access to the policymaking process. As the HIV/AIDS policy area reflects issues pertinent to marginalized groups, an
emphasis on policy orientation allows us to better understand how the state frames the issue area, and the target groups of policy, as an added variable in the various ways that civil society organizations negotiate with the state, in terms of both negotiating policy changes and negotiating their relationship to state agencies (Ingram and Schneider 1997). Further, because this approach examines the state and civil society in tandem, it also provides the opportunity to understand how civil society organizations’ framing of the policy issue might have a reciprocal impact on state policy orientations and framings.

The preceding section provided an overview of civil society by examining definitional debates surrounding the concept, providing insight into how civil society can enhance democracy generally, and establishing a theoretical framework that allows for a policy-centered analysis of civil society organizations and HIV in Mexico. In the following sections, I address general trends in the analysis of civil society in the three key areas of this dissertation: identities, rights, and spaces.

Civil Society and Identities

Citing Antonio Gramsci, Cox (1999) argues that civil society is not just the avenues through which social roles and norms are “grounded,” but it is also the avenues through which these roles and norms can be created, contested, negotiated and altered (4). Cox goes on to argue that civil society might be one vehicle through which societies can develop identities vis-à-vis the state, particularly in the challenging political moment of democratic transition (1999: 13). This sort of large-scale thinking attributes an identity-formation capability to civil society writ large: when individuals begin to participate and interact within larger communities, a collective sense of identity can be created from
these interactions and contribute to a development of national or civic identity (see also Calhoun 1993; Oxhorn 1995).

Oxhorn (1995) argues that common histories and experiences bind individuals together in civil society organizations, propelling them towards action and contestation. According to Oxhorn (1995), “shared identities, the ability of self-organization and even a history of collective struggle are sources of power which can enable disadvantaged groups to challenge the status quo” (8). This notion that individuals organize for civic and community reasons, in addition to organizing against economic or social marginalization, has been conceptualized within the context of new social movement theory. New social movement theory “stresses the identity dimensions of civil organization, arguing that the meanings invested in struggle are not economic but rather social and cultural” (Radcliffe 2004: 197).

Scholars of new social movement theory have identified three primary types of movement: instrumental, subcultural, and countercultural. Instrumental movements are those that are truly seeking material gains or focus their efforts on avoiding negative outcomes for their group. This variety of movement can be linked to resource mobilization explanations of organizing, in which groups take action to secure livelihoods and pay less attention to issues of identity (Kreisi 2008: 158). While HIV-focused organizations in Mexico do focus, even to a large extent at times, on the material survival of the organization and the mobilization of scarce resources, they deal with issues related to identity formation, reification and negotiation, as is more fully discussed in chapter 4.
Subcultural movements, on the other hand, “aim at the (re)production of a collective identity that is primarily constituted in within-group interactions, but which depend on authority-oriented action” too (Kriesi 2008: 158). This orientation differs from countercultural movements in that subcultural movements focus on an identity that is primarily a result of in-group interaction, whereas countercultural movements find their primary identity in terms of conflict with authorities or third parties (Kreisi 2008: 158). Much of this theorizing about new social movements reflects the shift to movement politics in which leveraging a group’s identity became a key strategy, particularly as novel issues, like HIV/AIDS, landed on public agendas (Benhabib 1999). In civil society organizing around issues of HIV/AIDS in Mexico, one can surmise that organizations develop identities that overlap instrumental, subcultural and countercultural typologies. Because they often represent marginalized and vulnerable populations, organizations might formulate identities based on subcultural affiliations, but may find that in their negotiation and contestation with the state and other organizations that identities are reified in countercultural ways.

In the case of HIV/AIDS in Mexico, the interaction between civil society organizations, policy and identities is arguably less about creating and connecting to an overall civic or national identity, and more related to how socially constructed, value based identities translate into public policy action or inaction. To accommodate this kind of analysis, I incorporate Helen Ingram and Anne Schneider’s (1993) social construction of the target population theory of policy development with an analysis of how organized civil society contributes to, contests and negotiates the identities of the population groups most in need of HIV-related policy interventions.
The theory of social construction in policy making presents an opportunity to study HIV policy development and civil society policy interventions by analyzing the manner in which local elites construct identities and employ biases about target populations during policy formulation. The theory of social construction posits that policies are created based on the socially constructed identities of the target population (Ingram and Schneider 1993). Social constructions refer to ‘(1) the recognition of the shared characteristics that distinguish the target population as socially meaningful, and (2) the attribution of specific, valence-oriented values, symbols and images to the characteristics’ (Ingram and Schneider 1993: 335). These constructions can be negative or positive, and play an integral role in how policy-makers define and rationalize policies for the target populations. The constructed identities of target populations creates a continuum of value, in which negatively viewed targets appear less deserving than their positively viewed counterparts for seemingly stable distributive and often turbulent redistributive policies (Lowi 1964). This provides an overarching explanation of policy change and variation: if we deconstruct the interactive and contextual nature of policy making and service utilization, we will encounter a deeper and more meaningful answer to Harold Lasswell’s (1936) question as to who gets what, when, and how by emphasizing not only why, but also who participates in the process.

Ingram and Schneider’s (1993) formulation of the importance of constructed identities in policy choices adds to the agenda-setting literature. Baumgartner and Jones (2009) argue that the principal ways in which scholars can understand policy stasis and policy change “lies in the process by which issues get defined for policy action” (25). While Ingram and Schneider’s (1993) theory permits an analysis of identities as the
principal drivers in agenda setting and policy formulation, Baumgartner and Jones (2009) emphasize the extent to which the public recognizes convergence between potential state-led solutions and policy images. A policy image is a less complex, “symbolic” way of communicating about a particular policy issue (Baumgartner and Jones 2009: 26). When a broad public accepts the policy image, it is more likely that a particular policy solution will be put into action. The effectiveness of the policy image helps account for how problems are defined, agendas set, and policies determined.

The problem of HIV/AIDS reflects a meaningful link between Ingram and Schneider (1993) and Baumgartner and Jones’ (2009) separate explanations for policy formulation and change. According to Baumgartner and Jones (2009), “private problems need to be linked to public causes in order to demand governmental attention,” noting that marketing a particular story about the problem, that is creating a policy image, is key in this process. HIV/AIDS in Mexico is contracted largely through private behaviors. For policymakers or civil society organizations to push this issue to the government’s policy agenda, it was necessary to link private behaviors with public consequences. The symbolic communication inherent in this linking process, in the area of HIV/AIDS, is deeply dependent upon socially constructed identities. How policymakers, civil society organizations, and the general public perceive the identities, behaviors, and social value of particular populations affects how the problem of HIV/AIDS is defined for the public agenda and how government interventions are designed, if at all.

On the whole, the literature on civil society and identities explores largely how social movements can leverage or reify identities through strategies, as described by new social movement theory. Identities can become an additional resource for organizations to
mobilize. This is particularly salient in the case of HIV/AIDS policy in Mexico where the identity of the target population for which an organization advocates becomes a key chess piece in the negotiation of new or expanded policies, and the negotiation of the relationships between organizations and the state, and among organizations. To examine how the identities of target populations matter when it comes to HIV/AIDS policy in Mexico, it is necessary to incorporate Ingram and Schneider’s (1993) social construction theory of policy development into an analysis of how civil society organizations navigate, negotiate and contest relationships and policies based on these socially constructed identities.

_Civil Society and Rights_

It is important to analyze the intersections of civil society and rights, particularly considering the vast expansion of political rights throughout Latin America over the last half century. As political rights have expanded, however, “other rights are precarious at best, declining at worst,” and “durable inequalities persist” (Oxhorn 2011: 5). How societies and states negotiate the everyday experience of democracy, and the everyday practice of rights in the face of these durable inequalities and curtailing rights protections, becomes an increasingly important mechanism for understanding the durability of democracy throughout Latin America, but also in Mexico in particular.

There is a vast literature attesting to the various functions of civil society organizations, and more specifically nongovernmental organizations, in asserting and defending human rights. Many of these studies largely analyze global civil society (Kaldor 2003), or transnational civil society connections (Keck and Sikkink 1998), in influencing larger discourse about human rights both on the global scale, and in
individual country cases. While international human rights discourse and framing, particularly with respect to the rights to health and education, are increasingly salient in civil society organizations’ advocacy in Mexico, the literature that emphasizes how civil society organizations and larger social movements leverage rights and legal mechanisms to accomplish policy change is most relevant to this study.

According to Hogerzeil, et. al. (2006), human rights at the most basic level create “state obligations and individual entitlements” (305). This means that rights provide a framework for government action, but also a set of expectations on behalf of individuals and communities about how their relationship with the government should operate. Rights-based approaches have been increasingly applied to issues of public health, particularly in the last two decades, as the international public health community progressively more recognizes that a “human rights lens on health helps shape understandings of who is disadvantaged and who is not; who is included and who is ignored; and whether a given disparity is merely a difference or an actual injustice” (Gruskin, et. al. 2010: 129). When rights are violated, there is, often times, a call to seek justice for these violations. Increasingly, according to McCann (2006), researchers emphasize the way that social movements, and perhaps more implicitly civil society organizations, utilize legal mechanisms and rights-based claims as a new and salient part of this “struggle[] for justice” (18).

Oxhorn (2011) criticizes scholars who prioritize notions of individual rights over other community-based or collective rights, particularly in the Latin American context. He argues:

“On the one hand, rights—regardless of their legal and normative justification as individual rights of citizenship—are in effect granted to
groups of people such as women, the elderly, illiterates, and so on. On the other hand, such rights for disadvantaged groups are frequently the result of collective struggles, as people often must organize to ensure that their rights are respected by the state and other individuals” (2011: 8).

This connection between individual rights and collective struggles is clearly demonstrated in the struggle for universal access to medicine within the HIV/AIDS policy area in Mexico. Discussed in more detail in chapter 5, the guarantee of the protection of health is an individual right established by the Mexican constitution and extended to all citizens; however, there is evidence that people living with HIV/AIDS are often denied this right because of stigma, discrimination and an overall lack of pharmaceutical supply. While this is an individual constitutional right, it took organized collective action, in the form of civil society organizations’ negotiation with state agencies, to create better institutional mechanisms for the everyday practice of the right to health.

Law and rights, then, can be best understood in this context as “a resource that citizens utilize to structure relations with others, to advance goals in social life, to formulate rightful claims, and to negotiate disputes where interests, wants, or principles collide” (McCann 2006: 21-22). When individuals and groups are able to access and leverage their rights, and to negotiate the everyday practice of these rights with their government, it is highly likely they will experience an increase in their sense of political efficacy (Piven and Cloward 1979). The process through which civil society organizations negotiate expanded access to rights and in their continued citizen vigilance of the everyday fulfillment of these rights in Mexico serves to build upon and reify their sense of effectiveness and inclusion within the political system. Therefore, the way that civil society organizations leverage rights and are affected by rights provides deeper
insight, not only into the many manifestations of state-civil society relationships, but also into how inclusive and expansive the democratic experience is in a given setting.

Another key issue with regards to civil society and rights is the many ways in which organizations articulate social and health policy problems as rights-based issues, and the effects of creating or reifying rights-based discourse in a newly democratic setting. Keck and Sikkink (1998) argue that “one of the main tasks that social movements undertake…is to make possible the previously unimaginable, by framing problems in such a way that their solution comes to appear inevitable” (40-41). As will be further discussed in chapter 5, when civil society organizations make rights-based claims with respect to universal access to treatment for HIV/AIDS, the solution in fact “comes to appear inevitable” in that the state is increasingly constrained in the ways it can limit access to health care services, particularly for people living with the disease. By framing HIV/AIDS as a human rights issue, as all the organizations under analysis in this dissertation do, civil society organizations incorporate international and national rights-based discourses that effectively limit the government’s ability to reduce services associated with HIV/AIDS for other reasons, economic, political, or otherwise. In an environment in which human rights create obligations and entitlements, the ability and willingness of organizations to assert health-related rights allows them to apply political pressure for the improved efficiency of existing mechanisms or the creation of new institutions for the guarantee of these rights. Further, the act of framing health issues within a human rights context may very well provide salient mobilizing frames for the creation of new organizations and the mobilization of a larger movement advocating for policy changes related to the disease (McCann 2006).
Civil Society and Space

Though the relationships between civil society and space are multiple, scholars largely ignore spatial aspects in their analyses of civil society mobilization. Within the academic literature, those studies that have addressed the intersections of civil society and space do so in two primary ways: analyses tend to revolve around metaphorical space, or openings in political dialogues for new social and political actors, and around how environments and physical spaces shape social mobilization. In this dissertation, I focus on civil society organizations’ access to and use of both physical space and political space to maneuver and negotiate with the state apparatus, leveraging Lune and Oberstein’s (2001) typology of civil society organizations participating in the fight against HIV/AIDS.

In terms of the creation and use of metaphorical space, Polletta (1999) describes and critiques the importance of “free spaces” in creating room for counter-hegemonic identities to participate in political processes. Evans and Boyte (1992), in their original theorization of the free space, argue that “free spaces are settings between private lives and large scale institutions where ordinary citizens can act with dignity, independence and vision” (17). While this conceptualization of the free space incorporates the definition of civil society as described above, Evans and Boyte further use the idea of free space to ask important questions about the quality of democracy in the United States: namely, “what are the environments, the public spaces, in which ordinary people become participants in the complex, ambiguous, engaging conversation about democracy: participators in governance rather than spectators or complainers, victims or accomplices?” (viii). Polletta (1999) critiques this view of political participation, offering
an explanation for civil society’s cohesion and mobilization more deeply rooted in associations and networks; however, it is clear from Evans and Boyte’s (1992) original argument that free spaces embody not only the physical environments that shape action, but also the metaphorical space at the table through which new social actors can collectively insert themselves in the political process. Oxhorn (2011) further argues that civil society organizations seek both autonomy from and inclusion in national political institutions. The issue of metaphorical space includes not only room for new social actors, but also the mechanisms that structure relations between the state and civil society organizations. In Mexico, the HIV/AIDS epidemic alongside structural political reforms created avenues for new social actors to confront the inequalities and rights violations associated with disease. Thus, civil society organizations representing traditionally marginalized segments of the population found new “space” within political negotiations to have their voices heard.

Beyond the metaphorical space, many scholars explore the ways in which physical environments affect how social movements and civil society organizations form. For example, Zhao (1998) explores how planning and spatial design on university campuses allowed for the consolidation and mobilization of student uprisings in Beijing. The fact that university campuses permitted large numbers of students to constantly be in close proximity to one another allowed them to form consolidated groups and eventually led to the 1989 Beijing student movement (1493). In addition to Zhao’s focused analysis of the Beijing student movement, political geographers have analyzed how urban planning either constrains or permits the growth of civil society, community organizations, and social movements. Douglass and Friedman (1998), for example, find
that the design of cities can facilitate the development of civil society, but also that both individuals and organizations can contribute to the design and development of cities. This dynamic mirrors the reflexive relationship between states and civil societies.

In chapter 6, I consider space in both its metaphorical and physical senses, arguing that the distribution of physical spaces shapes how civil society organizations operate, the strategies they choose, and whether or not they are included or excluded from policy negotiations. In order to accomplish this analysis, I use Lune and Oberstein’s (2001) tripartite typology of community based organizations. This typology, based on HIV/AIDS activist organizations in New York City, includes directly embedded (or insider), outsider and mediating groups. It is important to note that even the terminology used to describe these kinds of organizations maintains a spatial component. Insider organizations work closely with government agencies, and in the case of HIV/AIDS in Mexico City, literally occupy spaces within a public health institution. Outsider organizations select more transgressive strategies, and are literally left on the outside of public health infrastructure in Mexico City. I find in my analysis that both insider and outsider organizations choose strategies for action that correlate to their spatial positioning vis-à-vis the government. Further, civil society organizations in Mexico can move between typologies, from insider to mediating to outsider, based on the space they are allowed to occupy.

Discussion

While there is a vast literature on civil society, and in particular on the role of civil society in democratic transitions, there are insufficient analyses of the emerging relationships between states and civil societies as pertaining directly to public policy. In
this dissertation, by focusing on specific policy issues and processes, I am able to focus on processes of transformation within the state-civil society relationship. First, civil society, especially as it relates to health policy in Latin America, has long functioned in service delivery, but not as actively in channeling political interest or making demands (Gideon 1998). While Latin America in general, and Mexico in particular, serve as sites for massive social mobilization, little of this activity has been directed at changes in health policy. However, in HIV/AIDS policy, we see the various points of access that civil society organizations have to the state apparatus. This provides the potential to examine how civil society organizations navigate, contest and negotiate their relationship to the state within this policy area, highlighting the transformation that organizations can make from service oriented organizations in the early years of the HIV epidemic to more nuanced political demand makers and negotiators. Alternatively, focusing on policy issues and processes enables us to envision transformations within the state. Given the increasing importance and urgency associated with the HIV/AIDS policy area, the state has the opportunity to transform the way it operates through its interactions with civil society organizations. João Biehl (2002) describes how the Brazilian government, when faced with a worsening HIV/AIDS epidemic, was hugely pressured by AIDS activists to create an administrative apparatus for the distribution of free pharmaceutical treatment for HIV/AIDS, much like what happened later in Mexico. Through civil society actors’ penetration of the policy making process, Brazil became an “activist state,” consulting with experienced leaders of community organizations and developing a number of watershed policies for the prevention and treatment of HIV/AIDS in Latin America (Biehl 2002). Emphasizing the policy process enables us to highlight these shifts in state
behavior and orientation on particular policy issues because it focuses on both the state and civil society organizations as tandem, yet at times unequal, actors in policy development.

Beyond the negotiation of policy changes in Mexico, the extent to which civil society organizations feel incorporated into institutionalized political processes affects their overall sense of political efficacy. Soss (1999), in an analysis of welfare program use and democratic participation in the United States, established that individuals who had positive interactions with government agencies were more likely to participate in democratic practices. He further found that these individuals had higher self-reported degrees of political efficacy; they were more likely to feel like they could competently and successfully interact with the government. While Soss focuses on individual recipients of U.S. welfare programs, one could imagine that these patterns apply to organizations. The repeated interactions between civil society organizations and the Mexican state, within the context of identities, rights, and spaces, provides evidence to organizations as to their effectiveness and their ability to navigate political processes. In my interviews with leaders of civil society organizations, all participants indicated that they had both positive and negative experiences working with government agencies, but that they would continue to seek out opportunities to participate in official forms of political action.

Finally, while scholars recognize the challenges to democracy in Mexico, there is an overwhelming sense that ineptitude, corruption, and a failure to address pressing social needs shape citizen-government interactions (Huys 2009; Merchant and Rich 2005; Sabet 2008; Dryzek 1996). As the Mexican government instituted new channels for civil
society participation in the past decade, through civil society registries, competitive funding, and avenues for public consultation, it is time to question the assumption that government-civil society engagement is plagued by corruption, cronyism or failure. At the outset of this dissertation, I hypothesized that positive political institutions, such as public consultations on policy problems or the institution of civil society registries with competitive funding opportunities, shape organizations’ tactics more so than negative political institutions, like clientelism or corruption. What I present over the following chapters is a more optimistic view of the negotiations that take place between civil society groups and the state in Mexico. Despite challenges and stumbling blocks, civil society organizations continue to create, maintain and transform productive relationships with the government. On the government side, despite continued challenges to its authority through narcotics-related violence, the Mexican government continues to seek and provide opportunities for public consultation on issues of HIV/AIDS and to provide institutional opportunities for civil society organizations to participate in political processes.

Through the lenses of identities, rights, and spaces, I present an analysis of how civil society organizations and the state continuously negotiate their relationship to one another. Beyond the specific policies that emerge from these negotiations, I point towards larger political outcomes in each of these areas: how the negotiation of identities, rights, and spaces allows for the political inclusion and exclusion of particular communities. In the next chapter, I provide a historical analysis of civil society in Mexico alongside an overview of the key milestones in the development of HIV/AIDS policy. The “awakening” of civil society in Mexico in the aftermath of the 1985 Mexico City
earthquake provided the foundation for pro-democracy movements across the country, and increasing political space for HIV-oriented organizations to make demands of the Mexican state (Walker 2013). After this historical overview, I proceed with analyses of the negotiation of identities, rights, and spaces.
Chapter 3:  
Civil Society, the State and HIV/AIDS in Mexico

HIV/AIDS is a complicated policy issue, interconnected with other policy areas, bridging a public-private interface and largely affecting socially and politically marginalized and already vulnerable populations. Policy in this area often involves multiple agencies within governments, alongside public and private partnerships, in order to be effective at reducing infection rates and increasing treatment rates. In this area, civil society, including nongovernmental organizations and community-based groups, have been actively involved in the fight against HIV/AIDS from the beginning of the epidemic. That civil society has been an actor in this policy area is not new (Rau 2006); however, the ways in which organizations prodded, shifted and negotiated HIV-related policies throughout the epidemic provides important insight into how communities can effectively engage in and influence government processes in transitioning democratic settings.

In an effort to provide appropriate foundation for the analytical chapters that follow, I begin this chapter with a brief overview of the growth of civil society in Mexico. By most accounts, civil society in Mexico has historically been fairly weak and disorganized. However, throughout the democratic transition, the Mexican government passed key legislation that provides civil society organizations with opportunities for financing, professionalization and increased interaction with governmental agencies. After a brief overview of the development of Mexico’s civil society, I will concomitantly trace civil society organizations’ key responses to the disease, as well as the government’s policy responses and achievements in the area of HIV/AIDS. I address
these responses simultaneously because approaches to HIV/AIDS in Mexico originated both within communities and from the government. As organizations and government agencies negotiated their relationships through the development of HIV/AIDS related policies, a distinct approach to HIV/AIDS, highlighted by state-civil society partnerships, emerged.

Civil Society in Mexico

“The government will always be limited in its ability to confront the country’s most powerful actors. What is really needed is to involve society by making people understand that they are the ones who are actually paying for these privileges” (Mayer-Serra 2009: 191).

Many scholars point to a historically weak civil society in Mexico, brought about by the institutional power of both the Catholic Church and the state in the everyday lives of Mexican citizens (Centro Mexicano para la Filantropía 1996; Fox 1996; Shefner 2008). Prior to the 1980s, key social services, like education, health and housing, were controlled by the benefactor state or provided on an ad hoc basis through the church community. This system, however, left increasing numbers of Mexican citizens without access to key services, not only in geographically isolated, rural areas, but also in economically isolated, urban communities. Economic crisis in the late 1970s and early 1980s brought about changes in Mexican philanthropy, as civil society shook off its “lethargy” and some of the state’s “oldest welfare institutions adopted new approaches…stress[ing] preventative and community development activities” (Centro Mexicano para la Fiantropía 1996: 189). The rise of civil society in Mexico was aided by international pressures, stemming from domestic changes initiated by international financial institutions and the need to “signal” a strong economy; and in the case of HIV/AIDS, the global public health community’s call to increase community
participation as a key to stemming the tide of the epidemic on the global scale.\textsuperscript{11}

Economic crisis and international pressure led to domestic reforms in Mexico that provided new political opportunities for civil society organizations to advocate for new policies and amend the state’s response to the HIV/AIDS problem.

The early development of civil society during this period is deeply connected to the economic crises and adjustments beginning in the early 1980s. Economic and political centralization characterized much of Mexico’s long political history, but political crisis and global economic recession in the late 1970s and early 1980s caused Mexico’s ruling party, the \textit{Partido Revolucionario Institucional} (PRI,) to rethink centralized budgets and power (Levy and Bruhn 2001: 151). During this period, like much of the world, Mexico faced a dire economic situation: it was characterized, according to Soederberg (2002), by “currency devaluations, heightened class struggle, high levels of unemployment, inflation, rising debt-to-gross-domestic-product ratios, balance of payments problems, massive migration to the urban areas, and capital flight” (107). The 1982 debt crisis arrived in Mexico at very much the same time as HIV/AIDS; the crisis created a domestic environment in which Mexico urgently sought to shift financial burdens away from the center and towards state and local governments, in part as a condition to receive much-needed aid and loans, but in which it needed to address a potentially catastrophic public health problem.

\textsuperscript{11} The United Nations AIDS Program has undergone several independent evaluations. In its second independent evaluation, for example, evaluators “recognized the pivotal importance of partnerships in UNAIDS’ success,” but also noted that there were limited examples at individual country-levels in which civil society organizations had a high degree of impact on the epidemic. As a result, UNAIDS published a strategic plan to harmonize partnership efforts. This strategy was not published until 2011, nearly thirty years after the beginning of the AIDS epidemic in many countries.
In Mexico, as in much of Latin America during this time, the International Monetary Fund (IMF) provided short-term contingency loans to countries in crisis, hoping to create a period of stabilization to offset the damaging inflation. While the IMF provided short-term stabilization loans, the World Bank shifted from “recessive to growth-oriented” programs for lending (Green 2003: 52). The World Bank, during the 1980s, became responsible, in conjunction with regional development banks, for both “lending and overseeing longer-term structural adjustment” (Green 2003: 53). Under the auspices of this relatively new role, the World Bank began to influence the ways in which development occurs by placing conditions on loans. While conditionality has always been attached to development lending, the World Bank “began linking health finance policy to conditionality for loans” in the 1980s (Smith-Nonini 2000: 359). The emphasis on decentralization as a development strategy, in general and in the area of health care, proved particularly influential in Mexico.

Decentralization schemes, intended to ease the burden of the economic crisis, alter state-society relations, too. According to Oxhorn (2011: 83), the “decentralization of social welfare services further fragments potential popular social movements, restricting popular-sector organizational activity to narrowly circumscribed communities.” As services are decentralized, organizations must focus on more local populations, creating barriers for large-scale, multisectoral movements. Beyond the decentralization programs linked with development initiatives in Mexico during this time, the 1982 economic crisis changed the way that the state and actors within society related to one another. Olvera (2001: n.p.) argues that, as a result of the crisis and an overall lack of state resources, the state was less able to co-opt social movements, at the same time that organizations within
society found less opportunities for “clientelistic bargaining” with the state. This new environment conditioned how the state and organized society negotiated new and evolving relationships. In Mexico City and other urban areas, for example, social movements became much more powerful political actors, as they responded to the failure of government during crisis, became more savvy in their organizational structure and took on a larger profile of issues (Olvera 2001).

Given the nature of the corporatist Mexican state and the influence of the Catholic Church in Mexico, many scholars argue that prior to 1985, civil society remained weak despite the student movements of the 1960s and 1970s (Gonzalez-Murphy 2013; Walker 2013). Prior to 1985, civil society was largely based on the Catholic charity model and did little to affect political change. While the tide began to turn in the aftermath of the 1982 economic crisis, the 1985 Mexico City earthquake provided the critical juncture that mobilized civil society on a broader scale (Walker 2013; Gonzalez-Murphy 2013). The 1985 earthquake was significant in its effect, killing hundreds of thousands, injuring many more and leaving countless residents without shelter. Low-income housing, built by the government, was destroyed, and authorities delayed sending rescue workers into these areas. The slow and inefficient response of the Mexican government to the crisis frustrated citizens and international aid organizations. In the weeks following the earthquake, rumors spread that the government would repurpose the low-income housing areas for other means, leaving these citizens without access to affordable housing. The earthquake, and the government’s failed response, provided a crisis situation that spurred the formation of neighborhood associations initially focused on earthquake relief, but eventually taking up larger anti-poverty banners. Louise Walker argues that the

12 Confidential interview with individual working for foreign agency in Mexico, December 2012.
“incapacity of the government to organize the [rescue] workers likely cost countless lives” (2013: 176).

It was in the aftermath of the earthquake, and in the well-documented failure of the government to appropriately prepare or respond to such a disaster at all, that residents of Mexico City began to “call[] for a more transparent and democratic mode of politics” (Walker 2013: 183). A host of new and reinvigorated community-based organizations entered Mexican politics in response to the government’s failure to handle the crisis. Anti-poverty organizations expanded to address more general political issues, such as a lack of transparency in government, concentrations of power and one party rule, and the need for communities to be more actively engaged in the development of policies that directly affect them (Walker 2013). Despite this push for social organizations, the “enduring nature of corporatist structures,” persisting through the 1985 earthquake debacle, limited the “space for autonomous organizational activity within civil society” to pro-democracy and transparency movements (Oxhorn 2011: 212). As a result, through the end of the 1980s and into the 1990s, civil society efforts focused on deficiencies in the electoral system, experiencing “impressive success” in this realm (Oxhorn 2011: 216).

The overall size of civil society expanded during this time period, as well. The number of recognized civil society organizations in Mexico operating in 2002 was roughly twenty thousand; this represents between a “500 and 1000 percent” increase over the pre-1982 period (Oxhorn 2011: 218). Further substantive changes in the political system provided impetus for the growth of civil society overall. For example, in the 1995-2000 Plan Nacional de Desarrollo (National Development Plan,) the federal
government recognized the importance of citizens’ participation in political processes while simultaneously noting the paucity of opportunities afforded to citizens to actually participate in these processes (Centro de Estudios Sociales y de Opinión Pública 2006). While this national plan recognized citizen participation, as a report of the Executive, it acknowledged the legislative branch maintained the authority to create the specific legal mechanisms that would facilitate systematic processes of participation. In 1996, the Cámara de Diputados (Chamber of Deputies,) organized several public fora in which they addressed individual citizen participation in political processes (Centro de Estudios Sociales y de Opinión Pública 2006).

Apart from these efforts during the Zedillo administration (1995-2000), the Fox administration (2000-2006), as the first post transition administration, focused on a platform of increasing transparency in government. During the Fox administration, two key legislative reforms enabled increased transparency in government, and also provided clear avenues for civil society organizations to more systematically participate in political processes. The 2002 Ley Federal de Transparencia y Acceso a la Información Pública Gubernamental (The Federal Transparency and Access to Public Information Law), introduced under Fox, created the right and specific mechanisms for all citizens to access government documents, and created a set of obligations and standards for how government agencies would make information accessible. The law provided new tools for civil society organizations to hold government accountable by increasing organizations’ access to documents and proceedings (Cámara de Diputados 2002). Within the area of HIV/AIDS, Luis Adrian Quiroz, director of the organization Derechohabientes Viviendo con VIH del Instituto Mexicano de Seguro Social (Insured Workers with HIV of IMSS, or
DVVIMSS), pointed out that this new law “comes in handy because they can point out publicly that the government has not done what it says. They can use the government’s own data in their work. [The law] gives them a process through which they can document complaints against the government.”\(^{13}\)

In addition to this measure guaranteeing access to public information, in 2004 the Ley de Fomento a las Actividades Realizadas por Organizaciones de la Sociedad Civil (Law Promoting Activities of Civil Society Organizations,) created even further structural conditions facilitating society’s participation in political processes. This law established the “measures, mechanisms and instruments” to promote the activities of civil society organizations in “defending their rights, obligations and programs that these new mechanisms of participation establish” (Centro de Estudios Sociales y de Opinión Pública 2006: n.p.) Most notably, this law created the civil society registry process. Through this process, civil society organizations elect to register with the Secretaría de Gobernación (Interior Department, SEGOB;) upon registration, they become eligible for certain tax incentives, government funds to carry out specified types of projects, and overall increased access to participation in round tables and meetings with government agencies. In 2006, HIV-related organizations were also required to register with CENSIDA.

The language used to enact the Ley de Fomento, and even the rhetoric used by outside observers to analyze it, portray efforts to increase community participation in governance, by incorporating measures for increased transparency and “mutual accountability” between the government and its citizens (International Center for Not-for-Profit Law (ICNL) 2012: n.p.). Both the Ley de Fomento and the Ley de Transparencia

\(^{13}\) Interview with Luis Adrian Quiroz, Mexico City, May 2012.
came on the heels of a new democracy in Mexico, just a few short years after the first candidate who did not belong to the dominant party won the presidency in over seventy years, and responded to domestic calls for increased transparency in government and among civil society organizations. The laws had significant effects on the way civil society organizations operate, and point towards the larger trajectory of state-society relations. The return to democracy allowed the “rhetoric of participation [to] be transformed into a reformist, technocratic project,” where participation is less about “fighting for our lives,” as it was with the HIV/AIDS epidemic, and more about procedure: registering with the appropriate agency, submitting proposals for the funding cycle, participating in forums when invited, and ensuring regular tax audits (Morgan 2001: 224). Further, scholars argue that systems designed to encourage civil society, or even broader community, participation in health in Mexico were designed “under tremendous internal and international pressure to expand health services,” and to ensure that these new mechanisms conformed to new Mexican democracy (Morgan 2001; Zackus 1998).

Responses to HIV/AIDS in Mexico: The State and Civil Society

In terms of HIV/AIDS, civil society organizations were actively addressing AIDS-related issues even before the first case was reported in Mexico in 1983. Transnational connections between civil society organizations, most prominently Colectivo Sol in Mexico and the Gay Men’s Health Crisis in the United States, allowed groups to share information and activist strategies, and to respond to the health needs of their communities (Barnes 2008). Thus, in Mexico, like in many other places, in the early years of the epidemic, AIDS organizations emerged from the work of gay and

---

14 Interview with Juan Jacobo Hernández, Mexico City, June 2012
human rights activists and the people most affected by the disease were generally the first to respond (Hernandez-Chavez 1995). Outside observers, however, noted that an overall lack of a professional civil society in Mexico that had the technical capacity to work on AIDS issues yielded an early response that was poorly organized.

In spite of the early organizing of gay and human rights activists, early efforts focused largely on sharing information between organizations and providing the general public with information about the disease because the “social stigma around homosexuality and HIV/AIDS was much more pronounced in Mexico [than in other places]” (Barnes 2008). Some activists reported that in the early years they struggled to prevent AIDS from becoming a gay-associated disease. While outside observers argued that early manifestations of AIDS organizations did little more than “criticize the government and complain,” activist Rosember Lopez notes, “at the beginning of the epidemic we had to break down doors to be seen, hold demonstrations so that people could see us. There were no resources, the diputados would not deal with questions of HIV, so we had to fight with them to get the resources.” In the larger sense, activist pressures lead to the creation of new government structures intended to coordinate disease efforts. In 1985, not only was Mexican civil society awakened by the devastation of the Mexico City earthquake discussed above, but the first International AIDS Conference, held in Atlanta, Georgia, focused the world’s attention towards how to coordinate responses to this novel disease. After the 1985 conference, AIDS community

---

15 Interview with José Antonio Izazola, Mexico City, May 2012
16 Confidential interview with individual working for a foreign agency in Mexico, December 2012. Technical training efforts, primarily among medical professionals, were widespread during the 1980s. Many of the individuals interviewed for this study participated in some kind of professional training, the most common training program being one coordinated by the United States’ Centers for Disease Control.
17 Interview with Jorge Saavedra, Mexico City, May 2012.
18 Confidential interview with individual working for a foreign agency in Mexico, December 2012.
19 Interview with Rosember Lopez, Mexico City, June 2012.
groups based in Mexico City “organized to demand the Health Ministry form a National Committee Against AIDS and add AIDS to Mexico’s General Health Law [Ley General de Salud] as an illness covered by public health services” (Barnes 2010: 9). As noted, in 1986 activist pressure brought about a National AIDS Committee, and in 1987 Mexico hosted its first National AIDS Conference with the participation of both governmental and non-governmental entities.

After several years of activist struggle, in 1986, the federal government made its first public move on the issue of HIV/AIDS by establishing the National Committee Against AIDS, and finally, in 1988, the Consejo Nacional para la Prevención y el Control del SIDA (National Council for the Prevention and Control of AIDS, CONASIDA) was created to coordinate prevention efforts (Barnes 2008; UNAIDS 2012). These early efforts created a degree of path dependency in AIDS policy, in which prevention discussions within the government focused on female sex workers and controlling the blood supply through the end of the 1980s. Initial efforts by the government continued to center on “clean[ing] up the blood supply and work[ing] on prevention among female sex workers” (UNAIDS 2012: 31). For example, in 1986 a group of female sex workers in Mexico City successfully lobbied the then-National Committee Against AIDS for testing and prevention information programs (del Rio and Sepúlveda 2002). In 1987, in a meeting of the Consejo de Salubridad General (General Health Council), those present argued that AIDS had often been an issue of concern for them, but that of all the implications of the disease, and of all the actions they could take,

20 Through a series of reforms, CONASIDA would eventually become CENSIDA, the Centro Nacional Para la Prevención y el Control del VIH y SIDA (The National Center for the Prevention and Control of HIV/AIDS). I refer to this agency as CENSIDA throughout the dissertation.
they could not ignore the important problem of prostitution in developing new strategies and policies. In 1986, mandatory testing of the blood supply went into effect and in 1987 the government passed a law prohibiting the sale of blood or blood products (del Rio and Sepúlveda 2002). As a result, the majority of early government-backed intervention strategies focused on these two target populations.

In the 1980s, overall, gay activist organizations worked hard to share information about HIV/AIDS, but fought equally hard to ensure the disease did not become a gay-associated disease. For this reason, early government prevention and treatment programs did not always reach the appropriate audiences. Further, civil society organizations in the 1980s pressured the government so intensely to avoid being stigmatized, that, for some, it was taken to the extreme. According to Jorge Saavedra, former director of CENSIDA, in the 1990s, there were government prevention programs for nearly every single population group except the gay community as a result of their own pressure.22

During the first decade of HIV/AIDS in Mexico, policy development and civil society’s role in defining and implementing this policy did not occur in a vacuum. Incredible economic and political factors took hold, greatly shaping the nature of policymaking. Decentralization, as administered in Mexico, sought to decrease central government budgetary obligations, but had the key side effects of increasing social inequalities with respect to wealth and the urban-rural divide.23 The efforts further complicated HIV/AIDS policy, in that it was viewed as a public health crisis needing federal attention, but health policy and services were undergoing the largest restructuring

---

22 Interview with Jorge Saavedra, Mexico City, May 2012.
23 It is important to note that as the country faced economic crisis and the government initiated austerity efforts, the federal government also expanded rights and protections for health. The contradiction between decreasing state support for social programs while expanding rights and guarantees is a pattern particularly relevant in HIV/AIDS policy, and is discussed in more detail in Chapter 5.
to date. Arguably the policy area has *not* been successfully decentralized: though many states have state-level AIDS councils (COESIDAs), few of them actually budget state money for HIV/AIDS. Further, we see this strange balance of federal and state level control over HIV/AIDS issues in that most civil society organizations simultaneously note restrictive state policies (and attitudes) make their work more difficult, but recognize that policy changes happen in and key resources come from the federal government. While UNAIDS applauds the state-level AIDS agendas in thirty-two states, AIDS politics remains highly centralized (UNAIDS 2012).\(^{24}\)

At the same time that the government was shaken by economic crises and political reforms, civil society organizations coordinated their own responses to HIV/AIDS funded by foreign donors. In 1989, for example, organizations in the state of Jalisco established a medicine bank for AIDS patients funded through international donors, including both monetary and pharmaceutical contributions, and the support of other AIDS organizations operating out of Mexico City.\(^{25}\) More broadly, civil society organizations coordinated efforts to secure HIV/AIDS medications into Mexico during this time, often procuring them from foreign sources (Barnes 2008). During this time, two glaring problems came to the surface: first, divisions within the AIDS activist movement created intense competition for resources, support, and notoriety, that often times undermined legitimate efforts; second, the overall lack of resources for HIV/AIDS related programs fundamentally structured the way that organizations operated and the means through which the state and society relationship was negotiated.

---

\(^{24}\) Interview with Carlos Garcia de Leon, Mexico City, May 2012.

\(^{25}\) Interview with Victor Dante, Mexico City, May 2012.
The second decade of the AIDS epidemic in Mexico brought further formalization of the institutional mechanisms necessary to stem the spread of disease. In 1992, the National AIDS Prevention Program was established in an unsuccessful effort to provide universal treatment for the disease, as well as the *Norma Oficial para la Prevención y el Control del SIDA* (Official Standard for the Prevention and Control of AIDS) in 1993 (Nom-010-SSA2-1993). The *Norma* is important because it established the first federal standard for dealing with HIV/AIDS, and it came about through consultation with seventeen government agencies and nineteen different civil society organizations. Interestingly, the language used to explain why the *Norma* was necessary prioritizes the need to be competitive in the global economy during a period of modernization; the national well-being was a critical component in Mexico’s ability to enter into “competition among equals” at a time when NAFTA was under negotiation (*Norma Oficial*). Overall, the *Norma* intended to create standards for the testing for and diagnosis of HIV/AIDS, treatment and adherence plans, prevention and control activities, and aligning Mexico’s actions with international standards of comportment (*Norma Oficial*). While *Normas* do technically hold the weight of a law, some civil society organizations still express concern over the lack of a federal law on HIV/AIDS. Particularly for organizations that operate outside of Mexico City, the lack of a law means that there is no specific national policy on HIV/AIDS.27

In 1994 the federal government undertook a second attempt to provide AIDS medications, including the antiretroviral (ARV) therapy of the time, through the main

---

26 The *Norma* states: “Mexico is living in a process of modernization of all orders, with the explicit purpose of inserting itself in a global economy, from now on with the clear option of competition among equals when we consider the quality and quantity of products and services available to Mexico and to the international community.” (Nom-010-SSA2-1993).

27 Interview with Rosember Lopez, Mexico City, June 2012.
public health program of the social security institution (Instituto Mexicano de Seguro Social, IMSS), despite the initial failure of the 1992 AIDS program. Under this new program, “hospitals and clinics supported by IMSS must provide free of charge medicine to eligible patients” (del Rio and Sepúlveda 2002: 1453). The major drawback of the program was that the majority of AIDS patients were not IMSS-eligible due to their employment status, creating incredible gaps in ARV coverage. In addition to this program, in 1995, free ARV access was extended to all pregnant women, regardless of their status within the Mexican social security insurance program. While vertical transmission in Mexico is now all but eliminated,28 at the time the majority of pregnant women were unaware of their HIV status, and, thus, not receiving medication through IMSS (Rico, Bronfman, and del Rio 1995).

The first period of HIV/AIDS in Mexico was one in which both the government and civil society worked to respond to this novel disease. In ad hoc partnerships, several efforts to develop AIDS institutions and infrastructure resulted in benchmark achievements: the creation of CONASIDA and the truly collaborative development of the Norma Oficial. Despite these changes, the initial response to the disease came from civil society, and these organizations were able to shape the response to a certain extent, largely avoiding the stigmatization of HIV/AIDS as a gay-associated disease. In turn, the government focused its efforts on prevention among commercial sex workers and ensuring the blood supply. As a result, the policy trajectory through the 1990s reflected these initial actions, marginalizing to a certain extent the epidemic concentrated within certain populations. The economic burdens of debt crisis and the remedies prescribed by the neoliberal agenda further influenced these early efforts. The impact of

28 Interview with José Antonio Izazola, Mexico City, June 2012.
decentralization and the global pressure to address HIV/AIDS created an environment in which political opportunity structures facilitated civil society action, but did not create the rooted state-society bonds necessary for partnerships against HIV/AIDS. Further, the urgency of mortality and the pressure to secure funding created an intense competition among civil society leaders that, without a common mobilizing frame, made coordination and cooperation unlikely.

On a global scale, during the second decade of AIDS, solidarity among HIV/AIDS organizations grew, as highly active antiretroviral therapy (HAART therapy) was discovered and access to treatment became the intensified focus for civil society (UNAIDS 1998: 5). At the beginning of the epidemic, civil society organizations were concerned with sharing information and helping people die with dignity. These early years were precarious for civil society, and, at the time, people were literally fighting for their lives.\(^{29}\) With the discovery of life-prolonging treatment in HAART, networks of People Living with HIV/AIDS (PLWHA) developed around the world, and in Mexico, too. After the first national meeting of PLWHA was held in Mexico City in 1995, FRENPAVIH (\textit{Frente Nacional de Personas con VIH}, National Front of People with HIV/AIDS), a national umbrella civil society organization was established.\(^{30}\) FRENPAVIH negotiated access to treatment with agencies within the federal government, including the Ministry of Health, particularly focusing on the populations that were not already covered by the early efforts through the social security programs. At the same time that FRENPAVIH negotiated expanded access to treatment, the programs that already offered free access in Mexico, under \textit{Seguro Social}, were unable to

\(^{29}\) Confidential interview with individual working at a foreign agency in Mexico, December 2012.

\(^{30}\) For a more detailed discussion of FRENPAVIH and universal access issues in Mexico, please refer to Chapter 5 of this dissertation.
meet the needs of their current clients due to the overwhelming cost of HAART therapy (Barnes 2008). In light of these challenges, in 1997 Mexico signed an international declaration increasing the participation of PLWHA, intended to increase the capacity of organizations to participate in the political processes related to HIV/AIDS.\textsuperscript{31}

The outcome of the negotiations between FRENPAVIH and the Ministry of Health was the creation of a national health fund for HIV/AIDS, FONSIDA (\textit{Fondos Nacionales para SIDA}). Unfortunately, like earlier treatment efforts, FONSIDA folded after two short years because it simply did not have the financial resources to procure sufficient medicine supplies for the population in need. Though unsuccessful, FONSIDA is a clear example of how civil society organizations pressured the state to create new institutions aimed at meeting the needs of vulnerable populations within the HIV/AIDS issue area.

The shift in the mid-nineties towards a struggle for treatment continued into the new millennium, and into the new Mexican democracy under Vicente Fox. At the same time that FONSIDA was created (1998), activists in Mexico City advocated for a local clinic that would provide specialized treatment for HIV/AIDS patients.\textsuperscript{32} Civil society organizations invited Jorge Saavedra, a Harvard educated public health professional and former CENSIDA director of social prevention, to pressure the city government to open the clinic specifically for AIDS services. In 2000, the \textit{Clínica Especializada Condesa} (or \textit{Clínica Condesa}) opened in large part due to the civil society demand and years of community outreach and sensitization projects.\textsuperscript{33} The creation of the first public AIDS clinic was a critical moment for civil society and reflected their expanded access to

\textsuperscript{31} Interview with Luis Adrian Quiroz, Mexico City, May 2012.
\textsuperscript{32} For a more in-depth analysis of the creation of \textit{Clínica Condesa}, see Chapter 6 in this dissertation.
\textsuperscript{33} Interview with Jorge Saavedra, Mexico City, May 2012.
institution-building in Mexico, through the development of new public health infrastructure. Clínica Condesa represented a true partnership between civil society and the government: civil society organizations were provided space and varying degrees of programmatic responsibilities within the Clinic, and eventually worked alongside staff of the AIDS program of Mexico City. Clínica Condesa became a symbol in Mexico City of what civil society could accomplish and will be further discussed in chapter 6.

Following on the success of the opening of Clínica Condesa, further health care system reforms in the early 2000s created new opportunities for civil society organizations to further affect HIV policy. Jorge Saavedra was appointed director of CENSIDA, and brought with him a true desire to coordinate the center’s efforts with the input of civil society organizations.\(^{34}\) Under his leadership, civil society organizations had a key policy champion at the helm of the major AIDS agency, and an individual who perceived state-society partnerships as productive and necessary in the fight against HIV/AIDS. When Saavedra took the helm at CENSIDA, he admits he felt a lot of pressure from civil society organizations; organizations advocating for and serving the gay population put a lot of hope in him to initiate programs that would help the gay community.\(^{35}\) As part of his first year in the position, he launched a series of treatment and prevention centers, known as Centros Ambulatorios de Prevención y Atención en Sida e Infecciones de Transmisión Sexual (Ambulatory AIDS and STI Prevention and Attention Centers, or CAPASITS). Some of these Centers were mobile, using vehicles that could go out directly into communities in need, while others where more traditional

\(^{34}\) Interview with Jorge Saavedra, Mexico City, May 2012.
\(^{35}\) Saavedra would later come under fire from other, more technocratic government representatives, for using his position in government to push the LGBT agenda rather than working “just” on HIV/AIDS issues (interview with author, Mexico City, May 2012).
walk-in clinics. Because permanent infrastructure, like Clínica Condesa, was hard to come by, a new kind of mobile public health infrastructure became an innovation that served communities in need in a new way. While the fleet has grown since 2003, communities levy complaints against CAPASITS. Particularly for the walk-in clinics, these care centers were “intended to combat the inequality in access to medical services;” however, they were often located too far away from the populations that really needed them, and therefore, inaccessible still to many (UNAIDS 2012: 32).  

In addition to Saavedra’s new position at CENSIDA, universal access to HIV treatment was finally secured in 2003 through an overhaul of the Mexican health care system. In short, Seguro Popular created a safety net health insurance program for individuals and families that were not eligible for one of the already-existing employment-based insurance programs (Frenk, et. al. 2006). It achieved this through a tripartite finance mechanism, including federal and state resources alongside family contributions calculated on an income-based sliding scale. The program guaranteed a number of general health services to all those enrolled, and created financial incentives for states to increase their enrollments every year. Critical to the policy issue at hand was the inclusion of HIV/AIDS in the catastrophic illness fund (Fondo de Gastos Catastróficos). A selection of diseases determined to produce an undue burden on families and on the system as a whole, was included in this program. States received extra funds to ensure that health services for these specific diseases were available to all who needed them.  

As the disease evolved, and new science and technologies produced life-prolonging treatments, civil society organizations took hold of this common mobilizing

36 Phone interview with Steffanie Strathdee, July 2012.
frame and the pressure to ensure all citizens’ right to health through AIDS treatment increased. Julio Frenk, former technical advisor to the World Bank and Mexican Minister of Health from 2000-2006, initiated the Seguro Popular reform, using the rhetoric of both human rights protection and financial austerity and decentralization. Saavedra worked with Frenk, and within the government more broadly, to design the financing strategy for universal access to AIDS treatment. The major overhaul, the finance component, was designed and produced without the assistance or input of civil society. From the government’s perspective, civil society organizations lacked the technical capacity and understanding of economics and finance to contribute to the design of this reform.\textsuperscript{37} However, civil society organizations proved critical in their ability to pressure Congress to approve the new programs and expenses: in this sense, civil society was critical to the success of Seguro Popular.\textsuperscript{38}

In light of these key accomplishments, by the end of 2003, civil society organizations saw the fruit of much of their work. There were prevention programs in place for nearly all at-risk populations, often implemented in government-civil society partnerships.\textsuperscript{39} Despite popular misunderstandings, information about the disease was widely available; in 2012, radio spots and print advertisements that encouraged safe behavior were widely available in urban centers, providing prevention information, and directing citizens to the proper agencies or organizations for further support. Most

\textsuperscript{37} Interview with Jorge Saavedra, Mexico City, May 2012.
\textsuperscript{38} Interview with Jorge Saavedra, Mexico City, May 2012; Confidential interview with individual working at foreign agency in Mexico, December 2012.
\textsuperscript{39} Government programs are still lacking with respect to the injecting drug user (IDU) population and migrant populations. Mexico’s 2011 Migration Law includes the right to access health services for all migrants. It is too soon to evaluate how this new law affects access to HIV/AIDS prevention programs and medicines.
importantly, perhaps, universal access to HIV/AIDS treatment was not only the official position of the Fox administration, but it was achieved in 2003’s *Seguro Popular* reform.

After 2003, civil society organizations faced increasing fragmentation, as many of their principal aims, including access to medicines, were achieved on paper, but the reality of the implementation of these projects warranted further action. Long-standing, sometimes brutal, competition between organizations for resources or the control over particular projects became more pronounced as organizations’ access to government funds for prevention programs increased under the *Ley de Fomento* discussed above. Together, *Seguro Popular* and the *Ley de Fomento* had moderate demobilizing effects for HIV/AIDS civil society organizations as a whole, though a significant number of long-standing organizations continue to negotiate the state-civil society relationship.

In 2006, CENSIDA began receiving money, as a result of the *Ley de Fomento*, to begin funding civil society organizations’ HIV/AIDS prevention projects.\(^4\) Funds are only available to organizations that are legally constituted, maintaining the A.C. (Asociación Cívica, civic association) or I.A.P. (Institución de Asistencia Privada, Private Assistance Institution) status, and registered with the federal government (CENSIDA 2012). Additionally, civil society organizations seeking funding after 2009 need to register separately with both the general registry through SEDESOL, mentioned above, and with CENSIDA. Many HIV-focused groups lamented that a large number of organizations lacked the necessary level of professionalization and technical capacity to meet the requirements for funding through CENSIDA. Since 2010, for example, in the fifth public *convocatoria*, CENSIDA’s call for proposals, CENSIDA funded three projects on technical assistance to civil society organizations, including monitoring and

\(^4\) Interview with Jorge Saavedra, Mexico City, May 2012.
They funded additional projects pertaining to focused prevention efforts: sixteen projects in the same *convocatoria* period focused specifically on women at high vulnerabilities, while another sixty financed projects dealt with “Focused Prevention” (CENSIDA 2012). According to CENSIDA, since 2006, they have funded 568 projects totaling $180 million. However, it is important to point out that while the amount of money distributed has increased roughly from $28 million in 2006 to $40 million in 2011, the number of financed projects has decreased from 112 in 2006 to 92 in 2011, bottoming out at 70 in 2009 (CENSIDA 2012). In its 2006-2012 transparency report, CENSIDA does not specifically indicate who received funding and the exact programs implemented through these 568 financed projects.

Further, due to constitutional restrictions, the CENSIDA funding cycle is limited to a one-year period. Organizations must submit proposals for funding, the review process occurs, the funds must be dispersed and the project must be carried out all within a one-year period. Several participants in this study from civil society argued that by the time funds are received, organizations are limited to a mere five or six months to implement a full program and reapply for funding for the next cycle. This creates an environment of uncertainty and competition among organizations for limited, yet much-needed funds. Further, organizations rarely implement monitoring and evaluation plans to judge the effectiveness of their interventions. To this end, some organizations lack the requisite skills and capacity to carry out larger projects.

---

41 An external observer to the process noted during a 2012 interview that most organizations did not have monitoring and evaluation plans for their programs. This created challenges both for assessing the effectiveness of their work, but also for competing for funding for monitoring and evaluation.

42 Under the current rules, organizations cannot request extensions to use their funding or apply for new funds to be used on the same project. Each year, organizations must request funding for new projects.

43 Interview with Melissa Melgar, Washington, D.C. July 2012.
An overall lack of professionalization and technical capacity among civil society organizations became strikingly clear in 2010, when Mexico became a grantee under Round 9 of the Global Fund to Fight AIDS, tuberculosis and malaria. This was the first round that allowed more developed countries with concentrated epidemics to apply for funding to implement projects specifically for the populations most at-risk. According to grant management professionals working in Mexico at the time, the Global Fund project was in jeopardy when they were unable to find civil society organizations with sufficient capacity to manage a grant of the size that the Global Fund awards. Coordination among government agencies and civil society groups was a primary challenge, and the Global Fund eventually sent staff to the field to conduct capacity-building training for all involved, including government personnel. While the project eventually got off the ground, the grant was not renewed after 2012.44

In terms of HIV/AIDS policy specifically, issues with global finance continue to be a major obstacle to policy success. By some accounts, once CENSIDA was established, it was able to develop a relatively coordinated prevention and treatment effort, though it lacked the financial and technical capacities for success (Barnes 2010: 9). Most tellingly, CENSIDA operated until 2001 without resources from the federal government; it operated completely on foreign donor funds (Toumeh 2009: 304). The financial challenge continues today, though nearly in the complete reverse proportions. To further complicate limited resources, because so many different government agencies...

44 Some participants in this study argued that the Global Fund “pulled out” of Mexico, while others indicated that the government did not reapply for funding because the project failed to meet its benchmarks, and thus would be ineligible for subsequent release of funds. At the time of this writing, the Global Fund is immersed in a well-publicized financial crisis and is currently selecting not to renew grants in middle-income countries. They will focus efforts on the least developed countries with higher, more generalized, disease prevalence rates.
carry out HIV/AIDS programs, it is nearly impossible to trace the AIDS budget from the beginning to the final outcome. Althie (n.d.) notes that when resource transfers are made within and between agencies, the funds are not always used for the originally intended purposes. However, once the funds are transferred they are considered spent on HIV/AIDS and no longer traced (Althie n.d.).

Together, the public health reform and the *Ley de Fomento* changed the way that civil society operated within the context of HIV/AIDS. As previously noted, leaders of organizations felt they had achieved their principle aim when access to HIV/AIDS treatment was guaranteed, universally, through the *Seguro Popular* reform. Having succeeded in obtaining this institutional change, organizations shifted their focus towards *vigilancia ciudadana* (citizen vigilance) and prevention services. Public health reform had moderate demobilizing effects on civil society organizations, and this effect was exacerbated by the civil society reforms. In light of the changes brought about by the *Ley de Fomento*, the challenges organizations face are clear in that universal access has not been fully realized since the 2003 *Seguro Popular* reform. All the organizations participating in this study indicated that gaps in coverage, widespread shortages at medicine banks and discrimination still prohibit the full realization of universal access to HIV/AIDS treatment. Access to treatment continues to be an issue for civil society organizations, but they have not exhibited the same degree of access to policymakers or traction within the policy process as they did in the creation of *Clínica Condesa* or in the *Seguro Popular* reform. The reform efforts to systematize civil society participation, and enhance the democratic process, shifted political opportunity structures in such a way that organizations struggle with the financial and bureaucratic aspects of fund-seeking and
participating in CENSIDA forums. The health system reform addressed the most pressing issue of civil society organizations, in turn removing the urgency of the most prominent mobilizing frame. However, the divergence between the rights guaranteed under Seguro Popular and the realities of accessing AIDS services in Mexico produces a continued need for a strong civil society presence in this issue area, and will be further discussed in Chapter 5.

While a 2012 UNAIDS report noted that in 2009, the impact of the Seguro Popular reform was resoundingly positive, with overall reductions in AIDS mortality, civil society organizations routinely point to gaps in care and treatment. Dr. Andrea Gonzalez of the AIDS Program of the Government of Mexico City argued that overall adherence was the biggest problem in her program.\(^{45}\) Not only was the availability of medicine sometimes problematic, but also providing treatment in a way that made HIV-positive patients feel safe and not stigmatized continued to be an adherence challenge. Beyond issues of adherence, some point out that universal access is based on the government’s estimates of how many people are infected with HIV/AIDS, which are not always accurate.\(^{46}\) Further complaints include discrimination in health centers and pharmacies; lack of knowledge on the part of medical personnel with respect to treatment programs and the universal access program more broadly; the lack of other health interventions related to HIV/AIDS that should be covered by this overhaul (e.g. prevention services); and, finally, that organizations and clinics are reimbursed for the specific AIDS-related medications (ARVs), but that all the medicines needed to combat

\(^{45}\) Interview with Dr. Andrea Gonzalez, Mexico City, May 2012.

\(^{46}\) Interview with Enrique Hernandez, Mexico City, June 2012; Phone interview with Octavio Vallejo, April 2013.
the side effects of ARVs, and to fight opportunistic infections are not covered through universal access, placing an undue burden on service providers.47

While the universal access reform will be discussed in further detail in Chapter 5, it is important to note that civil society actors viewed this reform as a major, long-fought, victory. As one outside observer indicated, “once universal access was achieved, I think that civil society rightfully felt a sense of achievement. They really felt that the government was taking action in a very meaningful way, that their efforts had been successful, that they were able to bring about a major advance. But, it diluted their fervor and their sense of purpose.”48 Once civil society achieved policy success, to a certain extent, they lost a sense of common purpose—the very issue that had brought together a highly competitive and volatile civil society was now gone. Many organizations admit that, in this instance, they won, and then lost steam. One participant said it felt as if they had achieved their objective and they were tired of fighting; another argued, “the big confrontation between civil society and the state was over access to medication, but what now? It’s guaranteed.”49

The lack of universal access to HIV/AIDS medication, despite the guarantees provided through the Seguro Popular reform, continues to be a major issue in the post-2003 environment. For example, in 2008, Mexico City hosted the International AIDS Conference amid controversy about the cost of ARVs and lack of access, despite guarantees, in Mexico. It was reported at the Conference that the cost of treatment in Mexico was the highest in the developing world. Shortly after the conference, the Mexican government declared it would begin working to lower the cost of HIV/AIDS

47 Interview with Arelia, a nurse at Casa de la Sal, Mexico City, May 2012.
48 Confidential interview with individual working in a foreign agency in Mexico, December 2012.
49 Interview with Victor Dante, Mexico City, May 2012.
medications. The government introduced a program, *Juntos por la Salud* (Together for Health), shortly after to create state-civil society coordination on issues related to access to medicines by bringing together representatives from the social security institutions and civil society. By 2012, leaders in civil society had not yet seen the results of these efforts, claiming that “health financing [for HIV/AIDS] is going to collapse,” and that “we still have not seen this policy put into practice.” Some of the challenge extends from perceived NAFTA obligations and the limits placed on generic medications. Nevertheless, while universal access was a major victory for civil society organizations, and for its champions within the government, access to date is far from universal: CENSIDA reported in 2011 that nearly forty-four percent of HIV/AIDS patients were without treatment in Mexico (Montalvo Fuentes 2011).

In addition to the challenges with access to treatment, civil society organizations have struggled to hold government accountable to some of its other HIV-related commitments. At the 2008 International AIDS Conference, Mexico’s Secretary of Education, Josefina Vasquez Mota, signed a UNAIDS ministerial declaration committing to stem the HIV/AIDS epidemic by building comprehensive sex education programs into the school curriculum. According to civil society organizations, the key components of this declaration, *Prevenir Con Educación* (Prevent with Education), were not put into practice at the national level in Mexico. Gabriela Rodriguez, General Director of AFLUENTES, a civil society organization working in sexual and reproductive health, described the situation: “This [ministerial] declaration was incredibly progressive and was the face of Mexico in the global community. But the government did not provide any

---

50 Interview with Luis Adrian Quiroz, Mexico City, May 2012.
51 Interview with Enrique Hernandez, Mexico City, June 2012; Interview with Luis Adrian Quiroz, Mexico City, May 2012.
resources for the program to uphold the declaration in Mexico. They were concerned about their *imagen internacional*, but the Secretary of Education did nothing.”

Rodriguez further noted that they were working against years of conservatism, particularly in rural communities, where political leaders do not want teachers informed about or trained in sexual and reproductive rights.

After 2003, civil society organizations faced an uphill battle as shifting political opportunity structures damped their influence on institution building and policy development. The old demons of competition and a lack of professionalization and technical capacity for some organizations became a problem once again. New finance structures stemming from the *Ley de Fomento* reform shifted priorities away from HIV/AIDS advocacy towards searching out funding opportunities; one participant argued, “For many organizations, the main objective is financing. There are no strategies or objectives, they’re [civil society organizations] just chasing financing.”

In an era when universal access was guaranteed but far from implemented, and in an era of conservative politics at the national level, HIV/AIDS civil society organizations struggled to hold government accountable.

In late 2012, there were signs that the mobilizing frame of universal access might be increasing in salience once again for civil society organizations. In September of that year, José Antonio Izazola sent notice to state and local AIDS agencies that economic criteria should determine medicine provision, rather than evidence-based medical need. The primary concern was that the cost of the medication was not taken into account when

---

52 Interview with Gabriela Rodriguez, Mexico City, May 2012.
53 Interview with Gabriela Rodriguez, Mexico City, May 2012; For a more detailed discussion of *Prevenir Con Educación* in Mexico see Chapter 5.
54 Interview with Andrea Gonzalez, Mexico City, May 2012.
prescribed to new patients, although drugs with lower price tags may be available. Real controversy broke out when Izazola told states they would not receive their supply of AIDS medications if they did not comply with the new economic rules established. Not only did this cause conflict between federal and state agencies, but civil society organizations fervently fought for Izazola’s resignation. In December 2012, Izazola resigned from CENSIDA, noting the inefficiencies in the agency as a primary reason behind this action (Cruz-Martínez 2012). Izazola was replaced by Patricia Uribe Zúñiga, former manager of the Global Fund project in Mexico.

With the election of PRI candidate Enrique Peña Nieto as President in July 2012, and the resignation of José Antonio Izazola as the Director of CENSIDA in December 2012, there are likely changes ahead in HIV/AIDS policy in Mexico (“Patricia Uribe Zúñiga, nueva directora del CENSIDA” 2013). In fact, the new CENSIDA director, Patricia Uribe Zúñiga, has already pressed for an increased emphasis on HIV and women for 2014. Uribe Zúñiga took office with the support of HIV/AIDS activists, while some still criticize the overly bureaucratic agency for stalling on universal access (Cruz-Martínez 2012; Adrian Quiroz 2012.)55 In a period marked by the challenges of civil society organizations to adapt to and effectively use new institutional mechanisms, hope springs eternal for those activists who have been advocating for the rights of AIDS patients since the beginning of the epidemic.

Conclusion:

While it is still too soon to assess the effects of the new administration’s position on civil society consultation on the extent to which organizations are fundamental to new policy provision and implementation, it represents a clear finding of this research.

55 Interview with Luis Adrian Quiroz, Mexico City, May 2012.
HIV/AIDS policy, and the relationships organizations managed with the state throughout the development of policy, was shaped by economic and political reforms. Throughout the history of the epidemic, civil society organizations were most successful in achieving their policy objectives when they had a key policy champion in government. When the director of CENSIDA is amenable to civil society consultations, as in the cases of Saavedra and, potentially, Uribe, civil society organizations appear to have a greater influence on the substantive work of policy development and the vigilancia ciudadana necessary to ensure proper implementation.

This chapter provided the foundation necessary to better understand the analytical chapters that follow. We can see the overall development of civil society in Mexico, from fairly lethargic and disorganized to politically motivated and organized. The crisis of the 1985 Mexico City earthquake precipitated institutional changes that created new mechanisms by which civil society organizations could directly engage with government agencies in the development of public policy. The processes through which HIV/AIDS policy developed involved both civil society organizations and government agencies; true to this issue area, Mexico also felt international influences and pressures throughout this time period, both in the formalization of HIV-related public policy and in developing avenues for citizen participation in the creation of these policies. In the chapters that follow, I provide a more in-depth analysis of three key areas related to civil society organizations’ negotiation of HIV/AIDS policy with the Mexican government. Through the negotiation of various policy issues we can see the broader trend of the relationships negotiated through state-civil society interactions. In the next chapter, I address how socially constructed identities play a role in policy development, both in terms of how the
government focuses its efforts and how civil society organizations advocate for certain populations.
In designing and implementing public policy interventions, the constructed identity of the at-risk population matters a great deal (Ingram and Schneider 1993). The extent to which these identities are socially constructed, and the value applied to these identities by policymakers and civil society organizations presents obstacles to organizations seeking to affect public policy choices. In this chapter, I discuss the theoretical foundation for assessing the creation of identities in HIV policy discussions, and provide a brief overview of sexuality in Mexico, focusing on notions of masculinity and femininity as they relate to disease and policy. I then examine general trends among the organizations and policy measures in Mexico. Later in the chapter, I take a more in-depth look at the organizations under analysis in this dissertation, how they frame populations-at-risk and the impact these policy frames have on their negotiating strategies.

Before examining the role of social constructions in the development of HIV policy, it is important to understand the context of the HIV epidemic in Mexico. The epidemic is primarily concentrated within specific vulnerable communities, namely men who have sex with men. While government epidemiological data does not specifically indicate the prevalence rate for this community, it does separate prevalence rates by transmission mechanism. Table 1 shows HIV prevalence rates in Mexico based on the avenue of transmission: sexual intercourse, injecting drug use, and perinatal (mother-to-
Overwhelmingly, HIV/AIDS is spread through sexual contact in Mexico.

Table 1: Percent HIV Cases by Transmission Category, 2000-2013 (CENSIDA 2013).

<table>
<thead>
<tr>
<th>Year</th>
<th>Sex</th>
<th>IDUs</th>
<th>Perinatal</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>97</td>
<td>0.4</td>
<td>2.5</td>
</tr>
<tr>
<td>2001</td>
<td>96.8</td>
<td>0.7</td>
<td>2.5</td>
</tr>
<tr>
<td>2002</td>
<td>96.6</td>
<td>0.4</td>
<td>3.0</td>
</tr>
<tr>
<td>2003</td>
<td>96.4</td>
<td>0.7</td>
<td>2.8</td>
</tr>
<tr>
<td>2004</td>
<td>96.7</td>
<td>0.9</td>
<td>2.4</td>
</tr>
<tr>
<td>2005</td>
<td>95.8</td>
<td>1.9</td>
<td>2.3</td>
</tr>
<tr>
<td>2006</td>
<td>94.9</td>
<td>2.9</td>
<td>2.2</td>
</tr>
<tr>
<td>2007</td>
<td>95</td>
<td>2.8</td>
<td>2.2</td>
</tr>
<tr>
<td>2008</td>
<td>96.3</td>
<td>2.0</td>
<td>1.7</td>
</tr>
<tr>
<td>2009</td>
<td>96.5</td>
<td>1.6</td>
<td>1.8</td>
</tr>
<tr>
<td>2010</td>
<td>97.1</td>
<td>1.3</td>
<td>1.6</td>
</tr>
<tr>
<td>2011</td>
<td>96.9</td>
<td>1.8</td>
<td>1.2</td>
</tr>
<tr>
<td>2012</td>
<td>96.7</td>
<td>2.1</td>
<td>1.2</td>
</tr>
<tr>
<td>2013</td>
<td>97.6</td>
<td>1.4</td>
<td>0.9</td>
</tr>
</tbody>
</table>

Beyond transmission mechanism, the Mexican government also provides a statistical breakdown of HIV rates by gender, for young individuals (15-24 years old.) Table 2 shows HIV prevalence trends for men and women, ages 15 to 24, across Mexico between 2000 and 2013. Within this age group, it is clear that men have a significantly higher rate of HIV than women, though rates for both groups have been increasing over this time period. Further, the prevalence rate for women increased dramatically despite increased interventions aimed at this population group. For context, ten years prior, in 1990, the prevalence rate for both men and women in this age group was 0.1 percent.

--

56 HIV transmission through blood donation or transfusion was completely eliminated in Mexico by 1999. CENSIDA has not registered a case through this transmission mechanism since 1998 (CENSIDA 2013).
Table 2: *HIV prevalence rate for young people (15-24 years) by gender, 2000-2013 (CENSIDA 2013).*

<table>
<thead>
<tr>
<th>Year</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>1.7</td>
<td>0.9</td>
</tr>
<tr>
<td>2001</td>
<td>3.2</td>
<td>1.4</td>
</tr>
<tr>
<td>2002</td>
<td>2.9</td>
<td>1.6</td>
</tr>
<tr>
<td>2003</td>
<td>2.7</td>
<td>1.3</td>
</tr>
<tr>
<td>2004</td>
<td>3.9</td>
<td>1.9</td>
</tr>
<tr>
<td>2005</td>
<td>3.6</td>
<td>1.9</td>
</tr>
<tr>
<td>2006</td>
<td>4.5</td>
<td>2.2</td>
</tr>
<tr>
<td>2007</td>
<td>4.4</td>
<td>2.6</td>
</tr>
<tr>
<td>2008</td>
<td>5.5</td>
<td>2.8</td>
</tr>
<tr>
<td>2009</td>
<td>6.2</td>
<td>2.6</td>
</tr>
<tr>
<td>2010</td>
<td>7.7</td>
<td>2.6</td>
</tr>
<tr>
<td>2011</td>
<td>8.1</td>
<td>3.1</td>
</tr>
<tr>
<td>2012</td>
<td>10.7</td>
<td>3.7</td>
</tr>
<tr>
<td>2013</td>
<td>8.6</td>
<td>2.9</td>
</tr>
</tbody>
</table>

*Social Construction of Target Populations:*

Helen Ingram and Anne Schneider (1993) argue that how policymakers and societies perceive the potential target populations of policy interventions matters a great deal in terms of both setting the policy agenda and designing policies. The social construction theory of policymaking further posits that policymakers feel public pressure to invest scarce resources in interventions aimed at positively viewed populations, whereas there is also pressure to design punitive policies, or to not design policy interventions at all, for negatively viewed populations (Ingram and Schneider 1993: 334). Beyond the fact that the social construction of target populations affects how policies are designed, including which issues make it onto the public agenda, these socially constructed identities can have an effect on how target populations participate in democratic processes. In other words, these socially constructed identities can be internalized by target populations, affecting the way they interact in a social world, and limiting, or expanding, their options for political participation. It is the social construction of policy design that often yields less than ideal results when policies are formally
implemented: this theory helps explain why policy “fails in its nominal purpose, fails to solve important public problems, perpetuates injustices, fails to support democratic institutions, and produces an unequal citizenship” (Ingram, Schneider and DeLeon 2007: 93).

In addition to Ingram and Schneider (1993), Baumgartner and Jones (2009) provide insight into how policy images and problem definition affect the public policy agenda. They emphasize the extent to which the public recognizes convergence between potential state-led solutions and policy images. A policy image is a “symbolic” way of communicating about a particular policy issue as a means of convincing a broad public that this issue deserves a spot on the public policy agenda (Baumgartner and Jones 2009: 26). Overall then, the effectiveness of the policy image itself helps account for how problems are defined, agendas set, and policies determined. Considering Baumgartner and Jones (2009) alongside Ingram and Schneider (1993), the strategic creation of a policy image, or the marketing of a particular story about the policy problem, draws on how the public perceives the particular targets of policy interventions. With respect to HIV/AIDS, policymakers and organizations must link private behaviors with public consequences to effectively shape the public agenda. The symbolic communication inherent in this linking process is deeply dependent upon socially constructed identities. How policymakers, civil society organizations, and the general public perceive the identities, behaviors, and social value of particular populations affects how the problem of HIV/AIDS is defined for the public agenda and how government interventions are designed, if at all.
Ingram and Schneider (1993) provide conceptual definitions of both target populations and social constructions that prove useful in applying this theory to HIV/AIDS policy in Mexico. Target populations are categories of individuals at whom the government aims policy interventions. More than this, the goal is to change or shape the behavior of these populations through coercion and punishment, or by providing a particular benefit (Ingram and Schneider 1993: 335). In terms of HIV/AIDS, then, target populations are those groups of people deemed most at-risk of contracting the disease, or people already living with HIV and in need of treatment. Because HIV/AIDS is an infectious disease that spreads through bodily fluids, policy interventions now focus primarily on changing individuals’ behaviors surrounding sexual relations and drug use.\(^57\)

The social construction itself refers to “(1) the recognition of the shared characteristics that distinguish a target population as socially meaningful, and (2) the attribution of specific, valence-oriented values, symbols, and images to the characteristics” (Ingram and Schneider 1993: 335). In effect, social constructions are perceived or constructed “stereotypes,” that are applied in general to a given population (Ingram and Schneider 1993: 335). These stereotypes can be either positive or negative. Because of this, often times within the same policy area, some populations are deemed deserving of particular interventions, whereas other populations are viewed as “deviants” or undeserving of certain interventions (Ingram and Schneider 1997). The table below, recreated from Ingram, Schneider and deLeon (2007: 101-103), illustrates how different social constructions can affect policy design.

---

\(^{57}\) As noted in Chapter 3, initial interventions aimed to control the blood supply in Mexico. These policies were aimed at standardizing medical procedure throughout the country by screening all blood donations and ending donation for payment schemes (commercial blood banking.)
Table 3: Social Construction of Target Populations (Ingram, Schneider and deLeon 2007)

<table>
<thead>
<tr>
<th>Positively Constructed</th>
<th>Negatively Constructed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Target population has a high degree of power</td>
<td>Advantaged groups: viewed as deserving and important in overall social hierarchies</td>
</tr>
<tr>
<td>Target population has a low degree of power</td>
<td>Dependent groups: viewed as deserving, but because they lack political power they are viewed as “considerably less deserving of actual investments than advantaged groups”</td>
</tr>
</tbody>
</table>

In terms of HIV/AIDS policy in Mexico, one can argue that the national government creates policies based on both epidemiological surveillance data, or which populations are most affected by and most at-risk of contracting the disease, and the extent to which particular populations are deemed important or deserving. Ingram and Schneider (1997), for example, argue that women and children are often constructed as deserving of policy intervention. A United Nations Population Fund (n.d.) report card on Mexico’s policy intervention for women and children, examining the 2007-2012 Federal Health Plan, found that advances were made in every sector to address issues related to HIV/AIDS prevention for these populations. This report, in its entirety, illustrates the government’s efforts to increase spending and policies aimed at women and children.

Former director of the Centro Nacional para la Prevención y el Control del VIH/SIDA (National Center for the Prevention and Control of HIV/AIDS, or CENSIDA), José Antonio Izazola, argued that vertical transmission, also known as mother-to-child transmission, was all but eradicated in Mexico as of 2012. Additionally, civil society organizations in Mexico praised the decision to appoint Patricia Uribe Zúñiga as director of CENSIDA in 2013, because she would turn the program’s focus towards women and

---

58 Interview, Mexico City, June 2012.
HIV (Cruz Jaimes 2013). Each of these examples illustrates the extent to which policies focused on woman and children have been implemented in Mexico, at least since 2007. While HIV infection among women increased since the beginning of the epidemic, men still have much higher levels of HIV infection than women. As of September 30, 2013, CENSIDA reported that men made up 82.1 percent of all known HIV cases, whereas women only made up 17.9 percent of known HIV cases (CENSIDA 2013). Further, epidemiological surveillance data may show rising rates of HIV infection in women (see table 2 on page 84), particularly women who face a secondary vulnerability, like drug use or engaging in commercial sex work; however, the vectors of disease transmission, and those most in need of intervention, continue to be men.

With the social construction of the target population in mind, I now turn my attention to a brief overview of gender and sexuality in Mexico, focusing on dichotomous notions of masculinity and femininity. These notions continue to drive social conceptions of “correct” behavior, including those deserving of treatment and other policy interventions and those who are not deserving. This provides an appropriate foundation to understand the tensions among organizations, and many of the Mexican government’s responses to HIV/AIDS. To best understand the effects of constructed identities on policy interventions, it is important to examine the social construction of heteronormative sexuality in Mexico, in addition to how the government addresses individual target populations in its policies. What follows this overview of sexuality in Mexico is a brief look at policies aimed at the following categories: men and women, adolescents and children, drug users, and transgender populations.

Masculinity and Femininity in Mexico
Gender and sexuality in Mexico are complex and critical to understanding HIV advocacy since, “Mexican HIV prevention work [has] itself [been] inscribed in the larger history of contemporary Mexican sexuality” (Carrillo 2002: 4). Historically, there have been biases against women and homosexuals. While painting a brief picture of the nature of these identities, it is important to recall that civil society organizations often act in service gaps, where the government has been unable or unwilling to act, and on behalf of the marginalized segments of society. By taking a brief look at the construction of the identity of women and sexual minorities in Mexican history, a pattern arises in which complex matrices of oppression can lead to marginalization and increased risk of HIV/AIDS.

Though posited as a liberal alternative to colonial era religious morality, the 1857 Mexican Constitution and the Reform Laws of 1860 “rendered inadmissible any female participation outside the ‘holy zone’ (the bedroom, the kitchen, household chores, Mass, the confessional)” (Carrillo 2002: 4). One of the most important differences in interpretations of male and female sexuality at that time was that “true men indulged in sexual activity largely because of the reproductive instinct. It was their duty to reproduce…thus sexual activity and reproduction were work” (Bliss 2001: 133). In this way, male promiscuity was linked to the notion of instinct, whereas female sexuality was intended to be suppressed. More than 50 years after the passage of the Reform Laws, in revolutionary Mexico City, “the reform of ‘problematic’ female promiscuity was carried out in medical and educational institutions, while ‘problematic’ male sexual behavior” was largely ignored (Bliss 2001: 7).
Female sexuality has historically been a barometer for the health of the greater community and society. Stern (1999) argues this linkage between female sexuality and an overall notion of Mexican nationalism became even more prominent in the early post-revolutionary era, as eugenicists and medical professionals, among others, worked to define the new Mexican nation. These early nation-building projects focused specifically on motherhood, sexuality, and children. Part of these efforts included an explicit linkage of a woman’s value with her ability to bear and raise healthy children: “responsible motherhood” came to be a key value by which women were regularly assessed (Stern 1999: 375). Perhaps more importantly than these growing social values was the access granted to medical professionals through regulatory measures: the “rearing practices [of mothers] were increasingly monitored and tied to the nation’s need to secure a vigorous and healthy descent” (Stern 1999: 375). Medical professionals were given some leverage in determining how effective a woman’s childrearing practices were, and many women were counseled to avoid pregnancy as a result of these assessments. In extreme cases, medical professionals “forced sterilization of postpartum mothers” who did not meet the strict standards of motherhood promulgated throughout this period (Stern 1999: 375).

Alongside the need to control female sexuality and child-rearing practices as a means to maintain community health, gendered identities were also enforced through violence and criminal codes in Mexico. For example, in the early twentieth century, domestic violence was a “legitimate consequence of male defense of family honor and punishable only when it resulted in murder or excessive publicity” (Piccato 2001: 110). Piccato (2001) argues that relationships among members of the lower classes, particularly those in more urban areas, often existed beyond the scope of traditional civil law. As a
consequence, “male violence tried to legitimize those relations by publicly reinforcing prevalent gender roles in the family: men exercised force and control, women sacrificed themselves, and relations were stable” (Piccato 2001: 113). Through domestic violence, medical treatment or regulations pertaining to motherhood, men asserted their dominance over women's bodies. As the barometer of the health of a society, women's bodies are the sites at which the health of the community can be created and maintained.

Historically, efforts were made to control and quiet women in Mexico. Violence against women was largely accepted, particularly as a means to assert family honor, and painting female desire with shame was a common practice. Thus, historical constructions of female identity rooted in passivity and subjugation, while they have changed over time, nevertheless help us understand why an increase in HIV prevalence among heterosexual women stems from particular social norms that govern the relationships between husbands and wives. Quite simply, negotiating for safe sex is not part of their accepted social roles as wives and mothers (Hirsch, et. al. 2002; Pulerwitz 2001). In effect, these social constructions of femininity place women at an increased risk of contracting HIV, as they are less willing to negotiate their sexual relations with their male partners.

There is also another side to constructions of gendered roles in Mexico that is relevant to the application of social constructions to policymaking in the HIV/AIDS arena. Lynn Stephen (2002) argues, in her study of gender and sexuality in the Mexican state of Oaxaca, that:

“the various sexual roles, relationships and identities that characterize contemporary rural Oaxaca suggest that instead of trying to look historically for the roots of 'homosexuality,' 'heterosexuality,' or even the concept of 'sexuality,' we should look at how different indigenous systems
of gender interacted with the shifting discourses of Spanish colonialism, nationalism, and popular culture to redefine gendered spaces and the sexual behavior within them. Clear differences between elites and those on the margins of Mexican society underscore the importance of divisions by class and status” (41).

Stephen's argument indicates that one might find different formulations of sex and sexuality among different communities within Mexico, making it difficult to apply a single policy or program for HIV prevention to all vulnerable populations on the whole. In all of these communities, however, class and social status are an important measure when considering the potential vulnerability of a population.

Stephen (2002) gives a snapshot of the context of sex and sexuality in Zapotec Oaxaca, a rural indigenous community. She describes a community in which there are unique constructions of gender: a so-called third gender of biological males who take on certain female characteristics (called *muxhes*); a hidden gender hierarchy in which women's sexuality is controlled before and during marriage; a migrant construction of sexual identity that enables men and women to reach a level of equality in determining the boundaries of their relationships; and alternative sexual identities most often linked to homosexuality (Stephen 2002: 41). Stephen's study indicates that while there is a degree of egalitarianism in Zapotec Oaxaca, there are still means by which female sexuality is controlled, leaving women vulnerable to marginalization and disease.

Stephen points out the fact that alternative identities, most often associated with male homosexuality, are commonly expressed in Zapotec Oaxaca and largely socially accepted, if only socially tolerated. She further argues that female homosexuality is discussed exclusively in terms of *velas*, celebrations of patron saints that have a history in Zapotec culture where women often enter into sexual relations with other women, and
that the inverse of the third gender (biological females who take on the characteristics of males) are rarely, if ever, discussed. This tradition of the third gender makes some indigenous cultures in Mexico particularly unique due to the variation and complexity of their constructions of sexual identity. In the state of Oaxaca, those who identify with this third gender play an integral role in society, through their interactions with the community at large and by organizing AIDS awareness events in small towns, like Juchitan, Oaxaca. The “existence of the mux/h/e [the third gender] creates a social space that has permitted political organization and thus facilitates gay awareness elsewhere in Mexico” (Smallman 2007: 123).

But, this acceptance of a third gender is largely held to Oaxacan society, and even more precisely to the culture of Juchitan; the violence against and oppression of transgender communities is discussed in further detail below. More often across Mexico, there is an attitude associated with male dominance that can be traced back to the Mexican revolution, in which post-revolutionary projects set about to construct the “ideal” Mexican. This notion was largely constructed by conservative Mexicans and exhibited a dialectical quality, in which it represented, but also reified, tradition and custom. This construction became popular because “of its reliance on symbols that straightforwardly evoked the nation's pride in its people” (Carrillo 2001: 22). This sense of Mexicanidad had a great impact on what was “perceived as Mexican traditions about family, gender relations and sexuality” (Carrillo 2001: 23). There is a contradiction within the Mexican belief system about sexuality, “between a critique of homosexuality (equated with effeminacy) and sexual relations with transvestites entails that these relations be veiled with secrecy outside a close circle of male friends” (Smallman 2007:
The fact that the notion of sexuality in Mexico is so historically and distinctly linked to notions of tradition and nationhood indicates the veracity with which many defend traditional constructions of femininity and masculinity as they would defend the very core of *Mexicanidad*.

The nature of Mexican national identity fused with the construct of *machismo*, a preference for excessive masculinity. The fusion of these two identities “constituted a powerful ideology that justified the maintenance of patriarchal domination, women's subordination, and the traditional Mexican family (which included sexual freedom for the male outside monogamous marital relationships)” (Carrillo 2001: 23). However, Carrillo (2001), in a study of contemporary sexuality in Mexico, examines how modern Mexicans frame these mechanisms in new ways. These notions of “normal” and “abnormal” are a means of sexually identifying oneself. “Normal” is a term people use to distance themselves from those they perceive to be abnormal or deviant: “the use of the term provide[s] clarification about a person's sexual attraction and confirm[s] an essentialist perception of manhood and womanhood” (Carrillo 2001: 39). Abnormal, on the other hand, is a term used to describe those who defy traditional stereotypes about masculinity and femininity: men who act effeminately or women who appeared masculine. Abnormality is important because it is a distinction that enables men who have sex with “abnormal” men to maintain that they are heterosexual. According to Carrillo, “having sex with effeminate men, or men who act and dress as women might be the only strategy that simultaneously provides access to the enactment of same-sex desire and protection of masculinity” (2001: 57). For this reason, the HIV program in Mexico targets men who have sex with men in its prevention campaigns rather than only those who *identify* as gay.
It is important to note that this distinction between normal and abnormal is an overt linkage between behaviors and identity: “The relationship of identity to practice, always a complex one, is especially so when considering gay identity which is perforce negotiated in response/resistance to the homophobic construction of homosexuality as predicated upon execrated sexual behaviors” (Wilton 1997: 19). In resisting this social construction of their sexual identities as linked to behavior, an “oppositional discourse” develops, materializing in open, proud sexual interaction (Wilton 1997: 19). Ironically, it is the manner in which an open and assertive gay sexuality is celebrated that also leads to the spread of disease. According to Wilton, “one of the most painful—and politically difficult—aspects of the AIDS epidemic for gay men has been the recognition that the free market sexuality which embodied (though never unchallenged, and never for all gay men) a proud, assertive sexuality of resistance at the same time established the precise mechanisms whereby HIV was able to spread with such devastating swiftness through gay urban communities” (1997: 19). The attempt to be seen amidst a social environment seeking to impose invisibility created a climate in which HIV spread rapidly within these communities. This notion of abnormality and identity based on behavior extends to the perceived expendability of homosexual communities in Latin America.

In a more recent examination of sexuality in Mexico, Carrillo (2007) found generational gaps in constructions of sexuality. For example, women in discussion groups felt the need to discuss issues of “morality” when engaging with older generation Mexicans, but also felt the need to relay notions of fear when discussing the issues of sexuality, and AIDS in particular, with younger Mexicans (Carrillo 2007: 79). These subtle differences in the tenor of discussions about sexuality in Mexico reflect the fact
that social constructions of sexuality change over time, sometimes gradually and, other times, rapidly. In this same study, Carrillo (2007) recognizes that, as a result of the AIDS epidemic, some conversations about sexuality have become more commonplace. In particular, public conversations about homosexuality are now “standard” and widespread in Mexican media (Carrillo 2007: 80). Further, Carrillo (2007) finds that in urban areas there is even more widespread acceptance of public discourse on homosexuality and a diminishing of conservative anti-gay expressions.

*Government Responses to HIV/AIDS through the Lens of Target Populations:*

In light of the social constructions of sexuality presented above, we can examine the nature of government responses to HIV/AIDS through the lens of socially constructed target populations. As mentioned earlier in this dissertation, the majority of public financing for HIV/AIDS in Mexico is tied up in the procurement of antiretroviral medication and the related health services for people already living with the disease. The remaining ten percent of the Mexican budget aims to implement all other HIV-related policy initiatives, including diverse and aggressive prevention programs. An examination of government policies aimed at populations at-risk of contracting HIV/AIDS provides insight into how the constructed identities of these target populations map to actual policy design and implementation. This section explores two primarily positively constructed populations, men and women, and children, and two primarily negatively constructed populations, injecting drug users and transgender communities.

---

59 Interview with José Antonio Izazola, Mexico City, May 2012.
60 The author recognizes that there are other negatively constructed populations in need of HIV/AIDS interventions that are, unfortunately, beyond the scope of this project. Male and female prisoners, for example, are an important and often times excluded population in need of intervention. One organization participating in this study, Consultoria en Salud Pública y Gestión Sanitaria, carried out a research-focused project on prisons in the Mexico City area; however, this organization does not engage in policy advocacy.
According to the *Norma Official* on HIV/AIDS in Mexico, the Secretary of Health focuses its prevention efforts on those groups that are at the highest risk: men who have sex with men, commercial sex workers, injecting drug users, persons deprived of liberty, and street children. Programs have expanded since the *Norma* was originally drafted to include nearly all populations, but with an increased focus on women. In 2011, CENSIDA focused on financing prevention programs aimed at any woman who seeks out sexual and reproductive health services. While the original *Norma* maps out which vulnerable populations should be targeted through focused prevention efforts, through state partnerships with civil society organizations, most communities have some kind of prevention and outreach programs, whether carried out by the state or by local community groups.

*Men and Women*

One of the largest sources of tension in HIV policymaking in Mexico stems from the increasing emphasis on women, presumably at the expense of other vulnerable groups, in targeted policy interventions. In recent years, scholarly research points towards increasing HIV prevalence rates and risks specifically among women who believe they are in low-risk, monogamous, heterosexual relationships with men (Hirsch 2002). We see through the historical constructions of masculinity and femininity in Mexico that women can be at an increased-risk to contract sexually transmitted diseases when strong social cues condition them to obey the men in their lives (fathers, brothers, husbands, etc.) and not to be assertive in protecting their own health needs. Because these traditional relationships result in unequal power dynamics between men and women, women are left

For more information on the rights of prisoners with HIV/AIDS in Latin America, see the Pan-American Health Organization’s ongoing project on the health rights of persons deprived of liberty.
at increased vulnerability for sexually transmitted infections, including HIV. According to one participant in this study, the government, including the Secretary of Health and legislators, do not shy away from speaking about HIV/AIDS, especially when it comes to issues involving women and children. “They use the rhetoric of los culpables [those at fault] and los inocentes [the innocents]” to decry lapses in access to medication or prevention programs, clearly distinguishing between those innocent, vulnerable groups deserving intervention, and those groups whose disease is the result of their own immoral or socially unacceptable actions.61

_Salud Integral para la Mujer_ (Comprehensive Health Care for Women, or SIPAM), is an organization that brings a feminist perspective to the human rights of women, as they pertain to issues of health. As a registered civil society organization, they define HIV/AIDS as an issue of women’s human rights specifically, and have worked with executive government agencies and the legislature to promote HIV-related programming for women.62 As part of this work, SIPAM works nationally, for example as a member organization on both the prevention and the regulation committees of CENSIDA, and locally, in the _Comisión de Equidad de Genero_ (Gender Equity Commission) of the General Legislative Assembly of Mexico City.

SIPAM engages in both formal political negotiations, inherent in the activities listed above, and grassroots politics. One of SIPAM’s organizational objectives is to increase HIV programming for women, as part of a feminist agenda to expand women’s access to their human rights. In their public communications, SIPAM routinely exposes areas of HIV policy that excludes women, or does not deal directly enough with the

---

61 Skype interview, Maria Elena Rodriguez, Mexico City, May 2012.
62 Interview with Alejandrina Rojas, Mexico City, June 2012.
gendered dynamics of the disease. On their website, for example, they point out that CENSIDA prioritizes policy interventions for men who have sex with men, sex workers, injecting drug users, and mobile populations to the detriment of sufficient programming for women. While the Ministry of Health considers Mexico’s epidemic “concentrated” within these at-risk groups, SIPAM argues that the prevalence rate among women increases every year because they lack policy interventions. Advocates at SIPAM recognize that more emphasis has been placed on women and HIV since Patricia Uribe Zúñiga was appointed director of CENSIDA; yet the organization continues to decry a lack of access to services, programs, and a lack of sensitization on the part of medical professionals in dealing with women and HIV.

While SIPAM decries the state’s emphasis on policy interventions for men who have sex with men, statistics largely demonstrate that the HIV epidemic in Mexico is concentrated primarily within the men who have sex with men communities across the country. Through the end of September 2013, CENSIDA reported that a total of 136,570 men were infected with HIV, whereas 29,800 women were infected with HIV (CENSIDA 2013). Further, as mentioned earlier, of the percentage of Mexicans with registered HIV/AIDS cases throughout the entire epidemic, 63.82.1 percent are men and 17.9 percent are women. In terms of cases in which HIV is contracted through sexual relations, the rates for women have been on the decline since 2007, whereas the rates for men have remained somewhat stable, between 6.2 and 6.7 percent (CENSIDA 2013). Given the epidemiological trends in HIV prevalence among men and women, the

---

63 Physicians, clinic workers, etc., are all required to report new HIV diagnoses to CENSIDA, as a mechanism of disease surveillance. Statistics used in this chapter are publicly available through CENSIDA, but only represent those cases in which a positive HIV test is reported. Therefore, actual cases of HIV and AIDS are likely higher throughout Mexico.
increasing focus on programs for women reflects socially constructed identities in which women are often constructed as deserving of intervention, or in need of protection, and men, particularly those who operate outside of the standard or traditional notions of masculinity, are less in need of interventions.

However, in urban and politically liberal areas like Mexico City, there is an abundance of policies and programs dedicated to reducing HIV/AIDS prevalence among men, in particular among men who have sex with men. Dr. Andrea Gonzalez, former director of the Mexico City AIDS Program, pointed out the problem with the current model, arguing that money for HIV testing and prevention programs aimed at men who have sex with men, particularly in Mexico City, is concentrated in the Zona Rosa, a largely gay-friendly, high-income neighborhood that is already saturated with these kinds of programs. Rather than working in neighborhoods where alternative sexualities are less tolerated, and therefore open and frank programs would be more difficult to implement, the local AIDS program and the work of civil society organizations clusters in these more affluent neighborhoods. Further, HIV testing programs are generally aimed at individuals who medical professionals deem most at-risk. Because of this, presumed heterosexual men are often not targeted for HIV testing, leaving them vulnerable to the disease: if they are not targeted for testing because they engage in heterosexual behavior, or because they may not openly discuss risky behavior in which they engage, they have the potential to contract the disease and live without treatment. When individuals do not receive treatment, not only does their own health decline, but they are also more likely to spread HIV to others when engaging in risky behavior. Not only is there a tension between programs aimed at men and women in Mexico, there are divisions in the amount

---

64 Interview with Dr. Andrea Gonzalez, Mexico City, May 2012.
of programming among different communities of men. In Ingram and Schneider’s (1997) conceptualization of social constructions and policymaking, presumed heterosexual men may be positively constructed, but because their perceived risk is so low they are not considered for large-scale policy interventions; however, women are also positively constructed, but considered a dependent group, needing protection and assistance through policy intervention.

*Children and Adolescents*

Children and adolescents are another group that is also positively constructed, and often considered deserving of policy interventions. In nearly eliminating known cases of mother-to-child transmission, the national Mexican HIV program now focuses on prevention outreach among youth to keep them HIV-negative. As of September 30, 2013, CENSIDA reported that only 4.1 percent of all HIV cases from 1983-2013 were found in individuals nineteen years old or younger (CENSIDA 2013). According to this same data set, the large majority of these cases stem from perinatal transmission (mother-to-child HIV transmission,) but there are some cases of transmission through sexual means (2,421 accumulated cases) with many of these sexually-related cases clustered in the 15-19 age range (2,307 accumulated cases) (CENSIDA 2013). While the overall prevalence rate for children and adolescents is relatively low, because of their position of vulnerability within society, complex questions and problems come with an HIV diagnosis. For example, many times children are deserted due to their disease status. This happens when parents are unable or unwilling to care for them due to their own disease or misconceptions about what it means to have HIV. As a result, many HIV-positive children end up homeless. The *Sistema Nacional Para Desarrollo Integral de la Familia*
(National System for the Development of the Family, or DIF) works in concert with civil society organizations to place orphaned and homeless HIV-positive children in appropriate facilities. The civil society organization Casa de la Sal, created in 1986, operates a youth center in Mexico City housing abandoned HIV-positive children. Casa de la Sal only takes on those cases brought to them through DIF because of an overwhelming number of children and limited space and resources in the youth center.

For children and adolescents, civil society organizations, like Casa de la Sal, work in partnership with state agencies, notably DIF, to design interventions based on the idea that children are innocent and in need of state protection.

Children and adolescents, then, in Ingram and Schneider’s (1997) schema, are constructed largely as a dependent class by both government agencies and civil society organizations: vulnerable, powerless, and in need of targeted policy interventions. Some of the largest state policy interventions aimed at children and adolescents are the development of sex education programs in fulfillment of state obligations made under the 2008 Ministerial Declaration Prevenir con Educación (Prevent with Education). As of the writing of this dissertation, few efforts have actually been made to meet these obligations; however, the Prevention Committee of CENSIDA made several recommendations after its October 2013 meeting in which six civil society organizations participated. These recommendations were made to CENSIDA’s director, Patricia Uribe Zúñiga, to work with the Office of the Presidency in an effort to advance the commitments made in 2008. This committee recommended that Uribe work with the Minister of Health to pressure the Secretary of Education to make efforts towards achieving comprehensive sex education in Mexico. Further, the committee sent a letter to
Uribe requesting that she invite Mexican President Peña Nieto to the next CENSIDA meeting. If President Peña Nieto were to preside over a CENSIDA meeting, it would signal executive support for the 2008 commitment to comprehensive sex education.65

While some negative views still exist, for example in a border community where the mayor tried unsuccessfully to ban children with HIV from attending public primary schools, children are largely viewed simultaneously as the future of Mexico in need of protection and as innocent victims of HIV. For example, the Norma Official on HIV/AIDS elaborates the position of the Mexican government on youth and HIV: “Los adolescentes son una población vulnerable, por lo que se considera una prioridad evitar la deserción y la falta de adherencia al tratamiento” (adolescents are a vulnerable population and for this reason it is considered a priority to avoid desertion and the lack of adherence to treatment.)

Injecting Drug Users

The Consejo Nacional para Prevenir la Discriminación (The National Council for the Prevention of Discrimination, or CONAPRED) published a report in 2009 outlining the different kinds of stigma faced by injecting drug users along the U.S.-Mexican border, and the overall effect of stigma on this population group. This study found that the greatest sense of discrimination that drug users felt stemmed from the criminalization of drug consumption. Even campaigns aimed at dissuading individuals from using or trying drugs tended to stigmatize individuals who do use drugs by equating drug use with crime. The resulting effect of this kind of stigma is that individuals who use drugs are less likely or less willing to seek out and use public services, like basic

65 Minutes from this meeting are available at: http://www.censida.salud.gob.mx/descargas/comites/prevencion/minutas2013/comiteprevencion_3raord_15102013.pdf
health care or HIV-related prevention programs. In combination with this kind of stigma and discrimination, Strathdee, et. al. (2012) find that Mexico’s border with the United States has the signs of an emerging HIV/AIDS epidemic, due in large part to the concentration of injecting drug use in this region. Table 2 shows the percentage of HIV cases transmitted through injecting drug use across the country (CENSIDA 2013). The rate is unstable, indicating that further policy interventions are necessary.

### Table 4: Percentage of HIV cases transmitted through injecting drug use, 2000-2013

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage of HIV cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>0.4</td>
</tr>
<tr>
<td>2001</td>
<td>0.7</td>
</tr>
<tr>
<td>2002</td>
<td>0.4</td>
</tr>
<tr>
<td>2003</td>
<td>0.7</td>
</tr>
<tr>
<td>2004</td>
<td>0.9</td>
</tr>
<tr>
<td>2005</td>
<td>1.9</td>
</tr>
<tr>
<td>2006</td>
<td>2.9</td>
</tr>
<tr>
<td>2007</td>
<td>2.8</td>
</tr>
<tr>
<td>2008</td>
<td>2.0</td>
</tr>
<tr>
<td>2009</td>
<td>1.6</td>
</tr>
<tr>
<td>2010</td>
<td>1.3</td>
</tr>
<tr>
<td>2011</td>
<td>1.8</td>
</tr>
<tr>
<td>2012</td>
<td>2.1</td>
</tr>
<tr>
<td>2013</td>
<td>1.4</td>
</tr>
</tbody>
</table>

The government responses to injecting drug use have largely been punitive in nature, mirroring those of the United States, “with an emphasis on supply reduction and interdiction” (Bustamante Moreno, et. al. 2010). A primary emphasis on policing drug use contributes to the environment of stigma and discrimination encountered in the 2009 CONAPRED report. After 2009, the federal government made legislative changes aimed at decriminalization by “deregulat[ing] the possession of small specified amounts of cocaine, heroin, methamphetamine, and marijuana for personal use,” further specifying that rather than facing prison time, individuals arrested within the specified limits would
be required to enter drug treatment programs (Bustamante Moreno, et. al. 2010: 494). These changes to federal law reflect a shift in policy from punitive-based policies to harm reduction strategies; however, these shifts do not reflect public perceptions of drug users, as uncovered by the CONAPRED survey.

With respect to HIV/AIDS, there are very few cases reported to be the result of injecting drug use. According to the 2013 CENSIDA report, only 1.3 percent of all HIV/AIDS cases since the beginning of the epidemic in 1983 were known to stem from injecting drug use. Despite this low percentage of total cases, this number has been increasing steadily. For example, in 2003, 41 registered cases of new HIV infections (or 0.7 percent of total cases for that year) were attributed to injecting drug use, whereas in 2007, 200 registered cases of new HIV infections (or 2.8 percent of total cases for that year) were attributed to drug use (CENSIDA 2013). While the overall infection rates associated with injecting drug users remains low compared to the rest of the population, these large increases point towards much needed policy interventions for this population.

Initial government policy in this area focused largely on punishment for drug use rather than strategies to address HIV risk in drug-using populations. The Mexican government permitted civil society organizations to develop and implement harm reduction strategies, like syringe exchange programs, though organizations reported initially high levels of pushback from policymakers. Civil society organizations serving border regions and stemming from U.S.-Mexican clinical and research-oriented partnerships, like Prevenca, Programa Compañeros, initiated their own independent syringe exchange programs in Tijuana and Ciudad Juarez, respectively.

---

66 Interview with Maria Elena Rodriguez, Skype, June 2012; Phone interview with Steffanie Strathdee, July 2012.
These two cities have the first and second highest number of illicit drug users in Mexico, respectively (Strathdee, et. al. 2012). According to Steffanie Strathdee, founder of *Prevencasa*, negative attitudes in the United States seemed to have spread to Mexico with respect to needle exchange programs, wherein when the programs were first initiated they were not received favorably by local government actors. Regardless of attitudes towards the program, *Prevencasa* provided clean needles to individuals seeking them as a means of decreasing the spread of HIV/AIDS in the city. The negative climate created by U.S. rhetoric on syringe exchange programs created, until recently, certain institutional constraints in Tijuana, affecting how *Prevencasa* implemented its programs. Namely, they felt pressure coming from the U.S. to avoid creating partnerships with other organizations on the ground. In a 2012 interview, Strathdee attributed this pressure to fear on the part of the U.S. that collaborations with other organizations might lead syringe exchange programs to proliferate. In the same interview, she indicated the tide eventually shifted on the Mexican side of the border: local physicians and, eventually, policymakers recognized the success of *Prevencasa*’s harm reduction strategies. Local policymakers lobbied state and national leaders, using the data produced by *Prevencasa*’s research partnership, to endorse syringe exchange programs at the border. In turning back to the 2013 CENSIDA data, the percentage of reported new HIV cases attributed to injecting drug use has been steadily declining since it reached its apex in 2007.

---

67 The United States initiated a ban on federal funding for needle exchange programs in 1988. While the ban was lifted in 2009, it was reinstated in 2011. In the U.S., those who do not support needle exchange programs argue that these programs provide an “implicit approval of drug-using behavior by the government and can lead to increases in drug use” (Almazan 2013). This issue is a particularly useful example of the negative social construction of injecting drug users, as countless studies demonstrate not only the effectiveness of needle exchange programs in reducing HIV transmission, but also expose no connection between such programs and the increase or promotion of injecting drug use (Almazan 2013).
Individuals with addictions and those who regularly abuse injecting drugs are not viewed favorably by society, as evidenced in the 2009 CONAPRED report, nor have they historically been viewed favorably by government officials. Many of the civil society organizations working specifically with this population, as will be briefly discussed below, were the only entities addressing issues of risk and disease among drug users during the first half of the AIDS epidemic. Eventually, organizations, like Prevencasa and Programa Companeros, succeeded in securing a “change of position” from local governments in Tijuana and Ciudad Juarez, supporting their needle exchange programs. According to Rodriguez of Programa Companeros, one of the primary obstacles to achieving policy changes in support of this population, apart from the stigma associated with drug use, is that injecting drug users are not politically active. This makes it more difficult for civil society organizations, or for the drug users themselves, to position HIV and drug use as a health issue rather than a criminal issue. Rodriguez argued that in Mexico, the gay community has been involved in politics, fighting for their rights, whereas injecting drug users do not have this sense of political knowledge or efficacy. The distinction between the gay community’s ability and willingness to engage in policy-related processes, when compared to the experiences of injecting drug users who must rely exclusively on advocacy organizations, demonstrates how social perceptions of the deservingsness of a given population affect not only the design of policy interventions, but also how incorporated into the polity a group feels. The policy design itself, wherein drug users are treated as criminals rather than associated with larger public health threats, structures individuals’ experiences interacting with the government and can have long-
term effects on how willing or capable a given group is to advocate for policies on their own behalf (Soss 1999).

Transgender Communities

Whereas traditional conceptions of masculinity and femininity create policy tensions between programs aimed at men and women, the transgender community continues to face ostracism within the struggle against HIV/AIDS. Despite the acceptance of the *muxhe* in Juchitan, Oaxaca, and seemingly open views on sexuality in metropolitan Mexico City, the overall pattern indicates an overarching negative perception of transgender individuals on behalf of society and the government. Between 2008 and 2011, Transrespect, an international advocacy organization, reported that ninety-three transgender women were killed across Mexico (International HIV/AIDS Alliance 2012). A 2012 report compiled by the International HIV/AIDS Alliance, an international AIDS activist organization, highlighted key challenges to individuals advocating on behalf of the transgender population throughout Latin America. Some of these challenges included: extrajudicial killings, arbitrary detentions, cruel or inhumane treatment, and threats or extortion, adding that transgender individuals themselves often have their international “right to the enjoyment of the highest attainable standard of health” violated due to stigma and discrimination within health systems and within larger political arenas (International HIV/AIDS Alliance 2012: 16-18). In addition to the threat to their physical well-being that results from stigma and discrimination, transgender

---

68 In the U.S. court case, *Lopez Berera v. Holder*, an HIV-positive, transgender Mexican woman appealed her denied asylum request on the grounds that physical violence and discrimination within the health system would lead to a certain death upon her return to Mexico. In April 2012, an appeals court stayed Lopez Berera’s deportation based on evidence heard in the case.

69 In 2009, Mexico City reformed its local general health law, including coverage of hormone therapy and, potentially, sexual reassignment surgery for transgender individuals. This reform has not yet had an impact on national legislation related to required services for this community (Grajeda 2009).
communities are often excluded from other communities’ HIV-related advocacy initiatives: the needs and challenges of transgender women are generally not addressed by women’s movements throughout Latin America, whereas few civil society organization in Mexico, specifically, address the needs of transgender communities alongside those of the gay community or within women’s activist groups (International HIV/AIDS Alliance 2012). Further, a report released by the Instituto Nacional de Salud Pública (National Institute for Public Health, INSP) in Mexico, recognized that transgender individuals experience severe stigma and discrimination, not only by the population at large, but also particularly within Mexico’s gay communities (Infante, et. al. 2009).

There is limited HIV policy directed specifically towards transgender communities in Mexico. CENSIDA does not report prevalence rates within the transgender community, while it does report prevalence rates for men and women, and by method of transmission, like injecting drug use. While the government does not have a policy that specifically targets HIV among transgender individuals, they do support community based projects aimed at mitigating the vulnerabilities and effects of disease within transgender communities. For example, in 2008, according to the Office of Prevention and Social Participation, CENSIDA financed eight separate projects intended to provide prevention programs for the transgender. These projects were scattered across the country, notably lacking were any financed projects for civil society groups in Mexico City working on this topic. Largely, civil society organizations, like Colectivo Sol, discussed in further detail below, work to shape conversations about stigma and discrimination associated not only with HIV, but also with living as a transgender individuals.
According to Mexican government data, in April 2011 a total of 321 civil society organizations registered as official HIV-related organizations with CENSIDA across Mexico. In registering with the government, the organizations became eligible to compete for government funding for HIV prevention-related projects, while the government collects and maintains descriptive data about each organization. Because registering also confers a tax status on the organizations, they are further held to particular reporting standards, which some organizations profiled in this dissertation argued created the need for more personnel to deal with the increased financial reporting requirements.

As part of the registry process, each organization identifies with which populations it primarily works. The following categories were identified through the registry process: gay people; gay men; transgender, transvestite, and/or transsexual; men who have sex with men; injecting drug users; sex workers; people living with HIV/AIDS; migrants; indigenous populations; youth; women; and, finally, students. Table 5 highlights the whole number and percent of organizations that self-reported working with the above at-risk populations. Most HIV-related civil society organizations in Mexico work with more than one at-risk population. For this reason, the column \textbf{Percentage of Total Organizations} reflects the percent of organizations that self-reported working with a specified population, and the column is not intended to equal 100 percent.

<table>
<thead>
<tr>
<th>At-Risk Population</th>
<th>Number of Organizations</th>
<th>Percentage of Total</th>
</tr>
</thead>
</table>

\textbf{Table 5: Number of Organizations/Percent of Total Organizations that self-reported working with a specified target population for 2011 CENSIDA registry}
The organizations specifically under analysis in this dissertation represent a wider variety of target populations than the overall picture of organizations in Mexico depicts. Below is a table of the organizations under analysis here (n = 18). These organizations reported, either through the CENSIDA registry process or in their own materials, to represent the given target populations.

<table>
<thead>
<tr>
<th>At-Risk Population</th>
<th>Number of Organizations</th>
<th>Percentage of Organizations Under Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gay People</td>
<td>156</td>
<td>48.6</td>
</tr>
<tr>
<td>Gay Men</td>
<td>136</td>
<td>42.4</td>
</tr>
<tr>
<td>Transgender/vestite/sexual</td>
<td>89</td>
<td>27.7</td>
</tr>
<tr>
<td>Men who have sex with Men</td>
<td>152</td>
<td>47.4</td>
</tr>
<tr>
<td>Injecting Drug Users</td>
<td>57</td>
<td>17.8</td>
</tr>
<tr>
<td>Sex Workers</td>
<td>99</td>
<td>30.8</td>
</tr>
<tr>
<td>People living with HIV/AIDS</td>
<td>133</td>
<td>41.4</td>
</tr>
<tr>
<td>Migrants</td>
<td>87</td>
<td>27.1</td>
</tr>
<tr>
<td>Indigenous</td>
<td>106</td>
<td>33.0</td>
</tr>
<tr>
<td>Youth</td>
<td>204</td>
<td>63.6</td>
</tr>
<tr>
<td>Women</td>
<td>193</td>
<td>60.1</td>
</tr>
<tr>
<td>Students</td>
<td>161</td>
<td>50.2</td>
</tr>
</tbody>
</table>

An important trend to note is that as both international and national funding sources become increasingly scarce, civil society organizations are less able to focus on only one or two specific populations at risk. Mauro Santiago, Director of the organization Consultoria en Salud Pública y Gestión Sanitaria, a research-focused group, argued that
to stay viable, they need to work on as many HIV-related issues, and with as many at-risk populations, as possible.\textsuperscript{70}

Through the descriptive data, we catch a glimpse of clear patterns and demarcations in how well represented each set of target populations is within the universe of registered civil society organizations. More than fifty percent of organizations report to dedicate time and resources working for or with young Mexicans, including students, and women. The increasing emphasis on HIV interventions aimed at women has been a key trend in Mexican HIV policy over the last decade. We can see that women are increasingly targets of policy interventions because of the increased presence of this at-risk group in annual CENSIDA funding proposals. For example, in 2011, the CENSIDA \textit{convocatoria}, the competitive process through which organizations seek government funds to implement prevention programs, included “women of high risk” as a key category of participation. While this key category incorporated subcategories of multiple vulnerabilities, such as female sex workers and women deprived of liberty, it also includes any woman that seeks reproductive or sexual health services. This subcategory casts a wide net, and is inclusive of a much larger number of women than some of the other subcategories.

At the other end of the spectrum, injecting drug users, migrants and the transgender populations have the least amount of representation among the registered organizations, with less than twenty percent of organizations reporting to work with injecting drug users. As mentioned above, those organizations that do work with the drug using population face a number of serious obstacles, like a lack of consistent and regular access to the populations in need of interventions and the popular notion that individuals

\textsuperscript{70} Interview, Mexico City, June 2012.
who abuse drugs do not deserve programs that use public funds. Regardless of the negative public values often associated with drug use, CENSIDA included in its 2013 *convocatoria* two subcategories, women who use injecting and inhalable drugs, and men who use these drugs. By including these subcategories in the 2013 *convocatoria*, the federal government indicated its willingness to fund organizations’ projects aimed at decreasing HIV rates in these populations. On the whole, the general data on the at-risk populations represented by civil society organizations highlight that most populations (7) are represented by more than forty percent of registered organizations.

The transgender population, while lacking official government policies for treatment outside of Mexico City, is also one of the least represented groups within civil society advocacy groups. One organization in particular, *Colectivo Sol*, carried out a long term professionalization and training program to increase the extent to which transgender communities were represented within civil society groups. *Colectivo Sol*’s director, Juan Jacobo Hernandez, shared that this program, called *Vida Digna* (Worthy Life,) which lasted from 2006 to 2010, was one of the most successful programs because of its overall reach and its emphasis on limiting stigma and discrimination for certain populations.71

The program focused on men who have sex with men, injecting drug users and transgender communities to build community support, professional civil society organizations and mitigate stigma within communities. As a result of this project, *Colectivo Sol* facilitated the creation of three civil society organizations across Mexico that focus specifically on advocating for and providing services to their local transgender community. *Colectivo Sol* is one of the oldest HIV-focused civil society organizations in Mexico, as described in the previous chapter, and has long been known for its

71 Interview with Juan Jacobo Hernandez, Mexico City, June 2013.
international ties with other advocacy organizations, most notably those in the United States. This network enables *Colectivo Sol* to find international sources of financing for their projects, a quality which speaks to the longevity of the organization and the fact that it is viewed as a vanguard organization when it comes to professionalization and training.  

It is no exception, then, that ViiV Positive Action, an international organization, financed the *Vida Digna* project through one of its community grants.  

As a follow-up to the *Vida Digna* project, in 2011, *Colectivo Sol* worked, again, with organizations that serve men who have sex with men and transgender individuals to improve their access to international finances for their projects. Given the budget issues described at the beginning of the previous section, the need to shift focus from exclusively seeking national financial resources toward engaging with an international finance community is increasingly important. Organizations who secure international financing often times are more highly professionalized, have a more consistent portfolio of work, and are more likely to engage in direct consultations and negotiations with the Mexican government. This follow-up project, called *Respondiendo* (Responding,) attempted to facilitate communication among civil society organizations in Mexico as a means of establishing best practices and collaborating to overcome common challenges in prevention work in these communities. While new civil society organizations focused on transgender communities were born out of *Colectivo Sol’s* two programs, one that Hernández argued now “occupies a whole building, whereas we only have this small

---

72 According to the International HIV/AIDS Alliance, *Colectivo Sol* reached 108 civil society organizations with training and professionalization opportunities in 2011 alone. Further evidence to *Colectivo Sol’s* level of professionalization and institutionalization within the HIV/AIDS community, their *Vida Digna* model was extended and is being used through partner organizations throughout Central America.
house to work out of;”

this particular population still lacks the sustained response from civil society organizations that permeates the experiences of many other target populations addressed here.74

**Conclusion:**

The various categories of populations at risk that make up part of the registry help shed light on how both organizations and the government frame the issue of HIV/AIDS, and lend themselves to a policy analysis congruent with Ingram and Schneider’s (1993) social construction theory of policymaking. How the government and civil society organizations frame the policy issue, based on which populations they deem most in-need of policy interventions, creates opportunities and constraints for organizations’ activities and the negotiation of the state-civil society relationship. For example, SIPAM, an organization advocating on behalf of women, defines HIV as a human rights problem, but more specifically as a *women’s* human rights issue. This framing, in particular, sets this organization apart from other groups that view HIV as a human rights issue more broadly. Additionally, as the federal government, through CENSIDA, places increasing emphasis on programming aimed directly at women, an organization like SIPAM with a similar framing to the government, can gain greater leverage in negotiating new policy options. On the other hand, organizations advocating on behalf of less positively viewed populations face more of an uphill battle. *Prevencasa*, an organization working on Mexico’s northern border, experienced pushback from Mexican government officials when the organization initiated needle exchange programs. Because they work largely on

---

73 Interview with Juan Jacobo Hernández, Mexico City, June 2012.

74 See Chapter 6, *Negotiating Spaces*, for a further discussion of *ad hoc* groups that organize on behalf of transgender communities in Mexico City, in particular.
behalf of less positively viewed populations, like injecting drug users, they faced a more
difficult road in advocating policy changes.

All the participants in this study, representing both government agencies and civil
society organizations, noted a deficit in collaboration among organizations on issues of
HIV/AIDS. Conflict and tensions among civil society organizations has historically,
within this policy area, made collaboration difficult and resulted in less
professionalization for some groups. A lack of collaboration produces less opportunities
for organizations to engage in capacity-building trainings aimed at increasing
professionalization. Because different organizations disagree as to which populations are
most in need of policy interventions, civil society organizations in Mexico essentially
disagree as to how the policy problem is defined. Organizations must work, negotiate,
and often times renegotiate their relationships to the state and to one another in an
environment characterized by divergent policy frames.

The lack of collaboration participants noted in this study constrains organizational
activity and hinders civil society organizations’ success in advocating policy change and
monitoring implementation practices. While there is no doubt that funding streams, and
competition for scarce resources, certainly contribute to the tensions among
organizations, this chapter highlighted the divergent definitions of the policy problem
itself as a key obstacle to civil society organizations’ success in advocating policy
changes.
Chapter 5: Negotiating Rights

“What do we do with a state that does not provide its personnel with the capacity to deal with this disease? It is a question of citizenship.”

As noted in the introduction, a key question is why some organizations are more successful in the creation of new policies and institutions in instances where others are not as successful? The starting point for answering this question lies in the cases where guaranteed rights and citizens’ daily practice of those rights diverge. When the rights guaranteed by the state cannot be exercised fully by citizens, civil society organizations can seize these opportunities to make rights-based claims pursuing the creation of new institutions and policies that better address the needs of the population. The extent to which organizations are able to make rights-based claims in this area is structured by existing, or in some cases reformed, systems of engagement in Mexico is a critical component of organizations’ impacts. To further address this key question, this chapter will first establish both the international and the national Mexican context in which health, more broadly, and HIV, specifically, is framed as a human right. Next, I compare the varied roles civil society organizations undertake in response to perceived gaps between de facto and de jure health rights within the contexts of access to essential medicines and comprehensive sex education.

Health and Human Rights: International and National Contexts

Scholars situated at the nexus of health and human rights have questioned how access to medicine and treatment fits within general human rights frameworks. Broadly speaking, human rights create “state obligations and individual entitlements” (Hogerzeil,
et al. 2006: 305). Further, human rights “aim to empower individuals” in their relationships with states and are based on principles of “equality, participation, accountability, [and] attention to vulnerable groups” (Perehudoff 2008: xv). When health is framed as a human right, whether by the international community or by national governments, states have far fewer opportunities to restrict health care access, including those services specifically related to HIV/AIDS (Torres-Ruiz 2011). While a brief discussion of how health is constructed as a universal human right is warranted here, the notion that human rights create particular systems of obligations and entitlements between states and citizens serves as a key entry point at which to analyze state–civil society negotiations.

International organizations, such as the United Nations (UN) and the World Health Organization (WHO), have long established the global right to health, a value created at the international level, but implemented largely at the national level. Article 25 of the 1948 Universal Declaration of Human Rights includes that everyone “has the right to a standard of living adequate for the health and well-being of himself and his family,” further indicating, “motherhood and childhood are entitled to special care and protection” (UN General Assembly 1948: n.p.). Beyond the Universal Declaration, state signatories to the 1966 International Covenant on Economic, Social and Cultural Rights are obligated to “respect the right to health [which] requires States to, inter alia, refrain from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventative, curative, and palliative health services; abstain from enforcing discriminatory practices as a State policy; and abstain from imposing discriminatory practices relating to women’s health status and
needs” (emphasis in original; Office of the High Commissioner for Human Rights 1966: n.p.). Quite explicit in this document is the notion that discrimination in the protection of health by the state, whether it is in the form of, for example, permitting the refusal of care to an HIV-positive patient or a system-wide shortage of essential medicines, constitutes a violation of the rights put forth in the Covenant. General Comment 14 (2000) of the Covenant establishes not only that the full exercise of the right to health is a precursor to the exercise of all other rights, but also that this right includes legally enforceable elements. As a footnote to Article 1 of General Comment 14, the UN Economic and Social Council included the “principle of non-discrimination in relation to health facilities, goods and services [as] legally enforceable in numerous national jurisdictions” (18). Therefore, national governments have the impetus to legally enforce the right to health, through domestic legal instruments and processes. In a 2006 *Lancet* article, Julio Frenk, then Secretary of Health, argued the segmentation of Mexico’s health care system, in which salaried employees of the formal sector had access to health whereas others did not, directly violated the values and rights enshrined in the Covenant (Frenk, et al. 2006). Frenk’s statement provides evidence that the government, particularly in its health system reform, considered the international community’s framework of health as a human right in its assessment of the state of health care access in Mexico.

Apart from the primary human rights instruments of the UN, the WHO, the premiere international entity dedicated to coordination on issues of health and disease, establishes health as a human right. Most directly, the WHO Constitution states the “enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being” (WHO n.p.). Beyond this constitutional mission, the WHO
established the Health and Human Rights Team, which provides technical and political support to all WHO member states in the development of national mechanisms for the promotion and protection of health as a human right. The WHO also promotes access to essential medicines and medical technologies required for the fulfillment of the right to health. In the WHO’s Medium-Term Strategic Plan 2008-2013 and Programme Budget 2008-2009, Strategic Objective 11 focuses on equitable access to health products, including safety assurance and cost-effectiveness. Within this WHO objective, equitable access is measured by “availability, price and affordability” (158). These three elements remain an issue in Mexico’s provision of HIV/AIDS medicines, with price and affordability having the largest effect on the government while availability is most often felt by patients, as will be elaborated further below.

Not only do these international instruments establish the right to health, they also include the right to access information relevant to health. The UN’s General Comment on the International Covenant on Economic, Social and Cultural Rights, not only supports health as a human right, but also provides technical advice on how states can ensure this right. The General Comment addresses underlying conditions of poor health outcomes, and asserts that access to information, including sexual and reproductive health-related information, is key to the unfettered exercise of the right to health (WHO 2012). Further, the Office of the High Commissioner on Human Rights (OHCHR) argues that the right to access health-related information is an entitlement (3). Beyond establishing health information access as an entitlement that citizens can leverage, the OHCHR argues that within the context of sexual and reproductive health, lack of accurate and relevant information constitutes a violation of an individual’s human rights (13). By incorporating
access to health-related information as a human right, these international instruments speak directly to a key issue in the HIV/AIDS policy arena. Citizens’ ability to access information about HIV/AIDS, in addition to the essential medicines discussed above, represents another case of interactions between state obligations and individual entitlements. The state-civil society negotiation over comprehensive sex education in schools in Mexico, as will be elaborated below, provides insight into how civil society organizations operate at the interstices of guaranteed rights and the exercise of these rights.

When rights are enshrined in state constitutions, the resulting obligations states bear and individual opportunities to exercise these rights on a daily basis help construct citizenship within the state. In 2011, the Mexican government adopted the Human Rights Amendment (HRA 2011) to the national constitution, allowing the “application of customary international law and human rights standards to Mexican laws and allow[ing] human rights advocates to use international standards as a tool for asserting human rights violations” (Ek 9). In essence, HRA 2011 establishes the constitutional weight of international agreements: agreements such as the Covenant on Economic, Social and Cultural Rights hold the same legal weight as national constitutional rights in Mexico. There were minimal efforts to use the Mexican court system, via the ámparo process, as a response to violations of health rights related to HIV/AIDS prior to 2011. This reform provides additional legal weight with which civil society organizations can now leverage rights-based claims in the area of health and human rights. It provides an important shift in how law and institutions structure civil society organizations’ mobilization, as Bloemraad’s (2006) theory suggests.
Apart from the interaction of international and national rights frameworks, exemplified by HRA 2011, the Mexican national constitution long established health and access to education as fundamental rights of citizens.\textsuperscript{76} The protection of the health of the nation has been an integral part of Mexican political rhetoric since the Revolutionary Constitution of 1917, encompassed in Article 4 and in the 1983 amendment, the \textit{Ley General de Salud} (General Health Law). Mexico’s health care system, in general, is rooted in the social security systems developed shortly after the Revolution, and expanded further under the aforementioned legal reforms. The amendment to Article 4 is the social guarantee to health protection:

\begin{quote}
\textit{Toda persona tiene derecho a la protección de la salud. La ley definirá las bases y modalidades para el acceso a los servicios de la salud y establecerá la concurrencia de la Federación y las entidades en material de salubridad general...Toda persona tiene derecho a un medio ambiente adecuado para su desarrollo y bienestar.} (All people have the right to health protection. The law will define the foundations and methods for access to health services, and establish harmony between the Federal and state governments in general health...All people have the right to an adequate environment for their development and well-being.)\textsuperscript{77}
\end{quote}

Article 4 generates four important elements toward understanding the state-civil society relationship, as it relates to health as a right. First, Article 4 represents a social guarantee. As opposed to an individual right, which need only be respected by the state, a social guarantee means “that the state is responsible for doing whatever is required to see

\textsuperscript{76} While the Constitution established the right to health protection, it was not until the 1994 Constitutional Amendment “restructured and expanded the jurisdiction” of the Supreme Court that legal avenues of rights-based claims-making opened (Becerra Becerril 4). Though a full analysis is outside the purview of this dissertation, the 1994 amendment initiated a series of judicial reforms that lead to an increase in the power of jurisprudence and contributed to processes of democratization in Mexico. Further, the 2011 reform of the \textit{ámparo} system, which hears cases related to individual rights, potentially allows citizens to more easily access this process and make rights-based claims pertaining to health-related issues. To date, courts have heard very few cases related to HIV/AIDS and the right to access essential medicines. The Supreme Court has ruled in favor of individual rights in cases pertaining to discrimination against people living with HIV/AIDS in the armed forces. Also see footnote 80.

\textsuperscript{77} All translations are the author’s work, unless otherwise noted.
that this right is satisfied” (Tamez and Molina 2000: 139). It places a particular obligation on the state to ensure the protection of health. The Comisión Nacional de Derechos Humanos (CNDH) (2009), in its recommendation, argues that the state has the obligation to ensure the guarantee to the protection of health, by guaranteeing equal treatment in the social security institutions. Second, Article 4 expresses a universal guarantee. The only requirement for the full exercise of the right to health is that an individual be a citizen of Mexico. Third, it dictates that the state will determine how the guarantee will be fulfilled, and that there will be continuity between federal, state, and local government levels to ensure the right. Finally, it dictates which aspects the guarantee to health includes.

The Ley General de Salud is a one hundred and thirty page document that adds to and amends Article 4 by detailing what is protected and how this protection will be provided. In terms of what is protected, it includes:

(I) El bienestar físico y mental del hombre, para contribuir al ejercicio pleno de sus capacidades; (II) La prolongación y mejoramiento de la calidad de la vida humana; (III) La protección y el acrecentamiento de los valores que coadyuven a la creación, conservación, y mejoramiento y restauración de salud; (IV) La extensión de actitudes solidarias y responsables de la población en la preservación, conservación, mejoramiento y restauración de la salud; (V) El disfrute de servicios de salud y de asistencia social que satisfagan eficaz de salud, y oportunamente las necesidades de la población; (VI) El conocimiento para el adecuado aprovechamiento y utilización de los servicios de salud; y (VII) El desarrollo de la enseñanza y la investigación científica y tecnológica para la salud. (I)The physical and mental well-being of man, to contribute to the simple exercise of his capacities; (II) The extension and improvement of the quality of human life; (III) The highest protection of the values that contribute to the creation, conservation, betterment and restoration of health; (IV) The extension of responsible attitudes and solidarity with the population for the preservation, conservation, betterment and restoration of health; (V)The enjoyment of health

---

78 The population to which the constitution guarantees the right to health expanded in 2011, with the passage of the new Ley de Migración. The new Migration Law, a law that the Mexican Congress passed unanimously, guarantees the right to access health services without discrimination or penalty to immigrants, with or without documentation, within Mexico’s borders (Ley de Migración Article 27).
services and social assistance that satisfies the effective health needs and opportunities of the population; (VI) The adequate knowledge to use health services; and (VII) Development of training, scientific research and technology for health.]

*La Ley* further guarantees basic services to all Mexicans relevant to HIV/AIDS, including (among many): health education; the prevention and control of high priority communicable diseases; medical attention, understood as preventative, curative and rehabilitative services including family planning and social assistance to the most vulnerable groups (CNDH 2009: 3). In addition, *La Ley* established the *Sistema Nacional de Salud* (SNS, National Health System) and in large part elaborates how the SNS will run. According to Tamez and Molina (2000), the motivation behind establishing SNS was to extend health care coverage to the whole population, not just those individuals eligible and enrolled in the social security programs. The intent was to protect the most marginalized and vulnerable populations. This aim was not fully achieved, in that up until the 2003 *Seguro Popular* reform, only about half of Mexican citizens were fully covered by SNS or private insurance, illustrative of a “segmented model…marked by the separation of health rights between the insured in the salaried, formal sector of the economy and the uninsured” (Frenk, et al. 2006: 1525). More often than not, those individuals and families not covered by some insurance program were unemployed or in irregular employment; marginalized populations continued to be excluded from health protection programs.

At the national level, the Mexican government creates a right to health protection through the constitutional amendments and General Health Law. Specifically within the HIV/AIDS policy area, the government uses the rhetoric of human rights to address many issues associated with the disease. CENSIDA (the National Council for the Prevention
and Control of HIV/AIDS) maintains a separate section of its website, entitled “Human Rights,” where it warehouses government documents, legal instruments, and patient resources on the human rights of individuals with HIV/AIDS. Within this section, the government’s transition to a greater focus on human rights is clear. In the 1988 Decreto that formally created CENSIDA (named CONASIDA at the time of creation), the term “derechos humanos” (human rights) is not mentioned at all, while there is a single reference to “el derecho a toda persona a la protección de salud” (the right of all people to the protection of health) in the four-page document. This contrasts significantly to the Norma Official of 2010, an updated version of the 1993 Norma that deals with the prevention and control of HIV/AIDS discussed in more detail in Chapter 3. The 2010 document mentions the term “derechos humanos” (human rights) or “derechos” (rights) twenty-eight times in the nineteen-page document.

CENSIDA also maintains a Committee on Regulations and Human Rights (Comité de Normatividad y Derechos Humanos del Consejo Nacional para la Prevención y el Control del VIH/SIDA) that includes representatives of various government agencies and leaders of HIV-focused civil society organizations. Of the eighteen organizations under analysis here, eight organizations participated in the Human Rights Committee. The existence of the committee further points towards the government’s human rights framework on issues of HIV/AIDS. The fact that organizations actively participate in this committee, reflects not only each organization’s commitment to the human rights of people living with HIV/AIDS, but also that the shared state-civil society human rights framework serves as an entry point for organizations to work with the government.
In addition to the increase in rights rhetoric by the national government, the National Human Rights Commission (CNDH,) created in 1992 but gaining more independence from the government in 1999, maintains a program on HIV/AIDS and human rights (CNDH, n.d.) Under the auspices of this program, CNDH has issued twenty-seven recommendations relevant to HIV/AIDS and human rights, dating as far back as 1995. Again, we see an increase in HIV-related rights rhetoric in that only seven of the twenty-seven recommendations were published prior to 2000, while the remaining twenty recommendations were published after the transition to democracy in 2000. Eleven of the recommendations related to cases where complaints of rights violations were levied against IMSS (the Mexican Institute of Social Security,) one of the primary public health service providers in Mexico.

This section elaborated the varied ways in which health, and access to key health services, is framed as a fundamental human right by both international organizations and the Mexican government. While the Universal Declaration of Human Rights created the right to health in 1948, the Mexican government did not elaborate this right for its citizens until the 1983 health reforms. Increasingly, the Mexican government uses the rhetoric of human rights in documents addressing HIV/AIDS. Because the government established the right to health, and specifically the human rights of people living with HIV/AIDS, we would expect civil society organizations to leverage this framework in negotiating both expanded access to health services, and in monitoring the existing services available. In the remaining sections of this chapter, I turn to an analysis of organizations’ negotiation of the right to essential medicines and the right to comprehensive sex education in Mexico.
Daniel was a patient with HIV/AIDS that was pushed around for ten years, without receiving proper treatment. He did not make a formal complaint about his lack of treatment for ten years. As you can imagine, he got very sick and depressed during these ten years of not receiving regular medical treatment. IMSS said there was nothing they could do, and that there was no discrimination in this case. A different civil society organization told Daniel they would help him if he gave them a substantial amount of money. We [DVVIMSS] didn’t make Daniel any promises, but we stepped in to work with him to get medical attention...We see all the time that people want to live, but cannot get access. Can you imagine what happens to someone who has no access to human rights and all the institutions are against him for ten years?  

Daniel’s experience highlights challenges patients face in accessing treatment for HIV/AIDS in Mexico. These challenges came to the fore at the 2008 International AIDS Conference held in Mexico City, when the focus of the international public health community turned towards the Mexican HIV/AIDS program. This international focus, alongside public action by domestic civil society organizations, brought attention to a fundamental challenge in the program: the universal access to HIV/AIDS treatment guaranteed by the federal government had not yet been achieved. In the days leading up to the conference, reports surfaced that the cost of antiretroviral medication in Mexico was the highest in the developing world, a fact that many attributed to the lack of access to generic medicines in the country. The Mexican government responded with a renewed promise to negotiate lower prices with pharmaceutical companies, but as of the writing of this dissertation, significant improvement in the cost of medicines has yet to be achieved.

This issue, highlighted during the 2008 conference, provides insight into some of the key struggles of HIV/AIDS-focused civil society organizations in Mexico. While the Mexican government guarantees the protection of health in the constitution, expanded...

Interview with Luis Adrian Quiroz, Mexico City, May 2012.
upon this right in the *Seguro Popular* health care system reform, and increasingly uses the rhetoric of human rights in communications about these issues, the daily practice of the right to health is fundamentally flawed. The government has been unable to fully implement programs to ensure the free exercise of these rights. In the space between de facto and *de jure* rights, civil society organizations navigate the policy process and negotiate their relationship vis-à-vis the state. In the negotiation of rights, civil society organizations working on access to essential medicines largely operate in two areas: prior to the *Seguro Popular* reform, organizations pressured the government, using a variety of tactics, to establish universal access to HIV/AIDS treatment; after the reform, groups that did not experience organizational fatigue shifted towards “vigilanica ciudadana” (citizen vigilance) in which they actively monitor access to essential medicines. Scholars, such as Nielan Barnes, attribute the existence of a universal access program in Mexico to civil society organizations, noting that the tireless work of these organizations in the years preceding the program’s creation highlight how organizations drove the policy agenda. Despite this success, organizations working specifically on treatment and access issues face two primary challenges: first, they are largely constrained to working within the system in place, in that the great majority of organizations do not have the resources or the technical capacity to create pharmacy programs independent of the government; second, because organizations were successful in advocating for the creation of a universal access program, the movement lost steam as organizations shifted from *primarily* policy advocacy to monitoring the implementation of the program.

From nearly the beginning of the AIDS epidemic, access to medicine was the major confrontation between civil society organizations and the government. The

---

80 Personal communication with author, April 2013.
government, though far from disinterested, was arguably slow in its response; focusing primarily on epidemiological surveillance, it took four years for the government to take action, creating a national council on AIDS in 1987,\textsuperscript{81} formalized in the 1988 Decreto mentioned above. Beyond the creation of this council, early actions, as discussed in Chapter 4, focused on controlling the blood supply and preventing the spread of sexually transmitted infections among female sex workers. As will be further elaborated below, the shift at the international level towards increased inclusion of People Living With HIV/AIDS (PLWHA) in policy decisions alongside the discovery of highly active antiretroviral therapy (HAART) as a life-prolonging HIV treatment in 1996 contributed to organizations’ advocacy for essential medicine access programs in Mexico. Throughout the AIDS epidemic in Mexico, the segmentation that Julio Frenk noted remains apparent: there were marked differences between individuals with access to insurance and those without, and organizations used human rights rhetoric to push for expanded access to HIV/AIDS therapy for all Mexicans affected by the disease.

In a United Nations’ publication, Jorge Saavedra, former director of CENSIDA and Global Ambassador for the AIDS Healthcare Foundation, argued “estar afiliado al IMSS o ISSTE en México es tener la ‘esperanza’ de recibir ARV gratuitos” (those Mexicans that were associated with IMSS or ISSTE through employment had the good fortune of access to free antiretroviral medication) (125). This statement reiterates the key challenge in HIV policy in Mexico (and elsewhere, for that matter): those with access to health insurance have access to treatment; individuals without access to insurance, or the

\textsuperscript{81} Phone interview with Octavio Vallejo, April 2013.
underinsured, have little hope of receiving treatment for HIV/AIDS. However, being part of the IMSS and ISSSTE systems does not guarantee access to necessary medical treatment. Between 2000 and 2009, the CNDH received 11,854 complaints about violations of the right to health in the state’s public institutions, including IMSS, ISSSTE, the Secretary of Health, the Social Security Institute of the Mexican Armed Forces and the PEMEX Hospital (CNDH 2009). According to CNDH, the most common and serious complaint received was the lack of medicine and medical personnel, including disease specialists, to effectively meet the demand for services (2009).

Though few private clinics and pharmacies exist, the government is the primary provider of HIV/AIDS treatment in Mexico. Treatment happens, more often than not, in public clinics and hospitals; patients procure medicines through public, and sometimes private, pharmacies. In 2009, when CENSIDA began funding programs run by civil society organizations, there was a strict delineation made in which civil society organizations could receive money for and provide prevention services only, while disease treatment was squarely the responsibility of the government’s complex public health system. In this case, then, civil society organizations largely must respond to problems within the system; they do not have the opportunity to develop new systems of disease management. This stems from the notion that the government is obligated to guarantee the protection of the health of the nation, as outlined in Article 4 of the Mexican Constitution and discussed above. Within this policy issue, then, are multiple levels of complexity wherein the government guarantees particular rights, yet these rights

---

82 In this same publication, Saavedra argues that 40.9% of all accumulated HIV/AIDS cases up to 1998 were covered by IMSS and ISSSTE. Based on this statistic, he argues that the disease was predominantly focused in urban areas where there was a presence of the social security institutes, supporting the thesis that, in the first half of the epidemic, HIV/AIDS was an urban disease in Mexico (125).
83 Interviews with Jorge Saavedra and Carlos Garcia de Leon, Mexico City, May 2012
are not always fully extended or protected. Civil society organizations become critical actors in the negotiation of these rights; these organizations are able to work alongside and, at times, apart from the government, in the establishment of mechanisms that will provide citizens with better access to the exercise of these rights.

Despite the disparities between the actual right to health and the inclusiveness and effectiveness of the systems created to ensure this right, beginning in the 1980s, civil society organizations demanded coherent action from the Mexican government with respect to HIV/AIDS treatment. Demands ranged from procuring pharmaceutical treatments to setting aside funds for treatment programs to curbing stigma and discrimination of HIV-positive patients seeking care. Initially, some organizations also operated their own medicine banks, with donations from foreign NGOs or with assistance from civil society groups in Mexico City. When CONASIDA (now CENSIDA) was created in the late 1980s, it served as a coordinating body for direct medical treatment and medicine procurement (Saavedra 2000). Through much of the 1980s and early 1990s, treatment options were limited; however, in the mid-1990s, global solidarity around demands for access to treatment and the documented success of highly active anti-retroviral therapy (HAART) in significantly improving the life expectancy of HIV/AIDS patients created new sources of hope and support for civil society organizations in Mexico. In 1994, specifically, signatories to the Paris Declaration

A recurring theme in conversations about HIV/AIDS governance in Mexico revolves around the role of CENSIDA. Some proponents want the council to remain the national body dealing with research, disease tracking, prevention, and treatment. Others want to limit the scope of CENSIDA’s work to coordinating medicine procurement and distribution throughout the country (interview, anonymous external aid worker, December 2012).

“La politización del acceso a los ARV, si bien ha presionado para que toma dores de decisiones, sobre todo en la seguridad social, aceleren la incorporación de los mismos dentro de los catálogos de medicamentos susceptibles de prescripción, esto no ha repercutido de igual manera en el acceso a otros mecanismos que harían que una política de acceso a ARV fuese optima” (Saavedra 154).
prioritized the participation of people living with HIV/AIDS (PLWHA) in the policy decisions that most affect them, creating a new role for organizations representing this population to further negotiate the right to health (CNDH 2008: 24).

In 1995, the first national meeting of people living with HIV/AIDS (PLWHA) was held in Mexico City. As a result of this meeting, FRENPAVIH (Frente Nacional de Personas con VIH, National Front of People Living with HIV/AIDS) was established. FRENPAVIH, a national umbrella network, was initially created with the intent of mediating between people living with the disease, HIV/AIDS-focused civil society organizations and government agencies responsible for developing and implementing AIDS-related policies. Almost immediately after it was created, this organization began pressing for access to treatment with agencies within the federal government, including the Ministry of Health, particularly focusing on the populations that were not already covered by the social security programs. In November of 1996, FRENPAVIH took the lead among a number of civil society organizations in a meeting with the Minister of Health. At this meeting, the Minister of Health presented a plan, developed with assistance from the Universidad Nacional Autónoma de México (UNAM) for increasing access to medicines through the creation of an AIDS drug fund, FONSIDA (UNAIDS 1998; Saavedra 2000).

While negotiations with the Ministry of Health resulted in the creation of FONSIDA, this did not result directly in a sufficient supply of AIDS medication in Mexico. Upon FONSIDA’s creation in 1997, CENSIDA announced it would provide treatment for approximately five thousand people, including men, women and children, aiming to increase that number by 2,500 annually; however, when faced with the true
cost of providing antiretroviral medication to this number of patients, the federal government quickly amended the program to only provide treatment to children, extending services to pregnant women months later (Saavedra 2000). These kinds of policy decisions, focusing on specific populations, create an environment in which different categories of people can exercise rights in different ways (see Chapter 5 of this volume for a further discussion of the interaction between policy target populations and the effectiveness of civil society organizations.)

When faced with a lack of supply, FRENPAVIH coordinated protests and other direct actions. FRENPAVIH members and supporters donned white masks, maintaining their anonymity while shedding light on the issue of HIV/AIDS in Mexico (Brito 1999). One event in particular resulted in a negotiation with the Social Security Administration for a more regular supply of medicines and the inclusion of protease inhibitors into the basic medicine supply (UNAIDS 1998). At this protest, FRENPAVIH coordinated a demonstration of over one thousand people in one of the busiest intersections in Mexico City, shutting down traffic in front of the Social Security Administration. As a result of this protest, the Social Security Administration agreed to devise an alternative financing strategy to move towards universal access to AIDS medications (Saavedra 2000: 144).

While FRENPAVIH successfully negotiated the means to expanded access to treatment through FONSIDA, the Social Security Institute continued to make many medications, including protease inhibitors, available only to patients in the most advanced stages of the disease (UNAIDS 1998). While FRENPAVIH continued to pressure state agencies to provide medicines universally, we can see how pressure from civil society organizations helped shape the government’s policy agenda, in that new programs, even if
unsuccesful, were designed and implemented to create avenues for access to essential medicines.

The outcome of the negotiations between FRENPAVIH and the Ministry of Health was the creation of a national health fund for HIV/AIDS, FONSIDA (Fondos Nacionales para SIDA). Private sector donations created the bulk of funds in FONSIDA (Brito 1999). Much like earlier efforts to expand access to medication, FONSIDA was unable to meet the needs of the population. Created in 1998, it only lasted until 2000. In those two short years, it was intended to be a coordinating entity that purchased medication for populations that could not afford them. FONSIDA fell under heavy criticism when it was unable to fulfill this mandate. Besides the serious budgetary issues that plagued FONSIDA, there were accusations that women and children were the only people with access to medications through the fund (Brito 1999). One civil society leader argued that the program was not there to provide medicine to anyone that needed it without bias; rather, “they [saw] this illness as an opportunity to choose the buenos for medicine” and ignore the rest. According to government officials, the fund was created to gradually bring antiretroviral treatment to the population, focusing initially on pregnant women and children (Saavedra 2000). FONSIDA expanded to fourteen states in 1998 through the pilot program (Saavedra 2000), but remains a failed governmental attempt to make the right to health a reality for many living with HIV/AIDS.

According to Barnes (2010), FONSIDA folded because it was so grossly underfunded. FONSIDA is a prime example of how civil society organizations negotiated

---

86 In earlier years of the epidemic, Mexico financed its programs primarily through external aid and private donations. Finance mechanisms shifted and the vast majority of international aid programs related to HIV/AIDS ended in Mexico (e.g., USAID largely ended its program in 2013 and the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria did not renew its Round 9 grant with Mexico in 2012).

87 Skype Interview with Maria Elena, May 2012.
with the state to create a new institution meant to provide access for the most vulnerable populations to exercise their constitutional rights, in this case, the right to health.

However, despite this success in both directing the policy agenda and creating a new institutional mechanism, the federal government did not furnish this new institution with the capacity to fully extend the right to medication to all those in need. The federal government expanded its policy while it was unable to fully fund this unsuccessful project.

Apart from organizing public action and negotiating with the Ministry of Health, FRENPAVIH has also become a leader among civil society organizations in Mexico. For example, in 2003, FRENPAVIH, along with CENSIDA, organized a series of trainings in HIV treatment and adherence. Through CAI global, FRENPAVIH and CENSIDA developed their own joint program to provide capacity training to medical professionals and others that deliver services as a means to improve and increase access to medicine and treatment. FRENPAVIH’s work as a leader among organizations is obvious, not only in organizing this training, but throughout its other efforts to negotiate better treatment for patients. As HIV-positive patient adherence to medical protocols remains a challenge in Mexico, there is still work to be done.  

Within the work of FRENPAVIH, in 1997, a subgroup of the organization, called Procolarios, attempted to use the legal system to ensure the right to health and access to medications for the HIV-positive population in Mexico. They filed an ámparo suit against the federal government, primarily CONASIDA and the Social Security Administration (SSA). The ámparo argued that a violation of the fourth article of the

---

88 Interview with Dr. Andrea Gonzalez, Director of the AIDS Program of Mexico City, Mexico City, May 2012
Mexican constitution guaranteeing the right to health occurred when free antiretroviral medications were not made available to all HIV-positive patients (Saavedra 143). This ámparo was an unsuccessful attempt to hold the federal government accountable for the protection of health, and to further define the parameters of this right. However, it represents a key moment in which a civil society organization directly engaged the government by making a rights-based claim. CNDH indicates that an individual’s right to health must be protected because it is a right that permits the free exercise of subsequent rights (2009). Given the lack of success within the judicial system, the repertoire of strategies available to civil society organizations remains limited in responding legally to the lack of access within the public health care system. However, in light of the 2011 reforms, both the reform to the ámparo process and the adoption of HRA 2011 discussed above, the opportunity structures may currently be shifting in favor of rights-based legal claims on behalf of HIV-positive Mexicans.

The struggle over universal access reached a critical juncture in 2003, with Seguro Popular, the comprehensive health system reform. This reform, initiated by key actors within government, including Minister of Health Julio Frenk and CENSIDA Director Jorge Saavedra, created Seguro Popular, a health insurance program for Mexican citizens left out of the already existing social security programs, most often through lack of traditional employment. Through a tripartite finance mechanism,

---

89 The Mexican Supreme Court has heard two major cases on HIV/AIDS discrimination between 2007 and 2013. In 2007, the Court ruled a portion of the Social Security Institute Law for the Armed Forces unconstitutional. This section required HIV-positive soldiers to be discharged because they would no longer be fit for duty. In ruling this unconstitutional, the Court inherently made a statement against discrimination within state institutions. In another case heard in 2013, the Court rejected a discrimination case in which an HIV-positive individual was released from employment in the private sector because of his HIV status. While the court was split on this decision, the majority ruling against the individual offered little comment on their decision. As of the writing of this dissertation, no ámparo cases regarding access to treatment or medication have been successful within the Mexican legal system.
individuals and families could enroll in Seguro Popular, and receive access to a number of standard primary care services. A select number of diseases and health crises considered to pose an overwhelming burden on individual families, and on the health care system as a whole, were included in a separate payment structure, El Fondo de Gastos Catastróficos (The Fund for Catastrophic Expenses). HIV/AIDS was included in this program, and as a result, patients testing positive for the disease had access to treatment through this program. Universal access, thus, was a small piece of this large-scale overhaul.

External observers to the process and Mexican civil society actors themselves viewed the inclusion of HIV/AIDS into El Fondo de Gastos Catastróficos as a key victory for civil society groups after years of advocacy and attempts to shape the national policy agenda. Civil society organizations spent years advocating and pressuring for the universal access to treatment. This pressure played a large part in keeping access issues on the public agenda, and pushing through this legislative reform that sought to ensure the constitutional right to health for all. However, the Seguro Popular reform would not have been possible without key policy champions within government. In the post-2003 environment, many civil society organizations reported feeling exhausted by their struggle, and like they had achieved their objective of universal access. Despite an arguably diminished pace of action, with the reform in place, civil society organizations soon realized the need to shift their attention from advocating for universal access to essential medicines to monitoring the breadth of its implementation, or vigilancia ciudadana. Some participants in this study felt that monitoring the program was challenging because organizations that received funds from the government could not
adequately provide independent critiques of the program, while other organizations, like DVVIMSS used more savvy and strategic mechanisms, like the *Ley de Aceso a la Información*, to evaluate the extent this right exists in practice.

Among the organizations that regularly perform *vigilancia ciudadana*, one of the most active is *Derechohabientes Viviendo con VIH del IMSS* (Rightful Claimants of IMSS Living with HIV/AIDS, or DVVIMSS). This organization’s use of a human rights framing is evident right in their name. DVVIMSS advocates for HIV-positive users of IMSS, holding individual actors accountable, providing critiques of the system at large and using largely official government channels for redress. The degree of professionalization and the extent to which every act the organization makes is based on a clear strategy is evident in that the founder of the organization, Luis Adrian Quiroz, intentionally did not register as an *Asociación Civil* (A.C., civic association) to maintain the organization’s autonomy and ability to “confront and monitor government action.”

Many in Mexico point out the difficulties presented when civil society organizations register with and receive funds from the government to carry out programs. Some argue that it becomes much more difficult to monitor and critique government actions when an organization is receiving money from the government. According to Ricardo Roman of Population Services International/Mexico, “NGOs should be monitoring the government. But, when they get their money from the government how can they do this? They lose their sense of *vigilancia ciudadana*.” However, in order to be able to both “confront and monitor the government” and participate in *consejos* and receive government

---

90 Interview with Carlos Garcia de Leon, Mexico City, June 2012
91 Interview with Luis Adrian Quiroz, Mexico City, May 2012.
92 Interviews with Carlos Garcia de Leon, Mexico City, June 2012; Ricardo Roman, Mexico City, May 2012; Victor Dante, Mexico City, June 2012.
93 Interview with Ricardo Roman, Mexico City, May 2012.
funding, Luis Adrian created a second organization, *Justicia, Derechos y Salud*, (Justice, Rights, and Health) that is registered as an A.C. As part of *Justicia, Derechos y Salud*, Quiroz was named a *vocalis* of CENSIDA in 2013. Again, the organizational focus on the human rights framework is present in the group’s name: Justice, Rights and Health.

In describing why *vigilancia ciudadana* is a critical component of any post-2003 strategy for civil society actors, Quiroz argued, “The process of actually achieving universal access is a problem. There is such a bureaucracy behind medicine provision, that even if one person breaks the chain, the patient will not receive his treatment. The government provides universal access, but does not monitor the availability of the treatment.”

According to Quiroz, at the moment the government purchases HIV/AIDS medicine, it has complied with the universal access policy. In this instance, universal *access* must be differentiated from universal *availability*, particularly as the WHO, discussed earlier, distinguishes between cost issues and availability measures in its definition of equitable access as part of the human right to health. As part of its work, DVVIMSS uses the relatively new mechanisms established in the 2002 *Ley Federal de Transparencia y Acceso a la Informacion Publica Gubernamental* (Federal Transparency and Access to Public Governmental Information Law) to determine which hospitals and clinics are not providing the appropriate services, are denying particular services or in which institutes patients experience discrimination based on their disease status. The organization is also able to trace the government’s purchasing of HIV/AIDS medications, evaluating the extent to which they actually purchase the amount and kinds of drugs they report. In addition to the overall monitoring of access and availability within the public health care system, Quiroz collaborated on the creation of a guide to patient care for

94 Interview, Luis Adrian Quiroz, Mexico City, May 2012.
individuals with HIV/AIDS. DVVIMSS’ strategies clearly reflect commitment to the human rights framework, and are shaped by the existing, and newly created, institutions guiding state-society engagement in Mexico.

Further, DVVIMSS works with CONAPRED (Consejo Nacional para Prevenir la Discriminación, National Council for the Prevention of Discrimination) to help HIV-positive patients who experience discrimination seek redress through mediation processes. CONAPRED has two separate processes for redress: one provides mediation services among private individuals, while the other provides mediation services between individuals and private entities, like businesses. Many times, discrimination incidents, including breaches of confidentiality, become issues brought to CONAPRED. In an interview with several CONAPRED representatives, when asked if they work with any specific civil society organizations on discrimination in access issues, they indicated without hesitation that they work largely with Luis Adrian Quiroz of DVVIMSS. This points to the fact that individuals remain important to successful state-civil society relationships, and that DVVIMSS, under the stewardship of Quiroz, is one of the more successful and professional organizations, recognized and respected by national agencies. From the work in which DVVIMSS engages, it is clear that within the context of universal access and in performing vigilancia ciudadana, organizations must engage with the government, whether through collaboration, critique or in using established mechanisms to gain information.

---

95 CONAPRED is not a government agency; rather, it was a commission established by the government. The government does retain some budgetary discretion and the ability to approve personnel. While there is interaction between CONAPRED and the government, CONAPRED makes, what many consider, relatively independent decisions and recommendations.
It is important to note that though many study participants found it challenging to monitor government programs because they also received funding from the government, Quiroz remains one of the most vocal critics of the Mexican HIV/AIDS program. Both of these organizations, DVVIMSS and Justicia, Derechos y Salud participate in CENSIDA’s Human Rights Committee and Justicia, Derechos y Salud has received financing for prevention programs through CENSIDA’s competitive funding process. Quiroz does not hesitate to criticize government programs, despite this regular and consistent engagement. For example, in December 2012, Quiroz published an editorial in Salud, Sexualidad y Sida (Health, Sexuality and AIDS), a regular supplement in La Jornada, a Mexico City newspaper with national readership. In this editorial, Quiroz argues “CENSIDA se convertió en los últimos años en un monstruo burocrático, que buscó perpetuar el poder de quienes lo dirigen” (In the last few years, CENSIDA has become a bureaucratic monster that only seeks to perpetuate the power of those that run it).

In addition to FRENPAVIH and DVVIMSS, another organization that works on behalf of the HIV-positive population that has remained active in universal access issues is Red Mexicana de Personas que Viven con VIH/SIDA, or simply Red, (Mexican Network of People Living with HIV/AIDS.) The Red works on many issues on behalf of those living with HIV/AIDS; however, according to their own materials, one of their primary focuses is to “vigilar y documentar las violaciones de Derechos Humanos” (to monitor and document human rights violations) for people living with HIV/AIDS. While this is a broad mandate, and the Red performs monitoring functions at various stages,
including problems with testing and confidentiality, one of its principal concerns lies in access to treatment.

In their pamphlet, titled “Human Rights and HIV,” the Red lists various incidents they classify as human rights violations. Included in this list, among many items, is failing to administer or provide medicine, failing to provide medical attention to those living with HIV/AIDS, and unjustly isolating individuals living with HIV/AIDS in hospitals because of their condition. The Red regularly works with patients to ensure access to services, and connects individuals whose rights have been violated to the Comisión Nacional de Derechos Humanos (CNDH). A key component of this kind of citizen vigilance strategy, also practiced by DVVIMSS, is to trace systematic violations of universal access in Mexico’s public health system. Systematic abuses can be dealt with through CNDH, and CNDH can direct recommendations about the treatment of patients towards government entities. Mistreatment and rights violations that occur either on a person-to-person basis, or in a private setting (i.e., within a private company), when reported, are generally taken to CONAPRED for mediation. By monitoring access issues, and using existing national institutions 96 to hold public health officials accountable, the aforementioned civil society organizations work within the existing system to address issues of universal access. Despite the efforts of these organizations, universal access remains a key challenge to HIV/AIDS policy. In noting the severity of access problems, and the complexity of this policy area, Dr. Andrea Gonzalez, director of the government’s AIDS program in Mexico City, argued, “There was a big fight on behalf of civil society for universal access, and they won. But now the medicines are so expensive

96 Both CONAPRED and CNDH are national institutions; however, they are not government institutions. They were created by the government, and the legislative body has some degree of oversight, particularly in its ability to approve the director of CNDH.
…The primary problem [of Mexico’s HIV/AIDS epidemic] is purchasing medicine. The financing of AIDS medications is unsustainable. “Unfortunately, while civil society organizations can systematically monitor universal access and record violations of patients’ rights, they are unable to directly address the cost of AIDS medications, beyond aiming statements and complaints at the national government. Trade policy and the purchasing of pharmaceuticals remain strictly governmental prerogatives.

The 2008 International AIDS Conference brought together many of these organizations and provided them the space and opportunity to address the lack of universal access. For some, like Padre Oscar from Caritas Mexicanas, a Catholic AIDS relief organization, the issue of universal access defined the 2008 Conference. Given that Mexico, at this time, did not allow generic medications entrance into their market, the cost of HIV/AIDS treatment was one of the highest in the developing world. The outcry resulted in government promises to negotiate lower prices, and the creation of the Juntos por la Salud (Together for Health) program that brought civil society organizations and government actors together to work on access issues, particularly with respect to “difficult cases” involving drug resistance. During the summer of 2012, many civil society organizations, including DVVIMSS, noted that such minimal efforts were made that no real results came about and drug prices remained too high. Despite this critique, in one of his last efforts as Director of CENSIDA, Jorge Saavedra did negotiate directly with pharmaceutical companies, like Gilead, in 2008 in an attempt to lower costs (Kenslea 2008). In 2012, now former director of CENSIDA José Antonio Izazola noted

97 Interview, Mexico City, May 2012.
98 Interview with Padre Oscar, Mexico City, May 2012.
99 Interviews with: Jorge Saavedra, Mexico City, May 2012; Jose Antonio Izazola, Mexico City, May 2012; Enrique Hernandez, Mexico City, June 2012; Dr. Andrea Gonzalez, Mexico City, May 2012.
100 Interview with Luis Adrian Quiroz, Mexico City, May 2012.
that generic medications were still not allowed to be purchased in Mexico and the prices remain an incredible burden on the public health system.

There remain access issues, beyond stigma and discrimination. For example, a coordinator of the youth home for Casa de la Sal reported that the government does, indeed, cover the expenses of antiretroviral medicine for the HIV-positive youth housed there. However, all other medications, including those that the children now must take because of the side effects of the antiretroviral medication must be purchased independently by the organization. This creates a significant burden on the organization, as it represents a burdensome financial commitment. Nevertheless, the children at Casa de la Sal continue to maintain nearly universal adherence to their regimens. ¹⁰¹

Another major challenge for civil society organizations working on universal access is the fact that many organizations must work at both the national and local levels. While the Seguro Popular reform created new national programs with which states needed to comply, the degree of compliance and how extensive or limited universal access is practiced within states varies. While a systematic analysis of state-level HIV/AIDS policy is outside the scope of this dissertation, Jalisco provides a brief and interesting example of how state-level policies can create barriers. It is important to note that Jalisco is one of the few states that established its own, very small fund to provide financing to civil society organizations operating within the HIV/AIDS area. In 2006, the state government extended universal access to antiretroviral medication to include access to HIV/AIDS prevention services as well. ¹⁰² In this case, the state chose to extend universal access to include virtually all aspects of HIV/AIDS prevention and treatment, in

¹⁰¹ Interview with Arelia, Mexico City, May 2012.
¹⁰² Interview with Victor Dante, Mexico City, May 2012.
part through contracts with civil society organizations. Despite the expansion of this right, reality of access on the ground falls far from the codified ideal. Victor Dante, a civil society leader working in HIV/AIDS since 1989 and an integral part of the organization Comité Humanitario de Esfuerzo Compartido Contra el SIDA (Humanitarian Committee for a Shared Effort Against AIDS, CHECCOS), argues that “yes, there is access to antiretroviral medicines. Of course, there are absences within IMSS, but we have medicine. The rest of universal access doesn’t really exist [in Jalisco.] Atención integral is lacking, many patients will not get regular medical check-ups but will continue to receive their free medication.”¹⁰³ For organizations like CHECCOS, that operate at the state level but also must focus energies on national policy, the divide between what is guaranteed by the government and how these guarantees are implemented at both the national and local levels creates further obstacles for negotiating the state-society relationship. CHECCOS maintains a close relationship with Clínica Condesa, often utilizing office and meeting space there, attending trainings and networking with both government officials and other organizations through its relationship to the clinic. These efforts take time, staff and money, all of which remain scarce commodities.

This section outlined the many ways in which the ability to access HIV/AIDS medication is viewed by civil society organizations, and by many members of the government, as a fundamental exercise of human rights. The challenges to access are many, including: pervasive stigma and discrimination in public health institutions, lack of knowledge and a sense of political efficacy among patients and the overly burdensome cost of care. While civil society organizations worked tirelessly to achieve universal

¹⁰³ Interview, Mexico City, May 2012.
access to medicine, their work is far from over. They continue to monitor the right to access in a systematic manner, reporting violations and following them through the proper channels. Civil society organizations have the ability to educate the public about their rights, to monitor access and to develop guidelines and standards for treatment that they can then use to evaluate health access. All of these efforts require working within the system established by the government: they must educate the public about rights they are actually afforded by the government; they can monitor access and bring grievances to the appropriate authorities, but they cannot simply create their own universal access program, separate from the government; finally, they can develop their own standards to evaluate public health access, but they do not have the resources or capacity to fully replace Mexico’s public health system, even if only for the HIV-positive population. Though civil society organizations were successful in shaping the policy agenda, finding key policy champions in government that pushed universal access forward, they are constrained in that this particular aspect of HIV/AIDS requires government action. The organizations that are most active on issues of access and those that have the most interaction with the government on this issue rely human rights-based claims.

The Right to Education

While the cost of treatment was a fundamental issue at the 2008 conference, there were also high-level discussions around adolescent HIV/AIDS prevention in Latin America. This meeting, the first of its kind involving education and health ministers from countries throughout Latin America and the Caribbean, culminated in a Ministerial Declaration supporting comprehensive sex education programs in primary and secondary school settings throughout the region. Mexico’s Secretary of Education, Josefina Mota, was a signatory to the declaration, indicating support for comprehensive sex education in
Mexico. Heralded as a giant step forward by civil society organizations in Mexico, funding for the program was scarce and a shift to comprehensive sex education throughout Mexico has yet to be fully realized.

The right to education, and the further right to comprehensive sexual and reproductive education that came out of the 2008 Ministerial Declaration, serves as a case in which the Mexican government responded to both domestic civil society and international pressures to commit to extending a particular right to the polity. The 2008 Ministerial Declaration encapsulated the position on sex education of much of Mexico’s HIV-focused civil society organizations and became “the face of Mexico in the international community.”104 Beyond this, it reflected the government’s public commitment to the human rights framework: the international community established that access to relevant information was an integral part of the human right to health in the UN’s General Comment on the International Covenant on Economic, Social and Cultural Rights. Further, the Mexican government guarantees the right to education for all in Article 3 of the Constitution. Again, the interaction of Mexico’s international obligations and its national rights framework support the development and implementation of comprehensive sex education in Mexico.

In order to examine the extent to which civil society organizations and the state negotiate the right to education, more specifically comprehensive sex education aimed at increasing citizens’ knowledge about HIV/AIDS, this section first examines early governmental efforts at public prevention information campaigns, and the resulting conservative backlash from particular civil society organizations. It then turns to an analysis of two civil society organizations that have implemented programs aimed at

---

104 Interview with Gabriela Rodriguez, Mexico City, May 2012.
moving Mexico’s education system towards greater inclusion of sex education in the curriculum. It becomes clear that, in the negotiation of the right to sex education, international finance mechanisms and the ability to create educational support programs outside of the purview of the government create different opportunity structures for civil society organizations working in this area, as compared to those working on issues of access to essential medicines.

Prior to the HIV/AIDS epidemic, Mexican public schools incorporated various elements of sex education, including themes of puberty, reproduction, family planning and sexuality transmitted infections at the secondary level (Rodriguez 2009:1). In addition to the public HIV/AIDS prevention campaigns discussed below, when the epidemic came to Mexico, prevention education was incorporated into both primary and secondary education curricula. Comprehensive sex education was viewed by the Fox administration (2000-2006) as a scientifically legitimate means of reducing teenage pregnancy and the spread of sexually transmitted diseases, including HIV/AIDS. While there is a history of sex education in Mexico, full-scale implementation of comprehensive sex education was far from complete by the time the 2008 declaration was signed. In particular, individuals of lower socioeconomic status, and those living in rural areas, often did not have access to comprehensive sex education to the same extent that other populations do.

Before comprehensive sex education became a key element of public debate, the federal government initiated a series of controversial public HIV/AIDS prevention campaigns. Beginning in the late 1980s, the federal government responded with these prevention campaigns that aimed to increase the citizenry’s knowledge about the disease.
and encourage a shift in private behaviors, largely towards safer sex practices. The campaigns, beginning in 1987, emphasized abstinence as the best way to prevent the spread of disease, but also promoted condom use as the next best alternative (Sepúlveda 1992). These initial campaigns were broadcast on television and on the radio throughout Mexico and marked the first time that the Mexican government used the word condom, and promoted their use, through the mass media (Sepúlveda 1992). The Mexican government evaluated the effectiveness of these campaigns, conducting pre-and post-surveys with a representative sample. In three main areas of interest, there were significant improvements in knowledge or attitudes after the campaign. According to Jaime Sepúlveda (1992), individuals’ level of knowledge about AIDS increased, condom use increased (though use varied by population, age and level of education), and attitudes towards people with AIDS improved.

One of the most important outcomes of these early public prevention campaigns was the emphasis on scientific knowledge in delivering prevention information. Further, the campaigns focused on HIV/AIDS as a public health problem; a problem over which individuals had some level of control. One ad in particular included the tagline “AIDS is not a moral problem, it is a public health problem of greatest importance” (Sepúlveda 1992: 138). In this ad, it was clear the government intended to promote condom use, alongside abstinence, from the public health perspective and did not intend to engage in normative debates about the moral nature of prophylactics.

While the government may not have wanted to engage in such a debate, it did not deter backlash against the prevention campaigns from more conservative civil society organizations. After much controversy and through much frustration, the government
shifted their campaigns towards more ambiguous language, including phrases like “Get more information” in campaigns, directing people to the national AIDS hotline, rather than openly advocating for condom use. When a new administration took office in 1989, CONASIDA hosted a public consultation with a large and diverse group of civil society organizations with the aim of evaluating past programs and gaining insight into how the consejo should move forward. The consultation focused specifically on the following issues: sex education in schools, discrimination and human rights, and the roles of government and media in HIV/AIDS prevention (Sepúlveda 1992: 138). While the consultation included groups representing the full left-right political spectrum, according to Sepúlveda, an overwhelming presence of left-oriented organizations heavily shaped the resulting recommendations, which included the following resolutions: “1.) AIDS is a public health issue, not a moral one; 2.) Information should be explicit; [and] 3.) Non-governmental organizations must assume a more active role” (138).

As a result of this forum, the Secretary of Health again used the media to initiate an HIV prevention campaign. These campaigns maintained the somewhat ambiguous strategy of the pre-consultation campaigns, including actors posing as a variety of potentially at-risk individuals and ending in slogans such as “This is what I’m doing, and you…what are you doing?” (Sepúlveda 1993: 139). At the same time that these toned-down, opposition-accepted campaigns were designed and implemented by the Ministry of Health, CONSIDA, under the directorship of Jaime Sepúlveda, initiated a much more aggressive campaign to be implemented in Mexico City’s metro system. The CONASIDA campaign included specific and direct messages, including the idea that “information is the best weapon against AIDS;” further, the campaigns specifically
targeted women, advocating that they initiate condom use with their partners to stem the rising tide of AIDS in Mexico (Sepúlveda 1992: 139). In contrast to the ambiguity of the Ministry’s campaign, CONASIDA’s campaign, consisting of nearly two dozen different posters based on popular Mexican lottery games and two television spots, delivered a consistent and clear message: “AIDS is not a matter of luck, but of life or death” (Sepúlveda 1992: 139).

CONASIDA’s more aggressive Mexico City-based campaign came under fire from conservative civil society groups, culminating in a late 1989 lawsuit. The organization *Pro-Vida* (Pro-Life,) accused CONASIDA of promoting promiscuity through its condom campaign, and failing to protect the morality of Mexico’s citizens. The case did not go any further, as officials determined a crime was not committed (Sepúlveda 1992: 127), but nevertheless, the issue of condom promotion, and by extension comprehensive sex education, remains controversial. Some have argued that the federal government fears the power of the Catholic Church in Mexico, responding by cutting condom promotion and sex education programs aimed at adolescents (“Mexico, Treatment of Homosexuals” 1998). The contentious nature of this issue remains a challenge for civil society organizations advocating for comprehensive sex education.

The civil society organizations under analysis in this dissertation can be divided roughly into two categories with respect to sex education: there are organizations that focus on the expansion of comprehensive sex education as part of a reproductive rights agenda, and there are organizations that work specifically in HIV/AIDS, and administer organized or ad hoc prevention education programs. Each organization under analysis provided some kind of prevention education, from very informal one-on-one
conversations to internationally financed and strategically planned education programs. This section focuses primarily on those organizations, in particular Afluentes and Democracia y Sexualidad (DEMYSEX) that maintain a broad sexual and reproductive health agenda of which HIV/AIDS is a key component, with specific sex education initiatives.

Afluentes is a registered civil society organization, founded in 1998 with assistance from the Ford Foundation. Its primary organizational mission is to produce, systematize and distribute information, knowledge and technical methodologies related to sexual and reproductive health. As part of this broad mission, Afluentes provides particular services, including the design, development and evaluation of sex education activities and programs.  

Apart from Afluentes, another related group, Democracia y Sexualidad (Democracy and Sexuality, DEMYSEX), works specifically on sexual education, operating as a network of organizations dedicated to expanding and improving sex education in Mexico. DEMYSEX and Afluentes share a number of board members, including Gabriela Rodriguez, who helped co-found each organization. Rodriguez helped found DEMYSEX as a means of encouraging collaboration and cooperation among like-minded civil society organizations, noting that given the many electoral reforms, in 1998, they anticipated a conservative government was coming into power. DEMYSEX’s organizational mission is to “fortalecer la educación de la sexualidad comprometida con el ejercicio y defensa de los derechos sexuales y la equidad de género para avanzar la construcción de una cultura democrática.” That is, the inherently political purpose of the organization is to strengthen sex education as a means of enabling the exercise and

---

105 Further information on Afluentes’ mission is available at: www.afluentes.org
106 Interview with Gabriela Rodriguez, Mexico City, May 2012.
107 Further organizational information available at: www.demysex.org.mx
defense of sexual rights and gender equality to advance a democratic culture. Again, we see an organizational focus on the rhetoric of rights, and in this instance, the leveraging of these particular rights to foster a more democratic culture. While these organizations still exist as two separate groups, they share board members, a common agenda, and have received grants jointly from international sources. For the purposes of this chapter, they are discussed together.\textsuperscript{108}

Because of the nature of the HIV/AIDS epidemic, the Ministers of Health and Education committed to a number of provisions in the 2008 Ministerial Declaration. The 2008 Declaration is progressive and extensive, including both the evaluation of current sex education curricula in each country and the design and implementation of new programs that provide a comprehensive approach to sexual and reproductive health education. As it was signed by secretaries of education and health, it also includes provisions for sexual and reproductive health services, like counseling on sexually transmitted infections, drug and alcohol abuse treatment and condom promotion. The declaration goes even further to include stipulations that secretaries of health and education work with the legislative branches in their countries to ensure well-aligned policy and budget priorities to make “preventing through education” (or Prevenir con Educación) a reality; further it encourages collaboration with civil society organizations in the dissemination of accurate and relevant information (Ministerial Declaration 2008).\textsuperscript{109} Finally, the signatory countries agreed to implement policies that would reduce

\textsuperscript{108} Creating and maintaining more than one organization is a common strategy among civil society leaders in Mexico. Some, like Quiroz, use multiple organizations as a way to maintain autonomy from the government, whereby they register one organization for particular benefits, but keep one organization unregistered. Others, utilize multiple organizations as a means to maximizing the resources available through competitive funding processes.

\textsuperscript{109} In 2011, the Mexican Constitution was amended to reflect the position that international treaties and declarations that Mexico enters into carry the same legal weight as the constitution. As a result, if the
adolescents’ lack of access to sex education by seventy-five percent, and reduce adolescents’ lack of access to sexual health services by fifty percent (Rodriguez 2009, 2).

The expectation among civil society organizations was that there would be a near immediate response by the federal and state governments with respect to Prevenir con Educación. When, in 2012, comprehensive sex education programs were far from implemented, and in fact were intentionally derailed in some of the more conservative states, civil society organizations expressed frustration with the Calderón administration, blaming conservative political and religious ideologies for the lack of action. Conservatism, in both politics and society, did account for some of the reticence to implement comprehensive sex education, especially in places like Guerrero and Sinaloa where government officials destroyed textbooks with content that went beyond abstinence. However, the 2008 Declaration included a timeframe in which governments would evaluate their existing programs and “ramp-up” efforts over time. According to the Declaration, implementation of a new comprehensive sex education program was not expected to begin, in any signatory state, until 2015.

In 2009, the United Nations reported on follow up regional meetings that took place one year after the Ministerial Declaration was signed. The United Nations Children’s Fund, UNICEF, reported that the Secretaries of Health and Education of Mexico received the support of other regional experts to develop several technical instruments for education related to sexuality, sexual and reproductive health, and HIV/AIDS. This support aligned more specifically with developing the capacity to educate individuals working in the health sector, but also extended to adolescent and

---

Mexican government signs an international agreement on a particular policy issue, it is then responsible for developing the policy and regulations to fully implement the program.
youth education (UNICEF 2009). The report includes a reminder that countries should be working towards the goals outlined in the Ministerial Declaration, but makes no specific mention of the steps Mexico took towards its implementation beyond the vague references to receiving technical support from other regional experts.

Organizations, like Afluentes, expressed concern, not only that the government had not implemented comprehensive sex education programs, but also that it was not taking the appropriate steps to address capacity issues on the part of educators. In a 2012 interview, Rodriguez spoke with frustration that the government was not upholding the 2008 Declaration in Mexico, yet noted that because the government signed the declaration, Afluentes and other civil society organizations are able to work on this issue. Because “government is obligated to this declaration,” organizations can hold the government accountable. Rodriguez further argued that now, unlike in years prior, organizations can point to a declaration signed or statement made by the government and question why actions have not been taken. In previous political environments, according to Rodriguez, organizations experienced much more difficulty in holding government accountable, particularly with respect to issues of sexual and reproductive health rights. This ‘new’ environment might be because of the tireless efforts of civil society groups in the late 1990s to push for political reform. It could be because of the Fox administration’s (2000-2006) efforts made to increase transparency and accountability in government. Further, it could be, as Rodriguez suggests, that the “culture of rights in Mexico is new. The theme of human rights was not covered in schools until 1997. It was only in 1997 that the topic of human rights entered the curriculum in Mexico.”

110 Interview with Gabriela Rodriguez, Mexico City, May 2012.
111 Interview, Mexico City, May 2012.
Ministerial Declaration provides a key example of the power of rights rhetoric in Mexico, particularly in holding government officials accountable for program implementation.

A key issue, according to Rodriguez and other sex education-focused organizations, lies in an overall lack of capacity. According to Afluentes, although Mexico changed the curriculum in 1997 to reflect a new culture of rights, the government did not invest resources in training or educating the teachers so that they would be informed enough to teach the new curriculum. Rodriguez argues, “Teachers don’t know what human rights are. They don’t know what the international declaration is, or what obligation they have in the process.” In response to this lack of training, or an overall lack of capacity in dealing with issues of sexual and reproductive health rights, Afluentes created an educator training program to provide information to teachers on sexual rights. Funded generously by the MacArthur Foundation, it started with a pilot program in Mexico City that eventually reached three hundred teachers in the capital. The diploma program offered 150 hours of training on different issues related to sexual and reproductive health and rights, including ten hours of required study per week for a total of twelve weeks. One of the important things that Afluentes did when designing the program was to make sure it would be flexible and tailored specifically to their population of teachers.

Given the success of the pilot program, Afluentes designed and implemented a virtual training program for teachers in select rural areas which began in August 2012.

---

112 In this instance, Rodriguez referred to the 1989 Convention on the Rights of the Child. This convention required the Mexican government, as a signatory, to educate the population about the human rights of children, and brought about the 1997 curricular changes to fulfill this obligation.

113 Interview, Mexico City, May 2012.

114 According to Afluentes, many teachers in Mexico work multiple jobs because the salary is so low. This is especially true in rural areas where teachers earn only about 8,000 pesos per month (approximately US$638). Because of this, there is very little time for teachers to attend additional, often times optional, trainings, and limited incentive for the government to invest more money in providing such trainings.
Rodriguez noted that there are nearly five hundred centers nation-wide that provide teachers with all technology, including computers and satellites. These centers, alongside the fact that many people have computers in their homes, provided sufficient technology for Afluentes to prepare a fully online program. With similar programming and time requirements, teachers in rural communities were provided with the capacity to teach students in primary and secondary schools about sexual and reproductive health and rights. In addition, Rodriguez argues, teachers were able to gain comfort in using technology and learning that the Internet can be a valid instrument for teaching. Technology has become a key component of Afluentes’ programs of sexual and reproductive health.

Another critical piece of Afluentes’ response to what they viewed as a lack of capacity in the education sector is the idea that HIV/AIDS as a disease in Mexico is defined by the right to information. When asked to define the problem of HIV in Mexico, Rodriguez offered, “HIV is a problem of human rights, especially the rights of and to information. HIV is a disease, it is preventable and it can be treated. People should know to use condoms, always not sometimes, and to have fewer sexual partners. HIV is about the right to education; it is about the right to know your rights.”115 This echoes the thoughts shared by many civil society organizations in this study, including Luis Adrian of DVVIMSS, arguing that many patients, when denied medicine or medical services, do not know what rights they have, how to exercise those rights, or when and how to deal with a violation of their rights. The importance of information is evident in the many examples provided of the government’s HIV/AIDS prevention campaigns; the struggle over how much information to provide, and how explicit to be in providing that

115 Interview, Mexico City, May 2012.
information, is a driving tension that dictates how civil society groups interact with and respond to the government.

While organizations performing citizen vigilance of universal access were in a position to work nearly exclusively within the governmental system, organizations such as Afluentes and DEMYSEX were able to work with and outside the current system. Afluentes sits on consultative bodies with the Ministry of Education and with CENSIDA, and they have received funds from CENSIDA to implement prevention programs. Rodriguez says of the work Afluentes does, “Our work is very political, very strategic and very clear in the political context…We do not want to replace the state on this issue; we want to do enough to influence it.”\textsuperscript{116} This statement highlights how organizations like Afluentes and DEMYSEX view their work and their place within the political system: they do not want to replace the state in the provision of much needed public services, rather they seek to influence state action through research and the development of their own programs. Afluentes was able to develop its own teacher training program, independent of any state programs, in an effort to improve sex education in select parts of Mexico. This is an example of how an organization working within the sex education issue area was able to work outside and apart from the state, with the goal of influencing state policy. Organizations working on universal access to essential medicines have less freedom to work outside the system, largely because universal access is guaranteed through Mexico’s large and complicated public health system. In both cases, however, the rhetoric of rights was a key strategy for civil society organizations, and provided a significant entry point through which to analyze how organizations negotiate their

\textsuperscript{116} Interview, Mexico City, May 2012.
relationship to the state, and the extent to which organizations were successful in engaging the state.

Conclusion

This chapter provides an analysis of two key HIV/AIDS policy areas, access to essential medicines and comprehensive sex education, with a focus on the construction and use of human rights frameworks in both areas. The first section elaborated the international and national context within which health, and access to health-related services and information, is constructed as a fundamental human right. The following two sections traced the processes of civil society engagement in policy development and implementation. On the whole, leveraging the human rights framework is a strategy used by civil society organizations in both cases discussed above; however, varying political opportunity structures shaped divergent paths for organizations. Those organizations working towards comprehensive sex education, for example, have been able to work with the government and independently of the government to develop education programs and train teachers in sex education. They have also had increased opportunities to hold the government accountable, largely by using the framework of rights to demand the government honor its international commitments. In the area of access to essential medicines, organizations have very little choice but to work directly with the government. The structured opportunities these organizations encounter revolve largely around working within existing and new systems of engagement, and leveraging the government-perpetuated notion that HIV is a human rights issue.
Chapter 6: Negotiating Space

The successful attempt to establish the first public clinic for HIV/AIDS patients in Mexico City demonstrates the nature of state-civil society negotiations over the use of space. Clínica Especializada Condesa, established in 2000, is one of the results of the press for universal access to HIV/AIDS medications in Mexico, and represents an instance in which civil society organizations’ pressure resulted in the creation of new health infrastructure. The Clinic embodies the negotiation of space, in that not only did civil society organizations negotiate with the state to establish the clinic, but they created collaborative partnerships with the local government to facilitate the daily activity of the clinic. This is an interesting example of how the state legally creates the space for civil society to operate, yet civil society can help shape that space.

In the literature, analyses of space oscillate between the creation of free spaces for emerging counter-hegemonic identity claims (e.g., Polletta 1999), and the effects of planning and spatial design on the formation and ensuing success or demise of social movement groups (e.g., Zhao 1998). While there is much variation within each of these categories, the pattern in such analyses tends to examine either the shape movements take due to physical landscapes or the effect of intellectual or ideological space on the emergence of movements. As a means of expanding how we consider space as a variable in the negotiation of state-civil society relationships, I emphasize the physicality of space in creating a site of contestation for civil society organizations, but also the symbolism of that physical space in shaping new opportunities for civil society groups to make demands, assert their rights, or challenge government policies.
The analysis that follows largely complements Lune and Oberstein’s (2001) discussion of the organizational field of HIV activism in New York City and the three types of organizations identified in his study. Lune and Oberstein (2001) categorize activist organizations based on their relationship to the government, distinguishing among direct, outsider and mediating groups. Directly embedded groups recognize the significance of state institutions and actively seek to build partnerships with the state, whereas outsider organizations still want to see changes in public policy but do so from an extra-institutional activist perspective. Mediating groups are those that operate in the space between community based organizations and state institutions, seeking to affect changes to the policy environment by shaping state-civil society interactions.

This chapter adds an analysis of the role of physical space to Lune and Oberstein’s categorization, by asking: How did the process of creating physical space for the provision of health services recreate, reify, or shift existing hierarchies within civil society organizations’ activism related to the state; and under what conditions do certain organizations shift between Lune’s categories of embeddedness? In order to accomplish such an examination, I take the creation of critical public health infrastructure as the key point of analysis. I will demonstrate in this chapter how shifting policy priorities, notably the decentralization of health care services from the federal government to local entities and the struggle for universal access, served as the driving forces for demands leading up to the creation of Clínica Condesa. Further, I extend the examination beyond the initial establishment of the Clinic in 2000 to consider how the physical space created particular state-civil society relationships and led to the inclusion and exclusion of certain kinds of
organizations over the thirteen years the clinic has served vulnerable populations in Mexico City.

The negotiation for the establishment of a clinic in Mexico City is part of the struggle over universal access to treatment for people living with HIV/AIDS. I address it as a separate element in this chapter, rather than subsuming these negotiations within the earlier discussion over rights claims, because the physical nature of health service provision is qualitatively different from the creation of legal norms and instruments. In effect, the Clinic is part of the implementation of universal access policies, and, thus, creates a different set of opportunities for state-civil society negotiation. The physicality of service provision, that there must be a location where patients receive a health service, requires a separate analysis. Regardless, we can see the local experience of the national struggles over rights, discussed in Chapter 5, in the formation and operation of Clínica Condesa. Because the Clinic falls under the jurisdiction of Mexico City, this case represents the local interpretations of policy problems and roles of civil society organizations in addressing these problems. Mexico City is exceptional in both its population size and progressive political climate. It is the most populous city in Mexico, with over 20 million inhabitants in the metropolitan area, and has the highest rate of HIV in the country. According to a June 2013 report by the Consejo Nacional para la Prevención y el Control del SIDA (CENSIDA, National Council for the Prevention and Control of AIDS), Mexico City represents 15.5 percent of HIV cases nationally. The next highest percentage of cases is in the state of México, which surrounds the northern side of Mexico City, with 10.7 percent of HIV cases nationally.
To accomplish an examination of the negotiation of space, I begin this chapter with a brief explanation of the forces behind demands for the clinic: the decentralization of health care services and the commitment to the right to universal access for HIV/AIDS patients. I follow this with an analysis of how the physical space of the clinic shaped state-civil society relationships by, not only, providing a site of contestation, but also by clearly delineating space for insider and outsider organizations. Finally, I examine more recent conflicts between government and civil society organizations, as attempts to reorganize the space of the clinic have the potential to push insider organizations to the outside.

The political climate of Mexico City is a key context for this analysis. Mexico City was the location of civil society’s “awakening” after the 1985 earthquake, when groups of concerned individuals developed into democracy promoting civil society organizations (Walker 2013). The City is politically and socially liberal, a place where the Partido de la Revolución Democrática (Party of the Democratic Revolution, PRD,) Mexico’s leftist party, has been in power since the mid-1990s. That this party is more likely than its more conservative counterparts to be open to issues affecting HIV/AIDS policy means that we should expect to see robust HIV policy interventions and less exclusionary actions in Mexico City. What I find is that, while HIV policy has become quite extensive in Mexico City, including the establishment of the first public AIDS clinic, exclusionary practices, dictated by the appropriation of space, persist.  

Decentralization of Health Care Services: Concerns Over Local Capacity and the Right to Essential Medicines

Faced with an acute financial crisis, Mexico initiated a series of decentralization efforts in the early 1980s as part of a neoliberal reform agenda. Throughout Latin
America, the International Monetary Fund (IMF) provided short-term contingency loans, hoping to stabilize national economies and offset runaway inflation. While the IMF provided cash flows in the short-term, the World Bank, in conjunction with regional development banks, focused on lending linked to longer-term structural adjustment programs (Green 2003). In line with the growing international commitment to neoliberal reform, President de la Madrid (1982-1988) pursued decentralization within key sectors, including parts of the health system. During this early effort, the decentralization process specifically targeted the state institutions that provided services for the uninsured populations (Nigenda and Ruiz 1998). This initial reform effort should have resulted in universal health coverage in Mexico, but limited institutional buy-in among the three levels of government and resistance from the union representing health workers created barriers to its full execution and limited decentralization took place between 1988 and 1994 (Nigenda and Ruiz 1998).

Most pertinent to the case under analysis here are the reform efforts that began in 1995, under President Ernesto Zedillo (1995-2000). The National Development Plan designed by the Zedillo administration contained the Health Sector Reform Program 1995-2000, focused on expanding the decentralization of health services initiated under de la Madrid (Mogollon 2000). As part of this reform program, the responsibility to create and administer HIV/AIDS programs shifted, beginning in 1997, from the federal government to the thirty-two states and Mexico City (Saavedra et al, 2000).

---

117 The Mexican health system is roughly divided into three categories: social security, public assistance, and a small percentage of private insurance. Social security covers most formally employed Mexicans through the Mexican Institute of Social Security (IMSS, Instituto Mexicano de Seguridad Social) and those employed by the government through the Institute of Security and Social Services for State Workers (ISSSTE, Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado). The government has reformed the public assistance programs numerous times in the last thirty years; however, the primary state institution governing these programs is the Ministry of Health (SSA, Secretaría de Salud) (Nigenda and Ruiz 1998; Tamez and Molina 2000).
related policy was previously created through national institutions, including CENSIDA and the Ministry of Health. With these decentralization efforts, the local infrastructure in Mexico City, and in the thirty-two states, would newly bear the responsibility for creating and implementing HIV-related policy that aligned with national priorities.

At the same time that international institutions focused economic efforts on decentralization, they also emphasized involving civil society organizations in policy discussions and implementation. International development agencies, like the United States Agency for International Development (USAID), led capacity building workshops in Mexico aimed at promoting the professionalization of civil society organizations, and their participation in the national HIV response. The international and national focus on consulting with civil society groups on issues of HIV policymaking created opportunities for organizations to exert pressure and influence over the creation of new public health infrastructure in Mexico City. In fact, at the time the 1997 decentralization efforts were underway, civil society organizations were deeply concerned over the local public health system’s ability to adequately address the key site of Mexico’s HIV epidemic. This concern was not without foundations: Mexico City was subject to the 1993 national Norma Oficial related to HIV/AIDS, but had no local legal mechanisms governing its HIV programs, and the capital city lacked any publicly run specialized attention centers providing HIV-related services. It was not until 2008 that a Council for the Prevention of HIV of the Federal District was created, and not until 2012 that Mexico City had a Law for the Prevention of and Attention to HIV/AIDS. With these key coordinating legal mechanisms missing and concern that local political will to invest in HIV-related programs was lacking, civil society organizations, in partnership with key governmental
actors in public health policy, pressed for the creation of a public center for HIV treatment (Saavedra, et al. 2000).

*The Right to Access Medicine and Clínica Especializada Condesa*

While much of the history of the struggle over universal access to HIV treatment is recounted in Chapter 5, it is prudent to briefly outline the key events and actors that led to the 2000 opening of the clinic. National movements of people living with HIV/AIDS coalesced in Mexico in 1997, with the formalization of an umbrella network of AIDS organizations, called *Frente Nacional de Personas Viviendo con VIH* (National Front of People Living with HIV or FRENPAVIH). FRENPAVIH drew from a diverse repertoire of strategies, including both direct public action and organization-government policy negotiation, aimed at increasing access to HIV medications, primarily for those not already covered by public health insurance programs. The organization participated in direct negotiations with the Ministry of Health, and, alternately, organized massive street protests in Mexico City when negotiations failed. In the end, the program established to provide medicine through these negotiations, FONSIDA, was unsuccessful.

In 1998, civil society organizations, like FRENPAVIH, urged Jorge Saavedra to assist them in pressuring the local government to establish a specialized clinic for HIV testing and treatment in Mexico City.\(^{118}\) This collaboration first allowed for medical professionals and HIV experts to meet with the local government (Saavedra, et al. 2000). In addition to local pressure from civil society organizations, USAID, through its Policy Project, provided technical support for the clinic negotiation. USAID contracted with Saavedra, a medical doctor and Harvard-educated health policy expert, to lobby the local government to open the clinic. He had resigned from his position as the Director of HIV

---

\(^{118}\) Interview with Jorge Saavedra, Mexico City, May 2012.
Prevention and Relations with Civil Society for CENSIDA (formerly, CONASIDA) in 1997. This position helps coordinate state and civil society efforts to provide information and support to people with HIV/AIDS and vulnerable populations, and allowed Saavedra to develop key relationships with leaders of civil society organizations through collaboration. He ultimately became the public liaison between civil society organizations and the local government, providing an opportunity for dialogue that might not have existed otherwise. USAID financial assistance related to HIV/AIDS programming in Mexico reached its peak the same year that negotiations for the clinic began. The fact that a foreign donor agency provided some impetus and technical support for the clinic opening speaks to the fact that the clinic represents the daily, local experience of the broader international and national policy agendas related to HIV/AIDS.

The USAID Policy Project, completed in 2006, framed HIV within a human rights context, though, according to publications contained on the Project’s website, focused more narrowly on issues of stigma and discrimination than access to health services.119 Organizations, alongside Saavedra, met with then-Mayor of Mexico City, Cuauhtémoc Cárdenas to lobby for the creation of a local HIV/AIDS program and a specialized AIDS clinic. While the local government was run by the PRD, one of the strongest leftist parties in Mexico, it had been slow in its response to HIV/AIDS (Barnes 2010). When Rosario Robles Berlanga, also a member of the PRD, took over office in 1999, she created a Committee on AIDS and was receptive to creating a specialized clinic dedicated to AIDS in Mexico City (Saavedra, et. al. 2000). The push to create a

119 The website includes the Project’s publications related to human rights across the issues of reproductive health and HIV/AIDS. None of the documents refer to health care access as a human rights issue; rather, these publications focus on mechanisms for reducing, and eventually eliminating, stigma and discrimination associated with HIV/AIDS.
specialized AIDS clinic was, therefore, both an effort to create avenues for the exercise of the right to health for HIV-positive patients, and to establish a center of attention sensitive to the needs of at-risk populations. In the eyes of many organizations, a specialized clinic would allow individuals to access stigma and discrimination-free health services for perhaps the first time since the epidemic started in 1983.

It is important to point out that Clínica Condesa, or at least the actual building that houses the clinic, was established in 1938, under then-President Lázaro Cárdenas as a public health clinic to serve Mexico City residents of lower socioeconomic status. From 1938 until 1999, the clinic provided general medical, gynecological and pediatric care. In 1999, as a result of pressure from civil society organizations, a key policy champion with technical support from USAID, and the realization that 28 percent of national AIDS cases occurred in the federal district, the clinic was re-established as a specialized HIV/AIDS clinic. It provides HIV and reproductive health services to residents of Mexico City who do not have health insurance. The fact that the physical space the clinic inhabits has historically been dedicated to serving vulnerable populations, initially economically marginalized populations, speaks to the extent that the state creates specific spaces for the provision of health services for particular populations. To a certain degree, the state has set apart space for, initially the poor, and now the poor who also are at-risk of contracting or are living with HIV.

In the case of Clínica Especializada Condesa, it was not recreated from a general clinic to a specialized clinic without struggle. The plan to shift to the HIV-focused clinic met vocal resistance from residents in the Condesa neighborhood. Knowledge about

---

120 The Condesa neighborhood is often referred to as the “Soho of Mexico City,” and was reviewed extensively by the New York Times travel section in 2010. Condesa, located in the Cuauhtémoc
AIDS was fairly limited in the early 1990s (Sepúlveda 1992), and there was evidence of only minor improvements in knowledge and attitudes about HIV through the end of the 1990s. Several activist organizations noted that Condesa residents worried that they could contract HIV by living near the clinic, and that it would bring a certain kind of client into the neighborhood. In an effort to get the local government fully on board with the creation of the Clinic, civil society organizations initiated HIV/AIDS education campaigns in the neighborhood that were later supported by the government. Some organizations went door-to-door in the neighborhood, educating community members about basic facts about HIV transmission, that people living with HIV/AIDS are afforded the same rights to health and protections as any other individual, and that the clinic was desperately needed to meet the needs of the growing HIV-positive population. Saavedra recounted that organizations were successful in persuading the local community that the clinic would be good for the neighborhood. He argued that the clinic was a success of the pressure by civil society organizations to get a space dedicated to people living with the disease, later calling it “un gran éxito, un trabajo [del gobierno] conjunto con la sociedad” (“a great success, a joint effort [of the government] with society”). Saavedra became the first director of the clinic in 2000.

Delegation, is one of the safer and higher income neighborhoods in Mexico City. Sanchez (2008) notes that residential segregation by income is on the rise in Mexico City. This means that we might expect residential concentration by income to have an effect on where clinics serving uninsured populations are located. For example, in a study evaluating the attitudes of Mexico City residents, Irigoyen-Camacho, et al. (2003) found that only 21.2 percent of respondents would continue visiting their dentist, if they knew HIV-positive patients also received dental care at the same location. Further, only 20 percent of participants would continue to seek services from a particular dentist if they found out the dentist was HIV-positive. This study represents the attitudes about the disease, and knowledge about how the disease spreads in Mexico City. In a 2012 interview, Arelia, a nurse who works with HIV-positive children in Mexico City, explained that people would move away from or refuse to sit near her on buses if she was coming from her workplace. Interview, Mexico City, May 2012.
The actual opening of the clinic, a space dedicated to HIV/AIDS, is an indication of the local government’s commitment to protecting the rights of people with HIV/AIDS. By creating a space, set apart from other health issues and patients, the government validated the claims of civil society organizations that HIV testing and treatment needed to become a priority in Mexico City, as municipalities became increasingly responsible for the design and implementation of HIV programs in the late 1990s. That a foreign donor organization facilitated the collaboration between local civil society organizations and Saavedra, a key policy champion, provides further evidence to the local experience of international and national dialogues. While civil society organizations collaborated in the opening of clinic, providing key support in the form of community education programs, the state-civil society organization negotiation did not end when the first patient crossed the threshold. Rather, the use and meaning of space within the clinic allows a further discussion of how physical space shapes state-society relationships and hierarchies among civil society organizations.

_Civil Society, Space and Political Opportunities in the Condesa Clinic_

With the pressure of civil society organizations, the support of the USAID Policy Project and a key policy champion in Jorge Saavedra, the Condesa Clinic opened in January 2000. Barnes (2007) notes that the national AIDS agency conferred with local civil society organizations as to how the clinic should be run and what function it should serve within the community; she found further evidence that civil society organizations participated in the full process of clinic creation, from initial conception to daily operation. In terms of how civil society organizations used and responded to the physical space, two key themes emerge. First, civil society organizations had official space within the clinic, ranging from meeting and counseling spaces open to most organizations to the
clinic’s medicine bank, which was managed and staffed by particular organizations. The organization and use of clinic space created certain kinds of relationships between organizations and the state, as the clinic is officially a government-run entity. Second, the assignment of space within the clinic resulted in insider and outsider civil society organizations. Organizations on the “inside” respond to and interact with the state in ways generally different than organizations on the “outside.” Notably, the inside-outside dichotomy, though not perfect, reflects and reifies hierarchies within the AIDS activist movement in Mexico.

*On the Inside*

Of the organizations analyzed for this study, there were, roughly speaking, two categories of “insider” activity: organizations that used civil society-dedicated space for meetings, workshops and networking; and organizations that maintained dedicated space within the clinic for service provision. The organizations that used the space on a largely *ad hoc* basis for networking and meetings maintained a less formalized relationship with the state than those organizations using space for service provision. However, both types of organizations maintained more formal and direct relationships with the state than the organizations largely on the outside. In this case, the state is embodied in the clinic itself: the physical infrastructure is maintained and run by the state, and the clinic houses the AIDS Program of Mexico City staff.° The Mexico City AIDS Program was created in 2002. Therefore, in Mexico City, the allotment of physical space for HIV/AIDS preceded the formal local policy for the disease. The fact that the clinic preceded the policy highlights the extent to which securing space was a key priority of civil society pressure, and a point on which the government was willing to negotiate.

---

° The Mexico City AIDS Program was created in 2002. Therefore, in Mexico City, the allotment of physical space for HIV/AIDS preceded the formal local policy for the disease. The fact that the clinic preceded the policy highlights the extent to which securing space was a key priority of civil society pressure, and a point on which the government was willing to negotiate.
As noted, some organizations use space within the clinic on an *ad hoc* basis. There are rooms set aside for meetings, workshops, and networking. Such spaces provide opportunities for organizations without dedicated offices to have a temporary, shared workspace within the clinic. While many of the organizations profiled in this dissertation already maintained office space of varying sizes and in a number of locations within the city, the community spaces at the clinic allowed organizations based outside of Mexico City the ability to have a “home base” from which to work while in the city. Many organizations, including *Programa Compañeros* from the state of Chihuahua and *Una Mano Amiga* from Chiapas, noted the incredible burden of working on issues of national policy because they operate at such a distance from the capitol city. María Elena, of *Programa Compañeros*, admitted she spent more time and effort collaborating with individuals in the United States than in Mexico City, solely because her organization was headquartered in Ciudad Juarez, directly across the border from El Paso, Texas. These two examples highlight one of the challenges organizations face when trying to affect policy at the national level from afar. By providing space for organizations directly inside the clinic, the state enabled more organizations to access the policy process at the center of national policymaking in Mexico City.

Victor Dante of CHECCOS (*Comité Humanitario de Esfuerzo Compartido Contra el SIDA*, Humanitarian Committee of Shared Effort Against AIDS), a Guadalajara-based civil society organization often travels between Mexico City and Guadalajara, using space in the clinic to network with other organizations and government personnel. In our interview, he disclosed that networking with other organizations was extremely important to him, but would be much more difficult without

---

124 Skype Interview, June 2012.
For Dante, the clinic provided the physical space necessary to work with and learn from other organizations, but it also helped create an atmosphere of collaboration around issues of HIV/AIDS. The collaborative environment not only enabled training and best-practice sharing among civil society organizations, but the layout of the physical space reified the collaborative state-civil society effort to combat HIV/AIDS privileged in both national and international discourses. Barnes (2007) argues that a collaborative effort was necessary in the case of HIV/AIDS because neither the government, nor civil society organizations, were able to meet the demands of the disease unilaterally. In using the clinic for service provision, but also for state and civil society space, we see a physical manifestation of the attempt to create collaborative partnerships to fight HIV/AIDS.

While the *ad hoc* use of clinic space created an environment conducive to collaboration, the state-civil society organization relationship in this sense was much more informal. Consider the case of Victor Dante: his organization certainly benefitted from the experience of collaborating within the clinic, but he only made the trip a few times every year. This *ad hoc* use is much less formal and serves to structure state-civil society relationships to a lesser extent than the more formal use of space within the clinic. For instance, one of the significant accomplishments of civil society organizations’ pressure for the clinic was the provision for an organization-operated medicine bank. The medicine bank is managed exclusively by civil society organizations (Barnes 2007), stocked with medicine procured through the AIDS Program of Mexico City. This is the

---

125 Interview, Mexico City, May 2012.
epitome of state-organization collaboration and one of very few examples in which the state facilitates organizations’ involvement in treatment.\textsuperscript{126}

*Red Mexicana de Personas Viviendo con VIH* (Mexican Network of People Living with HIV/AIDS), or simply the *Red*, also operates a medicine bank within the clinic.\textsuperscript{127} The organization was invited by Saavedra to be part of the institutionalized response to HIV/AIDS in 2000 by operating the bank (“Red …” 2012). The organization opened the Centro de Apoyo a Personas que Viven con VIH “Ruben Perez Silva” (The Ruben Perez Silva Center of Support for People Living with HIV) within the clinic, housing its medicine bank (Red Mexicana n.d.). In a manual published through the USAID Policy Project, the *Red* describes its work, noting it provides services to people living with HIV/AIDS at the Clínica Condesa, promoting a culture of solidarity (Red Mexicana n.d.) Since its inception in 1996, the *Red* has received both international and national financing to facilitate all of its work, not just its work within the clinic. For example, the organization participated in a multi-year capacity building project, financed by USAID, called Alianza (Alliance), that sought to improve the activities and sustainability of Mexican-based organizations. In 2010, the organization participated in a CENSIDA project, Adelante (Forward), aimed at developing civil society leadership around issues of HIV/AIDS. Taken together, participation in these projects and financing

\textsuperscript{126} As noted in Chapter 5, the federal government provides opportunities for organizations to compete for funding for prevention, including anti-stigma and discrimination campaigns, exclusively. In a 2012 interview, former CENSIDA director, José Antonio Izazola argued that civil society organizations know how to do prevention, but the government is responsible for treatment.

\textsuperscript{127} Since the clinic was established a number of organizations have been involved in operating medicine banks. I focus on the *Red* for this chapter largely because it has been a consistent presence in the clinic. Other organizations and partnerships have operated for shorter periods of time, or consulted on daily operations.
received from CENSIDA, indicate that the Red is a highly professionalized organization operating at the interstices of the global and the local.\footnote{As discussed in Chapter 4, organizations that received both international and national financing tend to be more professionalized and long-lasting (i.e., they operate under a particular mission statement, develop regular strategic plans, and make efforts to ensure good accounting practices.) Professionalization is not necessarily a function of organizational size, as the Red is relatively small, reporting seven salaried employees and seven volunteers in the CENSIDA registry.}

While highly professionalized, that the Red was approached by Saavedra to run a medicine bank within the clinic is incredibly important. This new role, created through the assignment and occupation of space within the clinic, provided new opportunities for the organization to interact with and respond to state agents. In the beginning, the Red ran the medicine bank. Over time, the Red assisted in creating the Consejeros en Pruebas Rápidas de VIH (Rapid HIV Test Counselors), a group that carries out monthly sessions and trainings for patients of the clinic. The organization viewed their role to be that of leaders in civil society, negotiating with the various directors of the clinic (‘Red…’ 2012). Because the different clinic directors had varying sets of interests and priorities over time, the Red needed to consistently shift their approach to negotiation. For example, the Red negotiated with state personnel to solve problems related to the lack of medicine and the overall supply of antiretroviral medications.

Barnes (2007) notes that this collaborative partnership with the state, that organizations run the medicine bank within the clinic, serves as both an advantage and a disadvantage for civil society organizations. On the one hand, the Red maintained both a certain degree of control over the medicine bank and closer access to the city’s AIDS program directors. In Lune and Oberstein’s (2001) conceptualization, in this case, the Red operated as a directly embedded organization. A directly embedded organization relies largely on state institutions to carry out its activities (Lune and Oberstein 2001).
While the organization did perform activities outside of Clínica Condesa, their work within the clinic was conditioned by the state-civil society partnership created through the distribution of space within a state institution. Lune and Obsertein (2001) specifically recognize that directly embedded organizations, and the state-civil society partnerships that organically develop in this category, are more often times seen in cases of service delivery. The Red in running the medicine bank in the clinic, then, is a strong example of a directly embedded organization.

Research also identifies disadvantages of these kinds of collaborative partnerships, in which organizations are so closely associated, or embedded, with state institutions. Many argue that civil society organizations lose their sense of autonomy when they work so closely with the government (Barnes 2007, Oxhorn 2001), and in this case, perhaps, when they occupy and use state space. Other civil society organizations, those that do not operate formally on the inside of the clinic, accused the Red of “selling out” to the state, and losing their independence (Barnes 2007). Former Director of HIV Prevention and Social Participation for CENSIDA, Carlos García de León, having worked both for a civil society organization, Áve de México, and for the national government, expressed this concern in a more general statement, arguing that the government should not pay organizations, or contract with them to do particular projects in this case, because it then limits their ability to monitor government functions.129 The extent to which individual organizations view embedded relationships as limiting, or threatening to organizational autonomy, might depend on how likely and able an organization is to enter into a more embedded relationship. Those organizations in Mexico City that criticized the Red for the space it utilized within the clinic often did not

129 Interview, Mexico City, May 2012.
benefit as much from organizational networks and state-civil society relationships in the same way (Barnes 2007).

Further, in such a manner that directly embedded organizations are dependent on state institutions, or state space, for their daily practices, they are potentially held to higher standards of operation. Because the Red occupied clinic space, they were subject to stricter scrutiny of their programs. Beginning in 2011, the AIDS Program of Mexico City, under the leadership of Dr. Andrea Gonzalez, initiated a process to limit the operation of the Red’s medicine bank. This action created intense conflict between the organization and the City administration that was covered extensively in local media. The primary tension existed because the local authorities and the Red had divergent perspectives on the purpose of the medicine bank. Dr. Gonzalez noted that because there was not a lack of antiretroviral supply, and that supplying this type of AIDS medication was the responsibility of the government, the space used for the medicine bank should be rededicated to another organization, Actitud Positiva (Positive Attitude,) for self-help groups and condom distribution. In another proposal, Gonzalez recommended the space be transformed into a library of HIV/AIDS resources for patients and practitioners.

According to the Red, patients of the clinic often required medicines apart from antiretrovirals to safely and effectively live with HIV/AIDS. Because the government did not provide these medications, the organization’s medicine bank should remain intact.

In this initial conflict, we can see that the appropriation of space is distinctly connected to policy priorities and the perceived role of both government and civil society organizations in this policy area. Gonzalez, though recognizing that patients’ lack of adherence to treatment protocols is the most difficult challenge facing Mexico City’s
AIDS Program,\textsuperscript{130} noted that because the government provides this service, there is no need for an organization to occupy space in the clinic for this purpose. The \textit{Red}, on the other hand, recognizes access to space within the clinic as a key vehicle to the success and reach of the organization’s strategy. As the conflict over space between the \textit{Red} and the Mexico City AIDS Program continued, the effect of operating as a directly embedded organization becomes clearer. The \textit{Red} was accused by the AIDS Program of Mexico City of not maintaining the appropriate administrative sanitary licenses to operate a medicine bank (“Red…” 2012). Because the organization provided a specific service, the medicine bank maintained particular kinds of drugs, attending to a specific population group, it needed a more specific kind of license. The \textit{Red} later published in a local newspaper its approved sanitary license for the organization’s headquarters; however, it is not clear that the organization was actually licensed to operate a medicine bank within the \textit{Clinica Condesa}. In this instance, while occupying state space provided the \textit{Red} with access to local policymakers and allowed the organization to provide a health service and work to develop further interventions, it also opened the organization up to more direct administrative scrutiny.

In 2012, leaders of the \textit{Red} reported to an online newsmagazine that “\textit{han pretendido sacarnos del pequeño espacio que ocupamos}”—they planned to leave the small space they occupy in the clinic (“Red Mexicana de Personas Viviendo con VIH” 2012). Around the same time, the \textit{Red} orchestrated protests of clinic users, as the organization’s position within the clinic was increasingly threatened by state personnel (“Protestan Portadores de VIH en Clinia Condesa en DF” 2012). Street protests and direct actions are much more transgressive strategies for negotiating the state-civil society

\textsuperscript{130} Interview, Mexico City, May 2012.
relationship than meeting with local government officials, or trying to shape policy from the space occupied within the clinic itself. Eduardo de la Paz, past coordinator of prevention programs for the Red, detailed the conflict between the local AIDS program and his organization in a blog.  

He argued that the medicine bank, while providing medication for HIV-positive patients, also served as an orientation mechanism, allowing the organization to direct patients towards other services offered in the clinic (and not only the organization’s own services). De la Paz’s blog advertises the protests and the large scale public action, the “Entrega Simbólica del Banco de Medicamentos” (the symbolic “handing-over” of the medicine bank), in which the organization formally gave up its space within the clinic, in front of an audience of protestors. In doing so, de la Paz argued it was not in the organization’s best interest to operate in an environment where there was no longer interest in working collaboratively with civil society; he also felt the organization’s medicine bank could not be successful without the support of the city’s AIDS program. In this last action, when the Red closed their medicine bank in the clinic, they were one of the last civil society organizations still providing medicine for patients with HIV/AIDS.

In Lune and Oberstein’s (2001) typology, the Red represents a directly embedded organization, particularly in their occupation and use of space within the Clinica Condesa. Without that space, the organization would not have had access to the clinic clientele, nor to the local AIDS program personnel. Further, the organization’s use of that space conditioned their activities and interactions with the government, in both positive and negative ways. While the organization often participated in or organized protests in Mexico City related to shortages in the medicine supply and cases of stigma and

131 http://eduardodelapaz.wordpress.com/tag/vihsida-df/
discrimination in public health institutions, we can see that their strategies became more transgressive with respect to the clinic itself as their space was threatened. In Lune and Oberstein’s (2001) categorization, we can see a shift from the Red operating as a directly embedded organization to more of a mediating organization. Mediating organizations serve as interlocutors between government institutions and other community groups, or in this case, people living with HIV/AIDS, with an aim of affecting changes in public policy. We can see this change because, though the organization gave up its clinic space, it continued to operate as a community based group, providing support and services to people living with HIV/AIDS, in its own office located in an entirely different neighborhood from the Condesa clinic.

On the Outside

While the Red faced certain challenges related to its use of space within the Condesa clinic, it still had more direct and formal avenues to access local policymakers than organizations “on the outside.” Clinica Condesa is often a site of protest for organizations that find fault with the city’s AIDS program. Often times, these protests revolve around medicine shortages and discrimination in services, both within the clinic itself and in the AIDS program more broadly. As discussed in Chapter 4, “Negotiating Identities,” there is a hierarchy in the field of civil society organizations, and this fragmentation is acutely visible in the negotiation of space and the “outsiders” in two ways. First, the clinic, as a site of protest, is often targeted by largely unorganized individuals. Whereas the Red was a highly organized and professional, though small, organization, the kind of protest actions perpetuated by outsider groups are generally small, disorganized, and focused on one specific case or need. Second, the at-risk populations represented in these “outsider” protests further highlight fractures within the
activist community, as they generally belong to highly marginalized or socially excluded groups with limited access to services generally. In this section, I will address these two related elements of negotiated spaces concomitantly.

Outsider organizations, particularly in Lune and Oberstein’s (2001) typology, frequently “challenge decision-making processes, leadership and power centers” and are associated most closely with activist-oriented organizations (19). In this analysis, I identify a class of organizations as “outsider” groups; however, this classification differs from Lune and Obserstein’s in that the groups I analyze are *ad hoc* and informal, largely lacking the degree of organization and professionalization that other groups possess. Therefore, these *ad hoc* groups maintain some of the characteristics of Lune’s outsider organizations, but they lack the formality and organizational structure akin to the kinds of organizations Lune examines. In this sense, there is a contingent of groups in Mexico City’s activist scene that are outside the bounds of Lune and Oberstein’s framework, but most closely fit with the outsider organizations in that they challenge power through demands on the provision of public health services.

The clinic provides a physical site towards which groups can channel protests. It is *where* services are provided, and therefore serves as the ideal location to make demands and criticisms about the lack of or quality of health interventions. Prior to 2000, many protests, like the ones orchestrated by FRENPAVIH and described in Chapter 5, were directed at the Ministry of Health building, located in the center of the city. After 2000, many, though not all, protests have been directed at the clinic, instead. In this way, the site of health service provision specifically for HIV/AIDS directs and channels protest

---

132 In their 2001 study, Lune and Oberstein identify ACT UP/NY as an outsider organization in its relation to the state, a long-lasting organization with professional qualities (e.g., mission statement, stable membership, recognized leadership—though often aiming to be non-hierarchical).
outside of the center of the city, to a quieter, more residential neighborhood. The clinic’s location, on the street Benjamin Hill, is close enough to the major roadways in the city to be accessible, but far enough away from the city center to be less visible, particularly when protests are underway. Further, protesting the clinic makes sense for particular groups: if there is a medicine shortage at the clinic, or a patient experiences discrimination at the clinic, the reasonable strategy is to organize a protest at the clinic.

Protests against the clinic are often *ad hoc*, informal, and focused on one specific case, rather than directly addressing larger problems with the Mexico City AIDS Program, or the provision of health services more broadly. The degree of informality is clear in that most of the groups involved in these actions do not maintain formal means of communication (e.g., websites, office space, telephone numbers or email addresses associated with the group) and are difficult to locate when not protesting. These organizations are most often made up of the users of government services, highlighting why protest often responds to a particular incident within the health system. Andrea Gonzalez argued that these groups were the least professionalized she encountered and the most difficult to work with, from the state’s perspective. What was clear in Gonzalez’s statements, made during a 2012 interview, is that these user-based organizations often have limited representation in more formal civil society organizations. As discussed in more detail in Chapter 4, organizations representing the gay population, particularly in Mexico City, are highly formalized and fairly powerful, having had a lot of success in directing and negotiating certain kinds of policy.

---

133 Interview, Mexico City, May 2012.
interventions.\textsuperscript{134} A similar argument can be made for organizations representing people living with HIV/AIDS, as in the case of the Red or DVVIMSS, and for newer organizations focused on women’s health and HIV/AIDS, like \textit{Salud Integral Para la Mujer} (Comprehensive Health Care for Women, or SIPAM).

The informal, less professionalized groups, in the case of the clinic, most often organize protests and other direct actions on behalf of the trans population and sex workers.\textsuperscript{135} Many times, overlapping risk behaviors create additional sources of vulnerability for each of these populations. For example, transgender sex workers or sex workers who also use injection drugs are at a heightened risk to contract HIV/AIDS. The increased risk is accompanied by a greater sense of invisibility, making these particular populations more difficult to reach with standard policy interventions. The literature on HIV in Mexico does not recognize another place open to providing services for the transgender population until \textit{Clinica Condesa} opened in 2000. In fact, hormone therapy is considered part of complete treatment of transgender individuals at the clinic (Grajeda 2009)\textsuperscript{136}.

Despite limited attention to the health issues of transgender populations outside of \textit{Clinica Condesa}, there remain issues of stigma and discrimination within the clinic. Gonzalez affirmed that the majority of protests at the clinic focused on specific cases of

\textsuperscript{134} Gonzalez provides the example of condom distribution campaigns in Mexico City to highlight the effect of gay organizations. She argues that these campaigns are concentrated in particular “gay friendly” zones, like the \textit{Zona Rosa}, but do not have a presence in other neighborhoods. In effect, she argues that gay organizations work for their population, at times to the detriment of other populations. Nevertheless, Mexico, as a whole, has a concentrated epidemic in the men who have sex with men population; these interventions are not without cause.

\textsuperscript{135} It should be noted that there are some groups advocating on behalf of sex workers that are highly organized and formal, like \textit{Red Mexicana de Trabajo Sexual en la Merced} (Mexican Network of Sex Workers).

\textsuperscript{136} These services were added to the clinic’s repertoire in 2009, following a change to the \textit{Ley General de Salud del Distrito Federal} (Mexico City General Health Law). This move was heavily criticized as an act that pathologized transgender individuals by associating them with a risk of HIV/AIDS (Davenport Fentanes 2009).
perceived discrimination on behalf of the trans population. However, it is clear that trans-focused groups are on the outside of state space: they are not afforded space inside the clinic, like the Red, and agency employees perceive them as outside the bounds of normal or successful civil society organizations. Gonzalez noted that “these people have a lot of problems to begin with,” talking about political and social exclusion, and that they do not do much more than “demand more services” or “complain about services they have received.”137 That there are very few groups dedicating time and resources to the transgender population, and that the local government views their demands in this largely negative light, reflects that hierarchy discussed in Chapter 4: populations that are viewed negatively, like the transgender or the drug user, often have less power, and in this case, less access to space.

In this case, access to space conditions groups’ strategies, and without space such groups often rely on more impromptu protests. However, groups also make efforts to appropriate or use space during their protests in a way that frustrates the operation of the clinic. Gonzalez, in speaking about the local government’s interactions with less formal and professionalized groups, described how they occupied the space in front of the clinic, occasionally creating barriers between the people and the services. In this case, where groups, particularly those representing less-positively viewed populations, are not provided space in the clinic, and are, quite literally, on the outside, they find ways to make their “outside” space meaningful through protests and blockades. The outside space becomes the stage for more transgressive forms of action: the Red moves outside the clinic when it begins protesting and symbolically “handing over” the medicine bank; ad

137 Interview, Mexico City, May 2012.
hoc protest and attempts to block access to the clinic serve as a means to call attention to a lack of services or discrimination suffered there.

Conclusion

The negotiation of space, epitomized in the 2000 creation of Clínica Especializada Condesa, highlights key patterns in civil society organizations’ strategies and relationship to the state. Because health care requires physical space for the provision of services, the space itself becomes an important mechanism conditioning how organizations operate. This chapter followed Lune and Oberstein’s (2001) typology of organizations: directly embedded, mediating, and outsider. It showed that organizations within Mexico’s HIV/AIDS advocacy community can belong to different categories at varying times, particularly dependent on their access to state-sanctioned space. While Lune and Oberstein (2001) recognized that only the directly embedded organizations heavily rely on state institutions for their operation, this chapter makes clear that all groups rely on state institutions: the allotment of space conditioned organizations’ capabilities and strategies related to HIV advocacy in Mexico City.

In roughly differentiating between insider and outsider organizations, this chapter highlighted the importance of space to both organizations and the state. Under the stewardship of Jorge Saavedra, recognized as a key policy champion in this account, the clinic provided space, both formally and informally, to civil society organizations in an effort to create an atmosphere of collaboration in combatting HIV/AIDS. The allotment of formal space enabled the Red Mexicana de Personas Viviendo con VIH to directly provide a health service through its medicine bank, but also to have regular access to local policymakers and contribute to other efforts within the clinic. Under the direction of Andrea Gonzalez, the Red’s space within the clinic was eliminated. I provide evidence to
suggest a shift in strategy, from more conciliatory and negotiation-focused tactics, towards more transgressive direct actions, as the organization’s space was threatened. The *Red*, thus, ceased operating as a directly embedded organization in this case.

For outsider groups, they have not been provided with formal space within the clinic itself, and often face stigma and discrimination within the community. While on the outside, they are negatively perceived by local government officials, and largely considered unprofessional by other civil society organizations. Within this context, they had limited opportunities to negotiate policy changes or address barriers in service provision. As a result, they used more transgressive strategies, like protests and blockades, as a means to make demands on the local AIDS program. Key to this analysis is that these outsider organizations still used *space* as an integral component to their strategy: groups often occupied the space in front of the clinic, blocking access, as a means of drawing attention to their perceived lack of access to health services. Without being provided official space to operate, these *ad hoc* groups seized space through transgressive protest tactics.

The negotiation of space provides a closer look at the struggle over universal access in Mexico, and how the creation and use of physical space conditions civil society organizations’ relationship to the state. The phenomena outlined here further demonstrate how the negotiation of identity among the government and civil society organizations focused on HIV/AIDS creates tensions and reifies fragmentation among organizations representing populations of varying degree of marginalization. This chapter also examined how civil society organizations contributed to the creation of public health infrastructure related to access to essential medicines, a theme examined in depth in
Chapter 5, “Negotiating Rights.” Finally, the negotiation of space identifies how international and national discourses related to the decentralization of health services, the construction of health as a human right, and the value of state-civil society collaboration in HIV/AIDS, are experienced at the local level.
Chapter 7: Conclusion

A principal aim of this dissertation was to examine the role that civil society organizations play in advocating for new policy interventions and public health infrastructure relevant to HIV/AIDS in Mexico. Through the preceding analysis, it became clear that state-civil society relationships in Mexico are constantly renegotiated, and not entirely dominated by the state. I present a qualitative analysis of 18 civil society organizations (or cases) within the context of HIV policy attempting to explain how these particular kinds of organizations navigate the complicated waters of policy advocacy and development in an ever-changing, newly democratic environment.

The theory of structured mobilization largely shaped the analyses set forth in this dissertation. Structured mobilization (Bloemraad 2006) posits that the state’s orientation on a particular policy issue, that is, how the government defines the policy problem and potential solutions, shapes the strategies available to civil society organizations. Beyond the state’s actual policy orientation, this theory allows the inclusion of civil society organizations’ perception of the state’s orientation; I argue that organizations’ perceptions are just as powerful in shaping strategies as the state’s actual orientation. I extend this theory to incorporate not just the effects of the state’s construction of policy problems and solutions, but also to evaluate the effects of civil society organizations’ construction of the policy problem as a means of further understanding how organizations negotiate their relationships to one another, and to the state.

In examining state-civil society relationships in the context of negotiating identities, I provided a constructivist analysis of how policy responses in Mexico are
shaped by the perceived identities of target populations. Not only are government responses shaped by the socially constructed identities of the target population, as theorized by Ingram and Schneider (1993,) but tensions among civil society organizations often stem from dissimilar notions about which population is most in need or most deserving of policy interventions. Conflict and tensions among civil society organizations have historically, within this policy area, made collaboration difficult and resulted in less professionalization for some groups. In this complex environment, civil society organizations not only work, then, to negotiate, and often times renegotiate, their relationships with the state, but they also need to evaluate and negotiate their relationships to one another. When different organizations disagree as to which population is most in need of intervention, these organizations essentially disagree on how the policy problem is defined. Participants in this study routinely indicated that the lack of collaboration among organizations hinders civil society organizations’ success in advocating policy change and monitoring implementation practices. While funding streams certainly contribute to the tensions among organizations, this chapter argued that there is a deeper element to the tensions: divergent definitions of the policy problem itself.

Following this analysis of the role of socially constructed identities in shaping opportunities and constraints for civil society organizations, I provided an in-depth examination of the use of rights-based claims as an advocacy strategy. By incorporating a discussion of two policy issues relevant to HIV/AIDS, universal access to medicine and comprehensive sex education, I demonstrated that organizations that leveraged rights-based claims were moderately more successful in advocating policy changes and in
monitoring the implementation of those changes. There were differences in the way that civil society organizations navigate universal access to medicines and comprehensive sex education largely shaped by institutional opportunities and constraints. For example, organizations working towards comprehensive sex education were able to work both with the government and independently of the government to develop education and teacher training programs. In terms of universal access to treatment, organizations needed to work with the government not only to achieve legal access to treatment, but also to monitor the implementation of this policy. The opportunities and constraints that organizations face largely stemmed from working within existing and new systems of engagement, and organizations’ ability to leverage the government-supported notion that HIV is a human rights issue.

Finally, in chapter 6, I provided an examination of the allotment and use of both physical and metaphorical space as a tool for civil society organizations’ negotiations with the state. Placing the country’s first public AIDS clinic at the center of the analysis, I demonstrate how civil society organizations took on certain roles and used particular strategies based on the spaces they had access to within the clinic. Groups that were allotted space inside the clinic, like the Red Mexicana de Personas que Viven con VIH/SIDA (Mexican Network of People Living with HIV/AIDS, or Red,) generally used more formal means of political negotiation, seeking to work with government personnel, and be an integral part of the Mexico City AIDS response. On the contrary, groups that were not allotted space inside the clinic generally used more transgressive means of activism, whether through street protests or clinic blockades. What is innovative about my analysis is an expansion of space-based theory, finding that organizations’ possession
and use of space is not static. When the Red lost its space within the clinic, the strategies it used to interact with the government shifted. Instead of maintaining formal negotiation strategies, the organization shifted towards more transgressive, conflictual mechanisms of contestation.

Overall, this dissertation provided a nuanced analysis of a complex issue: the negotiation of state-civil society relationships within the realm of a policy area aimed primarily at vulnerable and marginalized populations. Through process tracing, I drew conclusions about how the timing and sequencing of particular events lead to a set of specified outcomes. I now turn to an explanation of the theoretical and practical significance of this study. At the end of this chapter, I highlight the limitations of this study by discussing three primary avenues for future research on this topic.

Significance of the Research

This research is important because it addresses questions of state-society relations and the impact of civil society on institution-building in a newly democratizing context. It contributes to the literature by providing a policy-centered analysis of civil society engagement with the state. This project accounts for the shifting policy orientation and preferences of the state and the many ways in which political institutions shape civil society mobilization. This research is different from those previously completed in that it attempts to examine civil society and the state in tandem, while attempting to develop a means of understanding organizations based on their likelihood and ability to access state mechanisms. By recognizing that states and societies are mutually constitutive, that civil society exists in a given political space because the state permits, and that state institutions and preferences can be shaped by civil society demands, this research
provides a more complete understanding of the dynamics of policy development and the points at which newly democratizing regimes can be accessed by citizens.

In terms of theoretical contributions, this research provides an important contribution to current understandings of democratic consolidation, by focusing on civil society’s role in the creation of new institutions and policies. By analyzing HIV/AIDS policy, I establish how state-civil society interaction in a policy area that bears on the most marginalized populations exposes how deeply democracy is experienced in newly democratic contexts. Because the most at-risk populations generally face social and political exclusion, how states and civil societies develop policies to address the needs of these communities are critical processes that attribute to a deeper scholarly understanding of democratic practices and experiences in the developing world. Not only does this research address the democratic inclusion or exclusion of the most marginalized populations, it also attends to how civil society organizations make use of the gaps between principles and practices to make rights-based claims in Mexico.

While this project is innovative, there are practical contributions of this research. It provides a rich, contextualized understanding of state-society relations that is useful for practitioners working in international development institutions, nongovernmental, and philanthropic organizations. A deeper understanding of citizen participation in institution building in Mexico, and a greater conceptualization of how these organizations and the state relate to one another within the context of contending rights claims, provides a framework for best practices for strengthening democracy, specifically with regard to building state capacity in the health sector. Lessons learned from this research in Mexico can provide context for how states and societies respond to public health problems, and
insight into state formation, capacity building, and rights regimes in other middle-income countries.

Avenues for Future Research

While this dissertation provides a nuanced and complex analysis of the many ways the state and civil society organizations negotiate HIV-related public policy and the creation of new public health infrastructure in Mexico, there are still clear avenues for future research on this topic. To reiterate the point made in the introduction to this dissertation, the findings of this qualitative analysis of state-civil society relationships have bounded applicability: one would expect the findings to fit a limited number of country and policy contexts outside of those presented here. However, future research can further define the boundaries of this work’s applicability. Future research should focus on three primary avenues: examining the phenomena presented here in a subnational comparison in Mexico, analyzing HIV-relevant state-civil society negotiations in a cross-national comparison (both within Latin America and cross-regionally,) and finally, exploring the developing relationships between states and civil society organizations in additional policy areas.

First, it would be prudent to investigate the phenomena analyzed here at the subnational level in Mexico. Devolution efforts in Mexico increasingly place emphasis on state and municipal governments. In this dissertation, I pay careful attention to the effects of local contexts. For example, in chapter 5, I address the fact that political and social conservatism in particular states hindered the implementation of comprehensive sex education, while in chapter 6, I provide an analysis of the creation of a public AIDS clinic that was, in part, contingent on the liberal political and social contexts of Mexico
City. Despite these efforts, the main thrust of my analysis is aimed at national level policymaking and negotiations. A carefully designed analysis of the variation in state-civil society relationships across states within Mexico would help expand or limit the applicability of the findings of this research.

Second, I produce an analysis and draw conclusions from data that come from a single country context. While there are multiple avenues of comparison throughout (e.g., among the 18 organizations examined and among the various policy interventions,) future research should include interrogations of the findings in cross-national comparative contexts. Analysis of state-civil society dynamics can be analyzed within similar country contexts within and outside of Latin America, but should also be attempted for dissimilar country contexts. How do the dynamics of state-civil society negotiations shift in less developed settings? What elements of the findings in this dissertation translate to less democratic settings? How do states and societies negotiate on issues of HIV/AIDS within countries with more serious, generalized epidemics? Targeted cross-national comparisons will provide opportunities to fortify the results of this work, potentially expanding the utility of the findings.

Finally, this research provides an in-depth, complex analysis of a single policy issue. While I analyze many different facets of HIV policy, from issues of universal access to treatment, comprehensive sex education, the creation of local public health infrastructure, and the extent to which policy images and social constructions affect policy development, this project is deeply situated within a single issue area. Replicating this kind of policy-centric examination of state-society relationships within the contexts of different policy areas can help bolster the results of this work, and provide deeper
insight into the key questions addressed in this dissertation. In selecting the policy issue for analysis in this work, I strategically selected a social policy area that had the capacity to affect the general population, but was largely targeted towards politically and socially vulnerable groups. Comparative policy analysis that engages in a similar examination of a broader range of policy issues could provide a deeper understanding of how states and societies relate to one another. Similar policy areas, for example an analysis of reproductive health policy, could provide additional support to the findings of this work, whereas analyses of different policy areas (e.g., education policy) could expand or constrain the applicability of the results of this work.

Conclusion:

At the outset of this dissertation, I asked a series of compelling questions: How do civil society organizations and states negotiate their new and developing relationships throughout the policymaking process, particularly in new or emergent democracies? To what extent do political institutions shape civil society organizations’ methods, tactics and perceptions about their internal efficacy in working with the government? And finally, might the relationships between states and civil society organizations be reciprocal and dynamic, rather than static and always dominated by the state? That is, do civil society organizations exert as much of a shaping influence on the state as the state exerts on civil society? Through an analysis of identities, rights, and spaces, I provide meaningful answers to these questions.
Bibliography


CENSIDA. (2011). “Convocatoria pública para el fortalecimiento de la respuesta en
prevención de la sociedad civil ante VIH/SIDA y ITS 2011.” Available at: www.censida.salud.gob.mx/convocatoria2011


Ingram, Helen, Anne Schneider and Peter deLeon. (2007). “Social Construction and


International HIV/AIDS Alliance. (2012). The Night is Another Country: Impunity and Violence against Transgender Women Human Rights Defenders in Latin America. Available at: http://www.aidsalliance.org/publicationsdetails.aspx?id=90623&dm_t=0,0,0,0


http://www1.umn.edu/humanrts/ins/mexico_demochumrts_98.html


Pulerwitz, Julie. (2001). “Extra-relational Sex Among Mexican Men and Their Partners’


Rodriguez, Gabriela and the Secretary of Public Education. (n.d.) “Sexualidad en el marco de las competencias de formación cívica y ética”. *En prensa*.


