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# NEOLIBERAL POLICIES, HIV-RELATED VULNERABILITY AND AIDS ACTIVISM IN MEXICO

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NEOLIBERAL POLICIES, HIV-RELATED VULNERABILITY AND AIDS  
ACTIVISM IN MÉXICO

by

Héctor Eloy Rivas Sánchez

A Thesis

Submitted to the Faculty of Graduate Studies  
through Sociology, Anthropology and Criminology  
in Partial Fulfillment of the Requirements for  
the Degree of Master of Arts at the  
University of Windsor

Windsor, Ontario, Canada

2011

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Neoliberal Policies, HIV-Related Vulnerability and AIDS Activism in Mexico

by

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27 July 2011

## **AUTHOR'S DECLARATION OF ORIGINALITY**

I hereby certify that I am the sole author of this thesis and that no part of this thesis has been published or submitted for publication.

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## **ABSTRACT**

This thesis interrogates how the institutional dynamics that have emerged in Mexico as a consequence of neoliberal state policies have shaped the vulnerability and violence to which people living with HIV (PLHIV) are exposed. Likewise, it interrogates how PLHIV have dealt with and transformed this context.

Based on an analysis of in-depth interviews, as well as primary and secondary data, this thesis: 1) Argues that the Mexican state's neoliberal reforms to health care system over the last 20 years, along with a set of representations that imagine HIV as a 'homosexual disease,' have underpinned the forms of displacement and vulnerability to which PLHIV have been exposed, 2) Analyzes the emergence and transformation of AIDS activism and its repertoires of protest, and 3) Contends that the struggles carried out by AIDS activists have generated social and institutional outcomes that are beneficial to the sick and the needy in Mexican society.

## **DEDICATION**

To

Victoria Simmons, Guillermo Núñez, and Federico Arcos

For bringing joy to my life, stimulating my intellectual activity, and feeding my convictions with exemplar coherence and loving complicity.

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Although I recognize the modest character of this thesis, its elaboration, submission and defence represents a huge academic and personal achievement for me. It is the culmination of a process that I started two years ago in very complex and quite difficult circumstances. My acknowledgments, for this reason, have a very profound and sincere meaning. Without the material, moral and intellectual support I have received in Mexico and in Canada, it would not have been possible to arrive at this stage of my academic career. First of all, I want to thank the generous support of my parents María Elena Sánchez Zepeda and Salvador Rivas Sandoval, whose 'faith' in education and scientific knowledge as a path to collective and individual emancipation have always provoked in me a deep admiration, particularly because they are illiterate. Victoria Simmons' moral, intellectual and material support has been also crucial in this academic adventure. Her patient, generous and loving guidance in a country whose rules I did not understand and with a language I still do not master has been a *sine qua non* condition for culminating this project.

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All the activists I interviewed for this thesis have a very special place in my heart. My deep admiration for the people who are capable of organizing against oppression and contributing to the creation of a better world for others was reaffirmed during our interviews. Thank you very much to all of you for sharing your stories and utopias with me.

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# I

## INTRODUCTION

### Antecedents

Since the second half of the nineties, Mexican society has experienced important transformations regarding the recognition of the human rights of people living with HIV or AIDS (PLHA), as well as the expansion and enrichment of rights related to health and non-discrimination that protect not only PLHA but also the entire Mexican population. In all these changes, the struggles led by women, gay and lesbian people, and PLHA, as a collective movement, have played a fundamental role. Three primary cases exemplify this<sup>1</sup>.

***The first case: Health as a constitutional right.*** In 1996, José Luis Castro Ramírez, a haemophilic man who was severely affected by HIV and who had been impeded from receiving health care at the *Instituto Mexicano del Seguro Social* (IMSS) turned to the *Suprema Corte de Justicia de la Nación* (Supreme Court) to seek legal protection and start a constitutional appeal against the health institute for what he considered a violation of his right to health protection. In 2001, the Supreme Court ruled in his favour and established that Mr Castro's constitutional right to health had been violated and that all Mexican institutions would be obligated to provide the medical attention and therapies available in the health care system to treat those suffering from HIV. The case created an important precedent that allowed people living with HIV and all people who suffer from illness to receive medical treatment as a part of their constitutional right (Medina 2000).

***Second case: Military personnel, HIV and health.*** On February 27 and March 06, 2007 similar legal decisions were taken by the Supreme Court after the analysis of seven constitutional appeals presented by HIV positive soldiers who had served in the Mexican Army and been discharged without receiving medical treatment due to their HIV status

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<sup>1</sup> These cases will be discussed in more detail in Chapter 4.

(Silva García 2008: 2-17). Because of the Supreme Court decision to rule in the soldiers favour, the Mexican Army is now prevented by law from discharging HIV positive military personnel. It must also provide integral medicare to all personnel that experience health-related problems for the entire life of the person, a right that was not recognized by martial law before these constitutional appeals were put forth.

***Third case: A law to protect PLHA and vulnerable populations.*** On December 25, 2008, the Chamber of Deputies of the State of Veracruz, one of the states most affected by the HIV, and with a reputation for having governments which hold conservative positions regarding sexuality and the rights of sexual minorities and people living with HIV, promulgated a law specifically oriented to protecting the rights of PLHA. Elaborated in 2007 (Cruz Martínez 2007), this law establishes a series of governmental duties regarding the protection of PLHA, sexual minorities and sex workers' rights to medicare, educational programs and protection from violence and discrimination. This law was made possible due to the activism and political work carried out by a multi-sectoral organism composed of activists, academics and health institutions. In terms of human rights, this law constitutes a significant advancement in the recognition and protection of PLHA in this part of México. It is also, one of the most important precedents in the matter of legislation regarding HIV in México.

Along with some important programs that were initiated by the federal institutions with the exclusive mandate of guaranteeing the protection of the integrity and security of PLHA in México, these legal amendments constitute important advances in the task of improving the life and protecting the dignity of PLHA and other populations that are not necessarily HIV positive.

What is important about these legal and institutional changes is that all of them were made by social struggles which were led by the people living with HIV themselves. And even more important and sociologically compelling perhaps is the fact that all of these changes, which have implied the broadening and expansion of the state role in providing social security and protection to all of the Mexican population, were made precisely at the

height of the processes of institutional deregulation put in practice by the Mexican state that have implied the progressive dismantling of a social security system (health, education, pensions and other social policies that are considered under neoliberal turn ‘protectionists’ and harmful for economy).

Despite the transcendence of such transformations, Mexican social sciences, and sociology in particular, have paid little attention to the study of the social movements which have emerged as a result of the AIDS crisis and the process of protests and institutional, cultural and political changes they have generated. It is the goal of this thesis to contribute to the understanding of the causes and social and institutional implications of such transformations.

### **Literature review: Studies of AIDS activism in México**

In México, the study of HIV and its effects on individuals and communities have been fairly popular in social sciences, in general, and sociology in particular, for the past fifteen years. This important body of academic knowledge has been fundamental for the understanding of two major areas of knowledge regarding HIV and AIDS. The first area concerns the understanding of the cultural and institutional arrangements that facilitate or obstruct the exposure to HIV infection (the prevention area). The second major area studies the ways communities and individuals react toward people living with HIV or AIDS in Mexican society. This second area of research deals fundamentally with the processes of stigmatization and discrimination associated with HIV infection and is much less popular.

Unlike the academic studies focused on the prevention of HIV or the stigma attached to HIV, the intellectual efforts focused on the understanding of the collective dynamics and the social movements generated as a response to the AIDS crisis, have been, very marginal in México. After an extensive search in databases and by asking academics and the activists themselves, we could find only four works dedicated exclusively to the study of collective mobilizations carried out by people living with HIV or AIDS and its

community-based organizations in México. They will be discussed in the next few paragraphs.

“Paradoxes and asymmetries of transnational networks: A comparative case study of México’s community-based AIDS organizations” (2008), written by American sociologist Nielan Barnes, is perhaps the first academic piece of work on Mexican AIDS organizations. In this article, Barnes examines the extent to which “transnational networks reconfigure state-civil society relationships in ways that lead to civil society empowerment and increased organizational capacity to address the HIV/AIDS epidemic in México” (Barnes 2008: 44). By identifying and comparing several AIDS organizations that provide AIDS prevention and treatment services in Tijuana and México City, the author finds that transnational networks created between AIDS organizations from México and United States provide opportunities that help some local organizations and affect others, contributing to processes of inequality amongst them in their access to resources, training and, therefore possibilities of success or failure. This study has contributed to an improved understanding of how civil society’s participation in transnational networks poses a challenge and simultaneously reproduces power relations and health inequities between community organizations and the state.

In “Subject, sexuality and biopower: Legal defence of soldiers living with HIV and sexual rights in México,” (2010) Ana Amuchastegui and Rodrigo Parrini analyze the court appeals put forth by 11 soldiers in relation to their unfair dismissal from the Army in 2008. Although this work does not analyze social movements, it is important since it sheds light on the processes of institutional transformation by legal means stimulated by AIDS activism since the second half of the 1990s in México. The authors argue that this judicial process which bases its process of argumentation on the ground of health and sexual identity, “opened an unprecedented chapter in the relationship between sexuality and the judicial system in México” (Amuchastegui and Parrini 2010: 233) and opened up the grounds for the construction of a democracy which includes the legal and institutional recognition of heterodox and non-heterosexual sexual practices and identities in the country.



The work entitled “Sociedad civil, movilización social y agenda pública: el caso del Frenpaviih ante la política de salud en VIH/SIDA en México, 1996-2004”, a research-based document elaborated by Miguel Rodrigo González Ibarra which was presented at the *XI Congreso Internacional del CLAD sobre la Reforma del Estado y de la Administración Pública*, held on November 10, 2006 in Guatemala City, constitutes a unique academic effort in México which studies the emergence, structure and ways of political operation carried out by the *Frente Nacional de Personas Afectadas por el VIH* (FRENPAVIH). Judged in the light of outcomes, this organization, as we will see in the third chapter of this thesis, has been the most influential in Mexican AIDS activism so far. For this reason, although this work has not been published in academic reviews or books, it represents a gold mine for the scholar interested in understanding the emergence of AIDS activism in México. This work is full of important and meaningful historical data on the history of contentious politics performed by AIDS activists in México.

The fourth academic effort which is exclusively focused on the study of AIDS activism in México is the work “Memoria del Activismo en Sida en México, los primeros años” published by the *Consejo Nacional para Prevenir y Eliminar la Discriminación* (Andrade, Maldonado and Morales 2010). This book is based on an oral history with 12 activists who were participated in the creation of the first community-based organizations since the first cases of HIV were officially identified in México. In this work, the historians Magdalena Andrade, José Ricardo Maldonado and Claudia Morales document the history of the very first efforts carried out by AIDS activists and organizations during the first decade of the eighties. This important and rich work also informed and guided in an important way the effort made in this thesis, particularly the first part of the chapter three.

The aforementioned works have made important contributions to the understanding of: a) the role played by the transnational organizations in the professionalization of AIDS and community-based organizations, and their strengthening in terms of capacity to provide services, advocacy and antiretroviral therapies outside of the institutional sphere, but also

in terms of the construction of processes of inequality amongst networks; b) the important role played by identity-based politics in the strategies used in organizations' work to attain protective legal rights; and c) the important role played by gay and lesbian people and the definition of the communitarian and institutional responses to address the health crisis of AIDS in México.

## **Objectives**

Despite the important contributions made by the studies mentioned above, no attention has been paid to the analysis of the way PLHA and their community-based organizations (CBOs) have been coping, resisting and transforming the context of vulnerability structured by the neoliberal policies that started 20 years ago in México. In other words, while research done in this area has shed light on the important role played by people living with HIV as a social movement in the configuration of institutional and legal changes, no attention has been paid to the specific forms and the extent to which the neoliberal social formation in México (and its process of marketization of health, deregulation of labour market and promotion of individual responsibility for risk management) has been organizing nodes of vulnerability to which PLHA have been exposed. Likewise, little attention has been given to the extent to which the AIDS activism has been dealing with and transforming these trends in public policies by making collective and individual rights possible in a context of hostility toward rights and forms of redistribution aimed to protect vulnerable population associated with welfare states. It is important to shed light on these issues, for two reasons. First, it could contribute to the understanding of the ways in which the institutional dynamics that have emerged in Mexico during the last 20 years have shaped the vulnerability of people living with HIV, an issue that has been explored in the broad area of the population's health, but that has been entirely ignored in what regards HIV and AIDS. Second, it could contribute to the documentation of efforts put forth by vulnerable populations to transform social dynamics and to advance in social justice issues in Mexico. This is an issue that has been extensively explored with regards to indigenous populations, women, gay and lesbian people, and other movements that have emerged out of "minority" groups, but, again,

scarcely explored in what regards the social movement generated by people living with HIV or AIDS. Therefore, with the intention of accumulating knowledge on these issues, the general objective of this thesis is to carry out a sociological study that questions whether and to what extent the neoliberal policies in Mexico have shaped the vulnerability to which PLHA are exposed, as well as the array of political practices that PLHA and their CBOs have exercised to transform the conditions that organize their vulnerability in Mexico. More specifically, the thesis aims to analyze:

- 1) The origin and characteristics of AIDS activism and their CBOs in Mexico.
- 2) How and to what extent the political and economic transformations in Mexico have affected people living with HIV/AIDS, as well as their different forms of activism.
- 3) Whether and to what extent AIDS activism and its CBOs have resisted and reshaped the social dynamics that organize their vulnerability.
- 4) The scope and limitations of AIDS activism and related CBOs in terms of the effects of their work on diminishing the vulnerability of PLHA and the protection of their rights.

The study focuses on community-based organizations that lead efforts in the areas of prevention, care and advocacy in the field of HIV/AIDS in México City. This city was selected for epidemiological, social justice and methodological reasons.

Starting with epidemiological reasons, México City is the most affected by HIV prevalence (CENSIDA 2009). According to CENSIDA, the capital of the country has the highest incidence of HIV (with an incidence of 168.0 per 100,000 habitants), as well as the highest number of cases of people living with AIDS (with an incidence of 254.1, which represents 16% of the total cases of AIDS) in the Mexican republic.

At the same time, from the social justice point of view, México City has also presented the highest rates of HIV-related human rights violations over the past 10 years in the country. Quantitative work done on HIV/AIDS and human rights in México, as well as

the official data provided by the National Commission for Human Rights, show that this city occupies first place with respect to HIV-related human rights violations (Hernández and Rivas 2006).

Finally, from the methodological perspective, México City has the highest number of community-based organizations in the country. According to Mexican government (CENSIDA, 2009), the official number of organizations that are located in this city is 69, which represents 32 percent of the total number of organizations in all the country<sup>2</sup>. In addition, these organizations have traditionally had great influence on AIDS public policy at the federal level, as well as on the dynamics of activism at the level of the states of federation.

## **Methodology and Profile of Participants**

### **Primary and secondary data sources**

In order to understand the impact state policy can have on persons living with HIV, as well as the impact of activism on AIDS-related public policy in the area of HIV and AIDS, I have analyzed public investment in medicine and infrastructure to cover PLHA (used by federal government). Two data sources have been used in particular. The first provides information on the evolution and characteristics of the public budget and AIDS-related expenses in México. The main source of this information is the webpage of the National Program on AIDS in México (CENSIDA). Through this webpage, the program offers: Budgets 2000–2010, expenses on retrovirals and condoms 2001 – 2009; and media campaigns 2000 – 2010. To analyze the characteristics and evolution of the Mexican government's public budget on AIDS, the information provided by the NGO *FUNDAR, Centro de Análisis e Investigación, A.C.* was also used.

To analyze the rise, characteristics and transformation of AIDS activism in México, I used the *Biblioteca Virtual en Salud y VIH/SIDA*. This virtual library offers: Conference

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<sup>2</sup> There are 211 Community Based Organizations in Mexico which work in the area of HIV AIDS, according to the *Censo Nacional de Organizaciones de la Sociedad Civil con trabajo en VIH/SIDA* created by the *Centro Nacional para la Prevención y Atención del Sida* (CENSIDA 2009).

proceedings of research projects and intervention programs on HIV AIDS (RIIMSIDA); Conference proceedings of papers presented at conferences on HIV AIDS; Electronic Books; Videos, and Mexican Legislation on HIV AIDS

### **Interviews and Profile of Participants**

A total of 10 activists from different community-based organizations were interviewed using the program Skype. These CBOs were, in most of the cases, amongst the first to emerge in México; they have the greatest number of members, and have the highest influence and visibility at the national level. These organizations are: 1) *Red Mexicana de Personas que viven con VIH o SIDA, Vanguardia Mexicana de Personas Afectadas por le VIH* (VANPAVIH), *Frente Nacional de Personas Afectadas por el VIH/SIDA* (FRENPAVIH), *Letra S, Salud, Sexualidad y Sida, Proyecto Condonmovil, Tabasqueños Unidos por la Diversidad y la Salud Sexual, Red Positiva de Quintana Roo, Identidad Saludable, and Grupo de Autoapoyo Conciencia para El Futuro*. The activists who were interviewed and who provided their insights for this thesis were: Antonio Medina, Antonio Alberto Solis Rodríguez, Georgina Gutiérrez Alvarado, José Cruz Guzmán Matías, Juan Alfonso Torres Sánchez, Juan Carlos Hernández Meijueiro, Magda Padilla, Polo Gómez, Roberto Guzmán Rodríguez, and other two people who asked to remain anonymous<sup>3</sup>. Since some of the activists have participated in several organizations during their time as activists, through these interviews, I was able to comprehend the key process of formation and transformation of at least 19 organizations and their politics of contention from the moment they emerged until the present.

Antonio Medina is a recognized journalist and gay activist in Mexico since the second half of the 1990s. His professional activities consist in publishing articles on sexual politics, human rights and HIV-related issues in the left-wing newspaper *La Jornada*, in the newspaper supplement *Letra S, Salud, Sexualidad y Sida*, and in diverse Mexican and Latin-American magazines. As activist, he has participated in key processes of legal and political changes. For example, he was part of the committee of gay activists who designed the *Ley de Sociedades de Convivencia*, a law proposal that aimed to allow same-

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<sup>3</sup> With the exception of the interviewees who asked to remain anonymous, the real names of the activists were interviewed are mentioned here by request of the interviewees themselves.

sex partners to build a family. After lobbying for several years, this committee convinced the local parliament to pass the *Ley de Sociedades de Convivencia* in 2006. Then, in 2009, the Mexico City's constitution was amended by the local parliament to allow the same-sex marriage due to the political work carried out by the same committee of gay activists. Antonio Medina and his partner were the very first couple who signed a *sociedad de convivencia* in Mexico City in March 2007, a fact that added even more notoriety and popularity to his activism, not only amongst the activist community, but also amongst the mainstream media and the general public. He was interviewed while general coordinator of *Letra S, Salud, Sexualidad y Sida*. *Letra S* is a monthly supplement of the progressive national newspaper *La Jornada*. It was founded in 1995 by Carlos Monsiváis, a prominent public intellectual in Mexico who was key figure in promoting the rights of vulnerable populations since the 1960s until his death in 2010. *Letra S, Salud, Sexualidad y Sida* has been the main source of information -and arguably the most influential, too- for people living with HIV and the gay and lesbian movement in Mexico since it was founded.

Antonio Alberto Solis Rodríguez has been involved in the AIDS activism for the last 15 years. He has been working for the *Red Mexicana de Personas que viven con VIH/ Sida, A.C.* since 2001. This organization has been very influential in Mexico City and in several states of the Mexican republic in issues regarding HIV-related discrimination, and universal access to ARV. It also provides psychological and medical services to the people living with HIV. As a public school teacher in Mexico City and as coordinator of the self-support group of the *Red Mexicana*, Antonio Solis has played a fundamental role in providing education and training to a large number of students, teachers, people living with HIV, and to the general public in HIV-related issues, from a human rights perspective. He has done this by convincing the *Comisión Nacional de los Derechos Humanos* and other public institutions to actively participate in the design and implementation of such educational programs.

Georgina Gutiérrez Alvarado has been part of national AIDS activism for more than 20 years. She was founder of the *Frente Nacional de Personas Afectadas por el VIH*

(FRENPAVIH), as well as founder of two self support groups for people living with HIV, and other feminist organizations in Mexico City. In the mid-1990s she designed the very first educative project on HIV-related issues that was implemented in Mexican prisons. This project has been very successful in providing training to prison staff on human rights of the prisoners living with HIV, as well as in providing tools to the prisoners living with HIV themselves for the defence of their human rights. The novel and creative character of her educational work and her political activism has been so successful in Mexico that AIDS organizations from Mexico and other Latin American countries frequently invite Georgina Gutiérrez to provide training to the activist community on issues regarding political incidence, educational work in prisons, and women's health, from a human rights perspective. Currently, she is member of the *Movimiento Latinoamericano y del Caribe de Mujeres Viviendo con VIH/Sida*.

José Cruz Guzmán Matías has been active in the fight against AIDS for the last 15 years. He participated for several years in the *Frente Nacional de Personas Afectadas por el VIH* (FRENPAVIH) where he developed a great deal of expertise in tactics and strategies to generate changes at the level of culture and public institutions. Then, he founded in Tabasco the grassroots organization *Tabasqueños Unidos por la Diversidad y la Salud Sexual*. *Tabasqueños Unidos* carry out its activities in the state of Tabasco and in several states of the Mexican republic. They provide legal, emotional and medical support to the people living with HIV, as well as to bisexual, lesbian, transgendered, and gay people who are victims of homophobic violence. His extraordinary skills in political incidence had made possible that *Tabasqueños Unidos* had generated important legal amendments to the local constitution, created specific governmental programs to protect people living with HIV from discrimination, and prevented people living with HIV from being discharged and fired from their work places due to their sero-status. He also provides training to grassroots organizations and self-support groups around Mexico in AIDS-related issues, from a human rights perspective.

Juan Alfonso Torres Sánchez has been involved in AIDS activism for the last 20 years. He was one of the first persons who received training in San Francisco California during

the first years of the AIDS crisis in Mexico. Since then, he has founded and/or participated as a volunteer in several key grassroots organizations which provide medical, psychological and legal support to the people living with HIV or AIDS, such as *Identidad Saludable* and *Frente Nacional de Personas Afectadas por el VIH* (FRENPAVIH). In 2002, he played a fundamental role in the design and application of a national education program to reduce stigma and discrimination in the federal institutions (particularly in public schools, public hospitals, and prisons) by providing training to public servants on HIV and human rights. This educational program was implemented by the *Comisión Nacional de los Derechos Humanos* (CNDH), the *Frente de Personas Afectadas por el VIH* (FRENPAVIH) and several AIDS organizations in Mexico from 2005 to 2008. Since 2007 Juan Alfonso collaborates with the Programa de VIH Sida y Derechos Humanos at the CNDH, in the area of education and training.

Juan Carlos Hernández Meijueiro is psychologist from the *Universidad Autónoma Metropolitana-Xochimilco* and received training in theology at the *Pontifical Urbaniana University* in *Castel Gandolfo*, Italy. He also holds a masters degree in public health from *Emory University* at Atlanta, Georgia. Juan Carlos Hernández Meijueiro has been a leading figure in the activist community in general, and amongst the AIDS activist community in particular. He participated in the creation of some of the very first AIDS organizations which provided education, health services and legal support to the people living with HIV at the beginning of the AIDS epidemic. Some of these organizations are: *Cálamo*, in Mexico City, and *Xochiquetzal, A.C.*, in Veracruz. Since the 1990s, Juan Carlos Hernández has been significantly influencing the formation and transformation of the ways in which AIDS activists, feminists and the gay and lesbian movement frame and conduct their political struggle in Mexico. He has done this by providing courses and workshops on the history of women's oppression in Mexico and in the western societies; on the impact of the dominant sexual ideologies on population sexual health and individuals' self esteem; on the history of sexual conservatism in the Catholic Church; on the Bible and homosexuality, and on the history of sexuality in prehispanic Mexico. His pedagogical work draws on a diversity of theoretical and pedagogical approaches to make sense of the social processes which have historically shaped the oppression experienced



by people living with HIV, women, and gay and lesbian people in Mexico, and to provide tools for organizing personal and collective forms of resistance and transformation, such as the pedagogy of oppressed by Paulo Freire, the genealogical and deconstructive work of Michel Foucault and the radical sexual thinking of the Freudian Marxism, particularly the theoretical insights made by Wilhelm Reich and Herbert Marcuse.

Magda Padilla has been involved in AIDS activism since the mid-1990s. She was founder of *Conciencia para el Futuro* at the *Instituto Mexicano del Seguro Social*. This organization was the first self-support group created and led by the people living with HIV themselves in the Estado de Mexico. She has also been a leading figure in Mexico amongst the groups of women living with HIV. She has done this by designing and/or participating in important grassroots initiatives to stop HIV-related social stigma, and to generate social inclusion and recognition for women living with HIV at *Colectivo Sol*, *Letra S*, *Salud Sexualidad y Sida*, and *Frente Nacional de Personas Afectadas por el VIH* (FRENPAVIH). Due to her extraordinary skills in building bridges amongst public institutions, NGOs and people living with HIV, all the members of the self-support group she coordinates at IMSS have received training on HIV AIDS and human rights. It is important to mention that large numbers of people living with HIV who could not have access to this type of training and information due to their marginalized social status in Mexican society have received training thanks to Magda Padilla's work at the grassroots level.

Polo Gómez has been a key figure in Mexican AIDS activism since the end-1980s. As founder and educational coordinator of *Colectivo Sol* -a pioneer AIDS organization in Mexico since the beginning of the pandemic-, Polo Gómez designed and implemented an educative project called *El Condonmovil*. This unique community project in Mexico consist of a condom-wearing car which travels around Mexico, particularly to remote and marginal villages, towns and neighbourhoods, to provide educative material on such issues. Dressing as a drag queen and accompanied by a group of other drag queens called *Las Condoneras*, Polo Gómez distributes free condoms and information regarding STDs, HIV prevention, and AIDS and human rights, in such places through performance,

theatre, and street art. Self-defined as left-wing activist, he also is involved in several neighbourhood associations in Mexico City which aim to improve the housing conditions of the urban poor. His participation as a Zapatista drag queen during several gay parades in Mexico City in the mid-1990s as a form of showing solidarity and making political links between the gay movement and the Zapatista struggle, significantly impacted the mainstream media and influenced the *Frente de Personas Afectadas por el VIH*'s decision to wear balaclavas during its first street protests and demonstrations in Mexico City.

Roberto Guzmán Rodríguez is an influential left-wing journalist who also has been involved in AIDS activism since the mid-1990s. In 2001 he founded the *Red Positiva de Quintana Roo* with the goal of influencing local and federal institutions in the design and implementation of specific programs aim to protect people living with HIV from institutional discrimination and other forms of oppression. In 'El Cielo de la Oposición', a weekly column he publishes at *Diario la Verdad* in Quintana Roo, he often criticizes the public policies affecting people living with HIV. Through his journalistic work and political activities as an AIDS activist he has been stimulating public debates which have led to constitutional amendments in the state of Quintana Roo, as well as to the creation of institutional programs aim to protect people living with HIV and other vulnerable populations.

The interviews conducted were based on the principles of the Active Interview proposed by James A. Holstein and Jaber F. Gubrium (1995). For these authors, the best way to collect information is by carrying out the interview in the context of a productive site (Holstein and Gubrium 1995:3) in which interviewer and interviewee give birth to meanings and knowledge in the frame of a dialogical and active relationship. According to this perspective, the active interviewer must: be flexible in the selection of the respondent; create a fluid and dynamic dialogical interaction with the respondent; stimulate the respondent's narrative; provoke and actively incite the answers without telling them "what to say"; use open questions, provocations and interactional gestures to maintain a fluid conversation; permanently stimulate the creation of connections among

disperse anecdotes; cultivate rapport with the respondent, and finally promote multi-vocality and permanent shifts in the roles of interviewer-interviewee.

Nine interviews were conducted via Skype and one via telephone. They were carried out in an in-depth and in a semi-structured format. Interviews were between 1.5-3.5 hours in length and all of them were recorded using a digital recorder with the consent of the interviewee and in accordance with the manual elaborated by the *Research Ethics Board* at the University of Windsor.

The areas that were explored in each interview include the profile and characteristics of the organization; its networks, spaces and resources; its emergence, political rationale, achievements and obstacles, as well as a personal biography of its activism (see Appendix A for a detailed list of the issues that were explored).

### **The coding and analysis of data**

As a way of ordering, classifying and analyzing the information that was collected through the interviews, the method proposed by Emerson, Frets and Shaw (1995) regarding coding and memoing, as well as the method provided by Norman Fairclough (2003), about how to analyze discourse was used. By using these techniques I hoped to be able to identify the regularities that can help us to understand the complex set of techniques, tactics and strategies used by activists in their work for questioning and transforming a specific social formation in a particular context of power relations, an objective of this research. The results of this process were fruitful.

### **Theoretical framework**

The field of study of social movements, collective behaviour, social dissidence and revolutions has been particularly fertile in sociology since the 1950s, and its paradigms have been subjected to transformations as a consequence of several epistemological revolutions in sociological theory, as well as a consequence of the impact in the field of

study of social movements led by the social movements themselves (Buechler 2000). During this process of epistemological transformations in the field, some approaches have tended to disappear while others have been subjected to a refinement and enrichment. In particular, the social psychology-based approaches, led by symbolic interactionism, also known as the Collective Behaviour Theory, have tended to disappear, while the new paradigms, the New Social Movement Theory and the Political Process Approach, have been transformed and even strengthened. In this part, a brief description of each paradigm will be offered before showing which paradigm will be used to carry out this research project.

### **a) The Classical Collective Behaviour Theory and its limitations**

The very first approach to the understanding of social movements was led by the collective behaviour theory. This theory and its variants have been influenced by three sociological traditions (the Social Interactionist Theory associated with George Herbert Mead, George Homans and the Chicago School, principally, the structural-functionalism associated with Talcot Parsons, and Role Theory, whose foundational father is Robert Merton) that, despite fundamental difference in orientations, share similar views with respect to the ways that social movements, their origins and manifestations are imagined. Some of the core assumptions of these different traditions are: 1) that people protest as a reaction to “disturbance in standard routines and rhythms of everyday life. When circular reactions becomes contagious, it can give rise to social unrest, with elements of randomness, excitability, apprehension, irritability and increased suggestibility” (Buechler 2000: 23), 2) that these forms of protest are in some sense anomic states of individuals and groups generated by problems in the stability and well-functioning of the social structure ), 3) that collective movements, being based on panic, anger and other irrational feelings as well as an attachment to a deviant behaviour generated for lack of institutional channels to canalize their demands, are poorly organized, spontaneous and have a short life (Buechler 2000).

Being based on a functionalist idea about society as a well-organized organism that works based on institutions that work smoothly, therefore imagining collective behaviour as an non-institutionalized, irrationally based protest structured by problems in such social structure, this perspective has been underlined by social scientists in social movements as one which is not only poor in theoretical terms, but also 'negative' in its approach to social movements and has been progressively abandoned by scholars in the study of social movements. This approach will not be used in this thesis.

### **b) The New Social Movements Theory and its limitations**

During the seventies, as a consequence of the emergence of student protests, the antiracial oppression movement, and the emergence and strengthening of the environmental, as well as the women's and gay and lesbian movements, a new turn in the studies of social movements emerged in Europe and in North America (Buechler 2000). One of the most influential of these trends in the sociology of social movements has been called the new social movements approach. The new social movements approach (that will be pointed out in this part), is composed of variants of post-Marxist and neo-Marxist theories in sociology. This approach was initiated by theorists such as Jurgen Habermas, Alberto Melucci, Ernesto Laclau and Chantal Mouffe, and others. Despite differences, this approach shares the idea that the social movements that emerged during the second half of the 19th century are different in their constituencies, goals and repertoires in respect to the labour movement, which is considered the 'old' and traditional emancipatory movement par excellence.

The theorists associated with this approach share the idea that what distinguishes the new social movements, from the old ones, is: 1) their rejection to the hyper-bureaucratization of the state institutions characteristic of the liberal democracies and soviet states, and their reactive defence of the 'life world' against the colonization of state intervention to the society diverse cultural manifestations, 2) their reaction to the hyper-rationalization, fact that is thought to be the cause of damage and destruction of the environment

(Staggenborg 2008), 3) their atomic character, that is to say, their abandonment of the old idea that one movement (the workers' movement) must lead the struggle for emancipation, and, finally, 4) their engagement in identity-based struggles and the defence of politics of difference (Buechler 2000).

Some sociologists who specialize in social movements have noted that one of the main weaknesses of this theoretical perspective is that, in the end, it shares some of the basic epistemological presuppositions held by traditional Marxism, ones which they had tried to get rid of in the past. For example, critics of the new social movement perspective, such as Buechler (2000), say that, if it is true that the new social movement theorists attained a separation from Marxian reductionism, which assumed that social movements in capitalist societies had the main goal of rebelling against economic exploitation, in the end these assumptions share the idea that there is a social totality from which social movements, such as environmentalist, feminist, student, pacifist, gay and lesbian, and so on, emerge and react.

Unlike this critique, I consider that the problem with this perspective resides, not in the fact that it shares the 'erroneous' idea that there is a totality from which social movements emerge and react, but rather in the very fact that the new social movement approach has not been capable of understanding the variety of ways in which the so-called new social movements are, in reality, not so new and the varied ways in which the 'new social movements' are actually immersed and deeply connected in complex ways with the social and economic structures of capitalist societies, and not only concerned with the transformations of the cultural sphere (Adam 1993). Following the theoretical critique provided by Barry Adam, who provides several key epistemological elements in support of this critique, in the next paragraph, an explanation will be given as to the importance of thinking about this set of social movements, arbitrarily considered 'new,' in the context of political economy. This will be done prior to explaining the theoretical perspective which will be adopted in this thesis

### c) Bringing the political economy back into the study of social movements

In 1993 Barry Adam wrote an incisive article in which he criticized the various neo- and post-Marxist approaches to the analysis of the “new social movements”, we broadly described in the last few paragraphs. In that work, Adam (1993) pointed out that “contemporary social theory continues to impede assessment of the new social movements by separating them from questions of political economy and by placing them on the side of “culture”, thereby denying ways in which the origins, identities, and development of subordinated categories of people remain fully rooted in the dynamics of advanced capitalism” (p.316). According to Adam, leading academics such as Jurgen Habermas, Henri Lefebvre, Alain Touraine, Claus Offe and others, conceived the new social movements as merely *defensive* (from state control), *individualist* and *separatist* (because of a supposed emphasis on cultural recognition-based politics), and even *reactionary* (because of their opposition to the changes generated by modernization processes), thereby ignoring the manifold ways in which feminists, environmentalists, gays and lesbians and other new social movements affect and are affected by the dynamics of capitalism.

Today, Barry Adam’s criticisms remain opportune and fundamental. A new turn in the sociology of social movements in North America has begun to question the traditional structuralist approaches that for a long time have prevailed in the study of social movements, by focusing its energies instead on analyses of the role of emotions in the emergence and transformation of social movements (Goodwin and Jasper 1999; Gould 2010). Motivated by the very justified necessity of overcoming the sometimes mechanistic, rationalist and determinist approaches provided by the resource mobilization and old versions of the political opportunities model, this new generation of scholars offers new and sophisticated theorizations regarding an old concern about the role played by emotions, affects and feelings in the eruption of social movements of protest and revolutions<sup>4</sup>. For them, one of the main weaknesses of the structural approaches provided

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<sup>4</sup> In an interesting account of the transformation of social science paradigms used in the study of social movements, Doug McAdam points out that the first generation of social scientists interested in social movements tended to think that people’s involvement in struggles was generated by a mix of personal

by the resource mobilization theory and the political opportunities theory is that they are excessively rationalistic since they share the presupposition that people's mobilization is always the product of a rationally orchestrated action to reach a political end and that the main source of motivation is the awareness of real possibilities of triumph. Based on this critique, the emotional turn in the study of social movements proposes to analyze the ways in which the collective mobilizations are shaped not only by the rational calculus of social actors, but also by feelings of anger, rage, disappointment, and so on.

Without denying the important contributions which the emotional turn has made to sociological theory and to the understanding of social movements, I consider that one of the main weaknesses of this approach is that, by focussing on emotions, this approach has almost entirely ignored accounts of the relationship between large economic, political and cultural processes and people's exclusion, resistance and mobilization.

My intention is to insist on the exploration of the mechanisms through which the neoliberal socioeconomic formation (De la Garza Toledo 2001) and other forms of oppression (i.e. the practices and systems of classification presented in Bourdieu 1990) stimulate misrecognition (Fraser and Honneth 2004) and organize particular forms of vulnerability and exclusion for PLHA. Likewise, we intend to examine the ways in which these forms have contributed to the organization of programs of collective action aimed to contest and subvert such conditions. Therefore, we consider that a mix of conceptual tools provided by the political sociology of neoliberalism and a more dynamic variant of the political opportunities approach, elaborated by the structural research approach led by Charles Tilly, Doug McAdam and Sidney Tarrow, can be more helpful in achieving the objectives of this thesis.

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pathologies and social disorganization. He says: "At the macro, sociological level, social disorganization was seen as the immediate precipitant of movement emergence. Movements were held to arise when rapid social change (e.g. industrialization and modernization) occasioned a generalized breakdown of social order (...). Movements, in this view, were groping, if ineffective, collective efforts to restore social order and the sense of normative certainty disrupted by change. As such, they owed more to psychological, than political or economic, motivations" (2003: 281-282).



#### **d) Political Process Theory and its advantages**

One major objective of this project is to understand the emergence and array of political practices that PLHA and their community-based organizations (CBOs) have put in motion to transform the conditions that organize their vulnerability. To explore the emergence of AIDS activism in México, as well as the array of social practices they carry out to address and transform the social structures that organize the vulnerability facing people living with HIV, we consider it pertinent to use the political process theory (PPT).

Led by scholars, such as Doug McAdam, Sydney Tarrow and Charles Tilly (2001), this theoretical account sustains five fundamental claims: 1) that social movements are political agents whose actions are an extension of 'politics by other means' (Buechler 2000: 34) and, as such, they possess a structure and organizational dynamic, 2) that, rather than being composed of anomic individuals governed by spontaneous and irrational outbursts of emotion, as the collective behaviour theorists have thought, social movements are normal, rational and institutional actors which engage in particular tactics and strategies aiming to generate social change or exercise influence on the state and its institutions, 3) the emergence of social movements and other forms of contentious politics is the result of the existence, appearance or expansion of political opportunities in a particular social structure; 4) the expansion of political opportunities, fundamental for the emergence of collective action, is always the result of cumulative work carried out by individuals and organizations whose work has opened up the window of opportunities throughout the elimination, for example, of excessive repression, etc.; 5) the existence of grievances is important, but not in itself a necessary condition to join or start a political mobilization. Rather, the existence of internal resources to start a mobilization (spaces, information, money, access to networks) is always necessary. The denser the resources, the more opportunities there are to start a contentious mobilization.

According to this approach, social movements and other contentious agents are seen as political entities that seek to create social change throughout the act of generating influence on the political institutions of the state, rather than creating a sphere of

autonomy with respect to the state and its institutions. This first important aspect is considered when studying contentious politics. The other aspect is that, since the interests of the groups involved in collective claims are always in conflict with other groups' interests, their claims will affect, if realized, other groups' interests. That is why their political actions are considered *politics of contention*. In McAdam et.al. words:

By contentious politics we mean: episodic, public, collective interaction among makers of claims and their objects when (a) at least one government is a claimant, an object of claims, or a party to the claims and (b) the claims would, if realized, affect the interests of at least one of the claimants. (McAdam, Tarrow and Tilly 2001: 5)

### **Political opportunities, repertoires of contention and collective action frames**

Three central categories from this perspective can be particularly useful for this thesis. These categories are: Political opportunities, repertoires of contention (or protest), and collective action frames. They will be discussed as follows.

#### **a) Political opportunities**

The first is the concept of political opportunities. Following Charles Tilly (2004), we understand political opportunities as, the set of resources, institutional arrangements, and cultural elements socially available in a particular social context which can stimulate and/or facilitate the emergence, configuration, or fortification of a social movement that engages in political struggles in order to transform or influence the course of a particular situation that is perceived as oppressive by the individuals, groups or communities that constitute the social movement (Tilly 2004). This set of features available in the political environment motivates people to protest and engage in collective mobilization by stimulating their perception that there are threats to their well-being, or, on the contrary, possibilities of modifying the structure that affects their well-being (McAdam et.al.

2001). In this theory, the targets or subjects of the claims of the social movements are always the state, particular institutions, or political groups. Their goal is, therefore not to create a space of autonomy with respect to the state and its institutions, but rather to engage in politics which aim to target and influence the course of action states, their institutions or other elite groups that are seen as political opponents (Staggenborg 2008).

The given structure of political opportunities in a particular social setting is not under the control of the activists or social movements, and has an independent existence. However, it is understood that the structures of political opportunities can be a by-product of the struggle carried out by social movements in the past (Tarrow 1998). For example, the existence of institutional mechanisms for defending the human rights of populations traditionally subjected to discrimination in a particular historical moment and which might currently stimulate some excluded people to come along to make claims of the state, could not have been under the control present-day activists, but could have been an institutional outcome generated by the struggle carried out by past movements of protest. That is why it is said that, although the structure of political opportunities is independent of the movements and activists engaged in contentious politics in a particular social setting, the existence of such political opportunities, or the windows of political opportunities, could have emerged as a result of social struggles carried out in the past by other social movements.

Sidney Tarrow (1998:77-80) points out that there are at least five elements comprising the structure of political opportunities. These are: 1) Openness in polity, 2) Shifts in political alignments, 3) Divisions among elites, 4) The availability of influential allies, and 5) Repression or facilitation of the state. To this list, it is important to add the issue of “threats” which, according to several social movement theorists, also play a very important role in the stimulation of protest. The broadening or constriction of these elements in the structure of politics always influences the emergence, constitution, or weakening of the social movements and other forms of insurgency, as well as their forms of contention and the outcomes.

## **b) Repertoires of contention**

This last point leads us to consider the concept of ‘repertoires of contention’, another key element of political opportunities theory. According to Charles Tilly (1995), the development of capitalism and the consolidation of modern politics led to the development of various forms of strategies and tactics used by social movements in order to participate in politics and address the state and its institutions. The term ‘repertoires of protest’, or ‘repertoires of contention’, refers to the set of political actions carried out by modern movements aiming to generate social and institutional change. These actions might include strikes, lobbying, petitions, mass protests, hunger strikes, public demonstrations and other forms of making claims visible and negotiable in the face of the state and its institutions (Tilly 1995:41-47). These repertoires are always modular in the sense that they can be moved from one place to another and repeated in variety of situations (Tarrow 1998). It is a ‘repertoire’ in the sense that it is constituted by a variety of political practices and strategies, and it is contentious in the sense that they are implemented with the goal of participating in a political contention and generating social change. Since it is assumed that the repertoire of contention and its outcomes change according to the structure of political opportunities that is present in a given particular social formation, in this thesis, the repertoire of contention put into practice by AIDS activists in México will be described, as well as the ways in which this repertoire has changed and the outcomes it has generated.

## **c) Collective action frames**

The structure of political opportunities, however, is not a set of objective elements that determine the way people come along and put in practice politics of contention. The critique elaborated by social movement scholars from diverse schools of thought, particularly those connected to the social constructionist tradition, as well as to collective behaviour theory and the emotional turn (Staggenborg 2008) away from the rigidity and structuralist character of the political opportunities theory, has pushed Doug McAdam, Charles Tilly and Sydney Tarrow (2001), the principal advocates of this approach, to

create a more dynamic version of the political opportunities approach in order to understand social movements. In their now classic work, *Dynamics of Contention* (2001), these authors state that, since humans are meaning-making animals, the structure of political opportunities must be understood as a set of institutional, political and cultural elements present in the environment that are *subject to interpretation*. As such, the opportunities that are present in a particular social setting are always subject to a process of interpretation, and its influence on social movements can be varied. Therefore, the emergence of elements in the political environment that are perceived as threats for the leaders of a social movement, for example, can lead to the strengthening, weakening, or change of its tactics. This is the reason why the elements present in the structure of political opportunities should not be seen as objective elements which are completely external to the movements, but rather as something that is always subjected to attribution.

With this recognition of the role played by subjectivity in the configuration and structure of collective action, it is important to borrow the concept of collective action frames developed in social movements theory since the mid-eighties (Benford and Snow 2000). The category of collective action frames refers to the schemas of interpretation and the perception of reality that allow the agents to make sense of the events around them and act in consequence. Social movements, according to Benford and Snow, always carry out acts of framing the social reality, labelling it out, and encouraging social action and mobilization. They distinguish between “master frames” and movement-specific collective action frames. While the master frames are “generic types of frames available for use by a number of different social movements” (Staggenborg, 2008: 19), the “collective action frames are action-oriented sets of beliefs and meanings that inspire and legitimate the activities and campaigns of a social movement organization” (Benford and Snow 2000: 614). Thus, it is important to make sense of the framing processes carried out by social movements or the sets of frames which are socially available and used by social movements and insurgents in their work of stimulating contentious politics and repertoires of protest.

One of the main advantages of using this theoretical approach and the aforementioned categories is that they will allow us to describe the processes by which political opportunities are created and expanded and, therefore, to foster an empirical understanding of the dynamic mechanisms that have allowed for the emergence of AIDS activism in México. Political opportunities theory is, in this sense, a very open approach that allows the researcher to find a wide range of resources, opportunities and variable political processes within the direct narrative of the activists, as well as in the analysis of the political and economic context in which the study is located.

**d) Neoliberalism as a class power restoration project and mode of government**

To understand how neoliberalism, both as a particular form of capital accumulation and a mode of government, is creating particular forms of vulnerability to which PLHA are exposed, it is necessary to follow the theorizations provided by David Harvey. His work places special emphasis on the material and ideological character of neoliberalism, as well as neoliberalism's utility as a tool that is designed to consolidate a class power restoration project. For David Harvey (2005:2), neoliberalism is a "theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong property rights, free markets and free trade". It also works as a "mode of discourse" that "has pervasive effects on ways of thought to the point where it has become incorporated into the common-sense way any of us interpret, live in, and understand the world" (p. 3).

Based on this rationale, neoliberalism will be understood as a particular form of comprehension, justification and design of a social order that, through an active process of discourse production, is materialized in individual, collective and institutional

practices. This discursive, economic and political regime is promoted by economic elites in order to establish an economic, political and ideological leadership in the social world<sup>5</sup>.

By mentioning these two components (economic and discursive) as constitutive of the neoliberal project, we want to underline the fact that, although neoliberalism is mainly driven by economic goals, the institutional logics that are put in motion in this context require a permanent production of discourses oriented to the governance of the population through the construction of schemes of thoughts, feelings, representations and behaviours coherent with the notions of self-responsibility, competitiveness, individualism, free will and other values that are coherent and functional to its project (Wacquant 2010).

In general terms, it can be said that the neoliberal project has launched a global process of market liberalization, labour flexibilization, deregulation of public enterprises, and it has implied changes in the forms of state intervention in the economic sphere, as well as the promotion of a supposed existence of a natural and spontaneous tendency of individuals toward liberty and personal gratification (Jameson 2004; Bezanson 2006). Although these are the general characteristics of such policies, it is necessary to point out that some variations can be found across between regions and/ or countries (Harvey 2005: 11-15). For this reason, one goal of this research is to understand whether and to what extent the particular ways in which the application of a neoliberal project México has shaped the particular forms and contexts of vulnerability of PLHA. This way of understanding neoliberalism as a form of capital accumulation and mode of government can be fruitful in light of my main goal of understanding the processes of economic, political and cultural exclusion, as well as the processes involving the institutional regulation of modes of political and social participation within and outside the state and their impact on vulnerability, as well.

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<sup>5</sup> In Harvey's view, the neoliberal "argument," as he also called it, works as a "*political* project to re-establish the conditions for capital accumulation and to restore the power of economic elites" after their loss of power during the crisis of Keynesianism. Seen in such a way, the neoliberal project "from its very inception, was about the restoration of class power and, in particular, the restoration of class power to a very privileged elite, i.e. the investment bankers and top corporate chiefs" (Harvey 2005: 12).

It is through this mixed theoretical approach that we aspire to analyze the ways in which people living with HIV/AIDS in México have been exposed to diverse forms of social vulnerability, as well as the ways in which they have organized themselves to dispute and transform the conditions of vulnerability generated by the social, cultural, economic and political processes which underpin the contemporary neoliberal project in México.



**II**  
**PUNISHING THE SICK:**  
**THE MATERIAL AND SYMBOLIC STRUCTURES OF OPPRESSION LIVED**  
**BY PEOPLE LIVING WITH HIV/AIDS IN MÉXICO**

In México, there is a master narrative that represents homophobia as the main source of the oppression experienced by people living with HIV and AIDS. In this account, powerfully expressed in government documents and in the state policies and programs, the forms of mistreatment and exclusion experienced by people living with HIV in the public and private spheres in México are a by-product of a widespread misconception in Mexican society which imagines Human Immunodeficiency Virus (HIV) to be a “homosexual disease”. The set of suggestions that stem from this diagnosis argue that public institutions must focus their efforts on educating the general population and public servants, in particular, so as that HIV is recognized as a virus which affects all sectors of the population (including, of course, the heterosexual population) and not only those people who have sex with people of their same sex. By carrying out this pedagogical process of “de-homosexualizing AIDS”, it is assumed that the forms of mistreatment and marginalization that people living with HIV experience in hospitals, workplaces, private houses, schools, and so on, will decrease and eventually disappear.

This diagnosis and political suggestion, which has been elaborated by AIDS activists as a response of an institutionalized homophobic climate which neglected the existence of this problem, makes a lot of sense. There is enough evidence to conclude that homophobia obstructs people’s capacity to have access to health care services, prevents people from using condoms to protect themselves from HIV, and discourages people from asking for medical attention due to the fear of being labelled gay and having to face discrimination. However, in this chapter, it will be argued that this understanding of the problem of oppression faced by people living with HIV, which stresses its moral or ideological basis, is correct, but incomplete. In this chapter, I will try to go beyond this *culturalist* account by showing that the structure which sustains the violence and marginalization experienced by people living with HIV in México has been underpinned by the mutually-

reinforced relationship between a set of structural reforms carried out by the Mexican state since 1983 (that have led to a progressive deterioration of health care services, permanent and chronic shortages in medication and diverse inequalities) and a set of social representations which interpret HIV as a homosexual illness. This has led to the structural formation of diverse forms of institutional and interpersonal forms of violence. We will demonstrate this by using the quantitative and qualitative data provided by diverse public institutions, in NGO documents and studies concerning the public HIV budget, in recommendations made by the *Comisión Nacional de los Derechos Humanos*, and research-based literature regarding the impact of structural reforms on the Mexican health-care system.

### **The material structures of oppression: Neoliberal reforms, the deterioration of health care services and HIV-related oppression in México**

In order to understand the material bases which help to configure the structure of oppression faced by people living with HIV or AIDS in México, it is necessary to look at how the processes of privatization, along with the structure of unemployment, both generated by the Structural Adjustment Programs (SAPs), have been modifying and limiting the access people living with HIV have to medicines and public treatment to deal with the symptoms of their illness. Let us start by providing a brief account of how these reforms were put in practice in México and their effects on the health-care system.

#### **a) Structural adjustment programs (SAPs) in México**

In México, the application of the structural adjustment policies (referred to as SAPs from here on) started in 1983 with the arrival of Miguel de la Madrid Hurtado to the presidency of the Mexican Republic and as a by-product of the direct intervention of international financial institutions. In effect, just one year after his arrival to political power, Miguel de la Madrid faced an enormous economic crisis derived from falling oil prices on the international market, as well other problems in the domestic economy, such as a high dependency on oil and a lack of support for domestic production (Laurel 1996). In an

effort to overcome the crisis, and in line with recommendations offered by the International Monetary Fund<sup>6</sup>, in 1983 President Miguel de la Madrid Hurtado announced a series of reforms which would gradually take effect over the six years of his term in office. These policies were oriented toward the stabilization of inflation through a number of measures. One important measure, the *Pacts of Economic Solidarity (Pactos de Solidaridad Económica)*, was an agreement between capitalists, workers and the state that basically implied wage control and the abandonment of state subsidies on basic goods. Other important measures included the privatization of some state-owned enterprises<sup>7</sup> and the invitation of foreign investment (Kelly 2005); the radical diminishment of public spending and subsidies in the areas of education, health and other social programs<sup>8</sup>.

The application of SAPs is a process which has not been discontinued in México since that time. On the contrary, despite the emergence of a strong opposition, led by political opposition parties and a variety of grassroots organizations, the four governments that have followed De la Madrid have continued to apply neoliberal policies and have actually radicalized the application of SAPs.<sup>9</sup> The most important reforms have been

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<sup>6</sup> Although several analysts stress the academic formation of Miguel de la Madrid (graduated from the School of Public Administration at Harvard University) to explain his particular “preference” for these neoliberal reforms, in my view, it is more sociologically accurate to refer to the historical interpretations that understand this economic and political shift as a consequence of the conditions imposed by IMF on Mexico in the renegotiation of its external debt or in the negotiation of more loans. David Harvey (2005:29) offers a detailed and research-based analysis of these politics imposed by IMF on the countries of the so called “developing world,” and their intimate relationship with the politics advocated by a specific US-based group of persons in the economic elite. For the specificities of the Mexican context, see Laurel (1996). For a detailed explanation of the negotiation process among “technocrats” and “politicians” in the context of the planning of the reform, see Schwegler (2008); this is a detailed ethnographic work which helps to understand the process of negotiation among the elite of politicians during the process of justification and negotiation of such reforms.

<sup>7</sup> During this administration, the number of state-owned enterprises fell from 1,155 in 1982 to 413 in 1988. Laurel (1996:76).

<sup>8</sup> These economic and political measures are specified in the Plan Global de Desarrollo (1988). In January 1986, México was accepted in General Agreement on Tariffs and Trade (GATT) which was created to eliminate barriers to international trade and, in general, to promote the principles of free market. As is very well known, it is the antecedent of the World Trade Organization.

<sup>9</sup> Actually, if there is something that characterized this first stage of neoliberalization, it was the pragmatism and the presence of a mixture of nationalist rhetoric and *pratique politique*. In some aspects, such as those relating to the subsidization of certain basic products as a way of negotiating with the resistance which emerged from unions, students and intellectuals, sectors that have constituted the most

implemented under the (sometimes mandatory) recommendations of global financial institutions to privatize banks, roads, railways, primary resource extraction industries (mining), refineries (sugar), food processing industries, communications (telephone and TV), film industries, fertilizer companies, airports and airlines. The progressive modification of federal laws has also been taken place, allowing for the intervention of private capital in public services, such as electricity, oil extraction and processing and health care, among others, which have led to the Mexican people's progressive loss of sovereignty over public goods and natural resources which originally belonged to them, as well to the privatization, in some cases, or deterioration in others, of public institutions and the services they provide. The way in which these reforms have been negatively affecting the health care system, stratifying access to health care, and impoverishing the sick and those people most in need will be shown in the pages that follow.

### **b) Impoverishing the sick: The impact of SAPs on the Mexican health care system**

Throughout México's modern history, all that concerns the protection, attention and administration of the population's health has been considered an obligation of the state and its institutions. Although health wasn't established as a constitutional right in the Mexican Constitution until 1983, the main body of the constitution emerged in 1917 as a product of the country's last major revolution. This original document outlined the obligation of the state to protect and provide health care attention to the workers. The public health care system is divided into three institutions: *Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado* (ISSSTE), *Instituto Mexicano del Seguro Social* (IMSS) and *Secretaría de Salud*. While the first institution provides health services to public employees, IMSS assists employees of private enterprises and *Secretaría de Salud* covers the 'open population,' that is to say, the ones who are unemployed or self-employed, generally the poorest of the Mexican population. Founded in 1959, 1943 and 1937, respectively, these three institutions have provided universal

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important bastion of opposition to certain political and economic powers in Mexican society. Nowadays, the process of imposing the neoliberal agenda has been accelerated with massive layoffs to the service of the state and the closing of several public companies.

coverage to its affiliated sectors of the population, and they have positively impacted the overall health and life expectancy of Mexican population. However, with the Mexican state's implementation of neoliberal reforms, the aforementioned health institutions have been subjected to a progressive dismantling and undermining of their capacities, which have affected the quality of the service they provide and, as a consequence, the Mexican population's health, particularly the health of those who are most in need.

The erosion of the Mexican health care system started in 1983 and has occurred in three stages (Laurel 2001)<sup>10</sup>. The first stage started in 1983 and was a transitional one. It consisted of significant reductions in funds provided by the federal government for the health services, as well as the introduction of a new schema that implied a federalization of health services as a way of making the states of the federation invest in their own health care services. As a result, within the years immediately after the 1983 introduction of such initiatives, the per capita expenditure for IMSS and ISSSTE dropped by about 50%, and it fell by 60% for *Secretaría de Salud* (SSA)<sup>11</sup>. According to official data, by 1996, this resulted in around 10 million Mexicans (10% of the total population) lacking any kind of health service (Laurel 2001).

The second stage of the health care neoliberal reforms was the most important one and consisted of a legal reform implemented in 1995 which introduced a partial privatization of the health institutions (Laurel 2001), or at least allowed the intervention of private capital in parts of its administration. This reform had two components. First, it implied a radical restructuring of IMSS and, second, a privatization of the pension system of contributions. Regarding the restructuring of IMSS, what this reform basically

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<sup>10</sup> Although this process has been subjected to several (and sometimes) contradictory changes on the surface, its objectives (reduction of public investment in the health care system) and its effects (the commodification of health) have always remained the same.

<sup>11</sup> Wage control, a policy implemented by the Mexican government to face the crisis of 1984, has also contributed to the diminishing of public investment in the federal health institutions, such as IMSS. Since the money collected by the health institutions relies heavily on the contributions of the workers who receive services in such institutions, and these contributions are based on a calculated percentage of their income, the health institutions did not receive enough funds as a product of the low wages of the workers. Laurel (2001: 299) says that this policy of wage control generated in IMSS, for example, led to a loss of more than 106 billion pesos between 1983 and 1994.

established was a major “modification in the scheme of contributions which shifted from contributions proportional to income to a uniform premium for employers, a small premium proportional to workers’ incomes, and a uniform government contribution to compensate for the employer contributions lost with to move to a uniform premium” (Laurel 2007: 516-517). This implied the abandonment of the principle of solidarity (contributions according to your income, services according to your needs) which characterized the public services in post-revolutionary México in exchange for a liberal principle of “equal pay for equal services” which, thus, introduced the first step to what we can call the commodification of health services.

But the above-mentioned reforms are not the only ones that have contributed to shifting objectives in the public health care system. The other very important one was the introduction of private capital to the public sector. This occurred through an exchange of the public pension system for a private one. This reform allowed banks (already privatized) and private insurers to administer retired workers’ funds (AFORES). By doing this, the Mexican State legalized the massive transfer of public money to the private sector, which strengthened financial groups and the mercantilization of the pension system (Laurel 1996).<sup>12</sup>

The third major neoliberal reform to health care system consisted in the decentralization of the services provided by the *Secretaría de Salud* and the creation of an ‘essential health package’ which was provided to the user population of the SSA. Regarding the first point, the Mexican state transferred its former obligation of providing health care to the open

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<sup>12</sup> According to the specialist Asa Cristina Laurel, the health care system reform was accelerated as a consequence of a set of recommendations made by the Mexican government in 1998. In an unpublished document cited by Asa Cristina Laurel (2007:517) called “Mexico’s Health Care System Reform”, elaborated by World Bank it is stated that a new reform was requested to the Mexican government as a condition of the provision of an adjustment loan for IMSS reform. Among other things that are basically the continuation of the reform that was already stated in 1995, Laurel points out, World Bank recommends the introduction of “a managed competition with a provider-purchase split through the establishment of a the creation of a Social security health fund, and managed care organizations, public or private, paid on capitation or ‘fee for service’ basis at specific hospitals. Initially, the managed care organizations would be reorganized into IMSS health regions and special hospitals. Nevertheless, it was considered that once the private sector was sufficiently strong, this model would be used as the general principle for the entire health care system”(p. 517).

population to the states of federation (Homedes and Ugalde 2005; Laurel 2001)<sup>13</sup>. By doing this, the services provided by *Secretaría de Salud* at the state-level, which have traditionally been of poor quality and lacking in sufficient public money to invest in infrastructure, and the public services became deteriorated. Another negative consequence of this reform was the stratification of the Mexican population's access to health as it allowed government and private sector employees (who were covered by IMSS and ISSTE respectively) to continue accessing the benefits of such federally-funded health institutions while the unemployed and self-employed people, most of them indigenous people and the rural poor, who were covered by the SSA, experienced the consequences of the progressive erosion of the services provided by *Secretaría de Salud*.

Finally, regarding the second point it is pertinent to mention that the creation of the 'essential health package' substantially changed the definition of the services that must be included in a free essential health package for those people without social security. The new package included basic medical attention, such as information on child nutrition, ambulatory services, information and education on disease prevention, family planning, essential medications and other basic and inexpensive components of health care, and it eliminated all the other services, the most expensive ones, normally, which the patient was required to pay for from that time on (Laurel 2001: 312-313).

Two decades of abandonment of the health care services in México, created as a political strategy to justify privatization, allowed the government of Vicente Fox to create a program called *Seguro Popular de Salud*. This program provides an insurance policy to each citizen who does not have any health coverage and must pay to access basic health services. The problem is that this package only covers basic medicines and attention. For example, the 'Paquete Básico', which includes 78 interventions, does not include detention, treatment of cancer and other degenerative or serious illnesses, such as Alzheimer's. Nor does it offer hospitalization services despite the fact that it is assured to target the most in need.

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<sup>13</sup> By making these changes, the federal government dramatically reduced its public expenses. At the same time, it generated a deterioration in the main institutions of public health (IMSS) and the Health Ministry and radically impoverished the health care attention in such institutions (Laurel 2007).

### c) Privatization through transfer

It is important to mention that in this process of reforms the point has not been the total privatization of services provided by the public health institutions, but rather through the transfer of public money into private hands. The executive directors of such institutes have been outsourcing, contracting private personal to cover a number of activities which were previously in hands of the state, including the administration of pensions, cleaning services, police surveillance and other services involved in hospitals maintenance. It is through this process that private entrepreneurs have benefited. Through this process, an economic elite in society has either been participating in the dismantling of the health care system, or has benefited from it.

The most dramatic of these manifestations of transfer and subcontracting which benefits the rich is embodied perhaps in the latest reform promoted by the Mexican government in matters concerning health care. In effect, on October 21, 2010 the *Congreso de la Unión* implemented a reform to the Law of IMSS that allows *Farmacias Similares* to provide medicines to the public when there is a shortage of medicine in IMSS. According to this legal amendment, the Mexican government will pay *Farmacias Similares* for the medicine it provides to the people. Research-based reports have made it public knowledge that this reform was made to favour the expansion and market of Victor González Torres, the owner of *Farmacias Similares* and long-time ally of the conservative *Partido Acción Nacional*, by selling generic drugs to those who do not have access to the health care system, particularly those who live in rural and poor areas of México (Flores 2010). By doing this, the press and opposition parties argue, the President of México has made it possible for ‘Dr. Simi’ to increase its market and fortune by covering not only the rural areas, his traditional clients, but also all the people who face barriers to receiving medicines from the IMSS.

By seeing this case, there is no doubt that the processes of health care service dismantlement, created by the political elites in México, have negatively affected the poor and benefited the rich. If Carlos Slim became the richest man in the world thanks to the privatization of *Teléfonos de México*, (a company which belonged to the Mexican people



before its privatization), Victor González Torres, owner of *Farmacias Similares*, may just become another of the world's multi-millionaires thanks to this reform proposed by the Mexican president and the right-wing parties who supported it. The class character of México's privatization process is quite evident, then, upon considering who benefits from these policies.

#### **d) The Consequences**

The inequalities in the access to the health services within and among the different states of the Mexican federation primarily affect the poorest and those who are most in need and live (mostly in the rural areas) in the states of Oaxaca, Chiapas, Guerrero, Veracruz and other poor states. As was mentioned above, the neoliberal reforms to the health care system have generated a *progressive impoverishment* of the people who only have access to the public health care system. In effect, according to data provided by the medical anthropologist Eduardo Menéndez (2005), each year more than 2 million families have to incur 'catastrophic expenses' as a consequence of a health crisis of one its household members. Because most of these families are poor and have access to the limited coverage provided by the *Secretaría de Salud*, these families have to pay the medicare in private hospitals out of their own pockets. They normally end up living in extreme poverty as a consequence of this situation. Based on this data, and on the fact that these kinds of expenses are a consequence of not having medical coverage in the public health institutions that offer integral coverage, such as IMSS and ISSSTE, Menéndez concludes that more than 50% of the cases of extreme poverty in México these days can be attributed to the expenses generated by the catastrophic expenses generated by a serious sickness. For this reason, it is not exaggerated to point out that the neoliberal reforms to the health care system have been punishing the poor and directly contributing to an exacerbation of extreme poverty.

Another factor that is pertinent to stress regarding the effects of neoliberal reforms in the health care system concerns the *deterioration of public health service and a chronic shortage of medicines* in public hospitals. As consequence of cuts to the budgets for

public health, major damages have been caused. There is a lack of professionals working at the hospitals, a lack of instruments and adequate infrastructure, and an excessive workload that makes it difficult for doctors and hospital personnel to offer quality services when there are long waiting lists, as well as a chronic lack of medicine and treatment options.

The last point is, perhaps, the most infamous effect of the deterioration of public health care in México. According to the National Commission for Human Rights, the human right which is most frequently violated in México is the right to receive medicine. Also, in 2009 this institution carried out an analysis based on the totality of complaints it received from citizens between 2000 and 2009 with regard to public health institutions . The study revealed that the main problems in public hospitals and clinics of the public health sector during this period of time included a lack of doctors, specialists and nurses, which is translated into an inability to satisfy the existing demand of people in the public sector and a lack of training for the provision of quality, professional health care and the appropriate treatment of patients. This public diagnosis also pointed out a lack of infrastructure and material resources, such as beds, medicines, instruments and equipment, in general. These were considered to be ‘chronic obstacles’ which prevented the provision of adequate service to the public. What people most complained about, however, according to the report, were the acts of discrimination; the lack of attention in emergencies; the non-existent or insufficient laboratory studies available to detect sicknesses; mistreatment; the denial of surgical interventions; and a lack of attention during pregnancy and the delivery of babies<sup>14</sup> .

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<sup>14</sup> Recomendación General Número 15, sobre el Derecho a la Protección a la Salud, dirigida al Secretario de Salud, a los Directores Generales del Instituto Mexicano del Seguro Social, del Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado y de Petróleos Mexicanos, a los Secretarios de la Defensa Nacional y de Marina, a los gobernadores de las entidades federativas y al Jefe de Gobierno del Distrito Federal. The recommendation literally says: “*Los problemas más graves que enfrentan las instituciones encargadas de prestar el servicio de salud es el relativo a la falta de médicos, especialistas y personal de enfermería necesarios para cubrir la demanda; la falta de capacitación para elaborar diagnósticos eficientes y otorgar tratamientos adecuados a las enfermedades, y la insuficiente supervisión de residentes o pasantes por el personal de salud.*”

*La falta de infraestructura hospitalaria y de recursos materiales también se presenta como un obstáculo para garantizar de manera efectiva la protección del derecho a la salud, ya que en muchas ocasiones en las quejas se hace referencia a la insuficiencia de camas; de medicamentos; de infraestructura hospitalaria, sobre todo en las zonas rurales; de instrumental médico o equipo indispensable para atender*

We have outlined, in general terms, the ways in which neoliberal reforms have been affecting the Mexican health care system and its institutions. Now, let move on to analyze the ways in which SAPs have been affecting the structure of work.

### ***Employment***

Unlike the major changes SAPs caused in the health care system, the neoliberalization project in México has not made changes to the Federal Work Act (*Ley Federal del Trabajo*) in order to change the relationships between capital and work, mostly because of the strong resistance on the part of the unions. The most important changes in the field of work have been determined by the shift toward a new configuration of a labour market called *terciarización* and by the flexibilization of employment, which has put workers in a position of vulnerability and at a disadvantage in the labour market. According to Oliveira (2006) and de la Garza Toledo (2001), the privatization process and the opening of the domestic economy to the international market have been the causes of this phenomenon.

### ***Consequences: What has been the impact of SAPs on work in México?***

Flexibilization and Labour Precariousness. Under conditions of unemployment, people who have been fired or those that do not find a job at the beginning of their productive period in life opt for self-employment or informal employment. These kinds of jobs are characterized by wage discretion (under the minimum established by the law), a lack of

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*a los enfermos o realizar las intervenciones quirúrgicas necesarias; de equipo y materiales adecuados para la elaboración de estudios y análisis clínicos; de material instrumental o de reactivos para la realizar los estudios de laboratorio, y de instrumental médico para llevar a cabo las cirugías o la rehabilitación; asimismo, en las quejas se menciona dilación en la práctica de estudios clínicos y retardo en los diagnósticos, lo que propicia una deficiente atención.*

*De igual manera, de las quejas recibidas en esta Comisión Nacional se desprenden diversas irregularidades en la prestación de la atención médica, como un trato contrario a la dignidad, poco respetuoso y, en algunos casos, conductas discriminatorias que afectan el bienestar de los pacientes; la falta de atención en las unidades de urgencias; la atención de manera irregular; el maltrato a los pacientes; las intervenciones quirúrgicas negligentes; la inadecuada prestación del servicio médico, y la deficiente atención materno-infantil durante el embarazo o el puerperio.”* This recommendation was made based on the analysis of 11,854 complaints received by the CNDH between January 2000 and January 2009. For access to the official document, visit: <http://www.cndh.org.mx/recomen/general/015.pdf>

health services, benefits, positions (*puestos de trabajo*) and vacations, as well as employment which is based on hourly pay, part-time contract work, among other characteristics which are against the law.

On the other hand, employment in industry has been decreasing, whereas employment in the service sector has been increasing (Alcaraz and García 2006). Workplaces in this latter sector commonly provide low wages, excessive work, pay in the form of honorariums and zero stability. According to a report elaborated by the *Coalición Nacional de Trabajadores del Instituto Nacional de Estadística y Geografía* (INEGI) (Muñoz 2004), 62 per cent of Mexicans are living under this form of labour precariousness, are employed outside of the labour rights established by Mexican legislation and do not have stable employment. As such, this union considers that, despite the fact the law has not changed, in reality, capital has already been flexibilizing employment.<sup>15</sup>

### **No jobs, no meds: Homophobia, neoliberal scarcity and its impact on people living with HIV**

Before showing how the two aforementioned factors interact and configure the particular forms of vulnerability experienced by people living with HIV in México, let us start by showing how the progressive deterioration of the health care system has led to some structural outcomes with regards to HIV.

Strictly in terms of HIV, the structural reforms in the area of health policy have led to three institutional outcomes that are important to underline here. These are: 1) a chronic shortage of antiretrovirals (ARVs) and other medicines needed by HIV patients, 2)

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<sup>15</sup> Some qualitative data presented by de la Garza Toledo (2001) can help us to understand the precariousness of Mexican labour in the neoliberal era:

- In 2006, just 41.7% of workers had written contracts for a determined time period.
- The percentage of waged workers without benefits was 41.7%
- The percentage of workers employed in micro-enterprises was 27.1%.
- 64% of new jobs created during the liberal administrations were temporary and without benefits.

limited access to last generation therapies, and 3) institutional mistreatment. Each one of these institutional outcomes alone or in combination and mutually reinforcing one another has led to the emergence, reinforcement, or perpetuation of five striking consequences that have negatively affected people living with HIV. These are: 1) Low increase of life expectancy for PLHA and low decrease of mortality rates, 2) High rates of co-infection, 3) Inability to adhere to the therapies, 4) Abandonment of therapies, 5) Unequal access to health care that particularly affects the more marginalized PLHA via a progressive impoverishment, and 6) High rates of mortality associated with AIDS.

#### **d.i) The shortage of medicines and ARVs and its impact on mortality rates**

Although since the 1980s all these outcomes have manifested themselves to various degrees and with different characteristics according to the region, level of attention, institutions and historical moment, what all of them have in common is that they are invariably related to the structural manifestations generated by the neoliberal reforms implemented on the health care system described above. The chronic shortage of antiretrovirals and other medicines for HIV in Mexican public hospitals, as well as the limited access to last generation therapies for the treatment of HIV and opportunist infections associated with the virus are the most evident consequence of the damage caused by the neoliberal reforms of Mexican health care institutions. This has been particularly evident in the case of *Secretaría de Salud* and IMSS, institutions that account for most of the complaints filed by individuals and NGOs over the last decade, and where the most dramatic and severe cases have been occurring. In effect, according to the data provided by the National Commission for Human Rights (CNDH), between 1992 and 2008, 60% of the human rights violations against people living with HIV were perpetrated by the *Instituto Mexicano del Seguro Social (IMSS)*, institution that, at the same time, has received 10 recommendations (out of a total of 22) issued by CNDH on the issue. The data provided by CNDH also shows that 40 % of such violations were due to a denial of medical attention and a lack of antiretrovirals and medicines used to treat HIV.<sup>16</sup>

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<sup>16</sup> <http://www.cndh.org.mx/comsoc/compre/2008/124.htm>

Shortages of antiretroviral therapies have become increasingly more commonplace over the last few years despite the fact that, since 2004, an agreement between CONASIDA, UNAIDS and the laboratories which produce antiretrovirals has created the conditions for universal access to anti-retroviral therapies. Likewise, there have been important increases in the availability of public funding designated specifically for HIV-related initiatives, and progressive members of parliament and AIDS activists have made possible a universal (at least in theory) access to medicine for all people living with HIV in México. This has occurred because of the fact that most money allocated in general to health institutions has not been distributed according to the density of PLHV population on the basis of rational criteria, and to the fact that some institutions have re-directed the money they received for HIV medicines to subcontract cleaning services, banking, security and other private hospital services. For example, based on an exhaustive and detailed review of the public funds which were approved by the *Cámara de Diputados* (Chamber of Deputies) to specifically cover the necessities of HIV and which were allocated by the Mexican government in 2005 the organization *Fundar, Centro de Análisis e Investigación A.C.* found that there was a lack of epidemiological criteria in the allocation of new funds among the institutions which would account for the number of patients living with HIV who are covered by each public health institution. In 2005, the *Secretaría de Salud* reported that the *Cámara de Diputados* had approved a budget increase of 200 million pesos for HIV/AIDS. This money, which corresponded to more than 100 percent of the budget, was approved in the final years and was assigned to other areas that were not related to HIV. This is to say, *Secretaría de Salud* re-directed the resources that should be used to treat people living with HIV to other ‘equally important issues’ faced by the *Secretaría de Salud*. As a consequence, important institutions involved in the research, diagnosis and treatment of HIV in México did not receive any more funds and, in fact, they received less funding than in past years. Surprisingly, *Hospital Juárez* and *Instituto Nacional de Perinatología*, institutions which do not offer specialized services for HIV and only eventually treat people living with HIV, received an increase of 19 million pesos that year (FUNDAR 2004: 45-58). By looking at these examples, it is possible to see that the problem has been generated not only by cut-backs

in health provisions, but by the allocation of the money within the institutional structures of health.

The problem does not end with this irrational allocation of funds to institutions, however. The most striking aspect of this is that these institutions, as is shown in the same document, spent most of these new funds on administrative tasks, which were completely alienated from the purpose of treating people living with HIV. For example, the *Instituto Nacional de Perinatología* spent most of its resources on subcontracting private enterprises for cleaning services. Likewise, *Hospital General Dr. Manuel Gea González*, which has one of the highest numbers of patients living with HIV, spent the resources principally on media commercials, banking, maintenance, and new cars (Lara and Hofbauer 2006: 26-28). This phenomenon cannot be attributed to the neoliberal agenda. Nevertheless, it, along with other factors that are related to the effects generated by the neoliberal agenda, has helped to reinforce the deterioration of health care institutions and the services they provide; this will be explained further in the following paragraphs.

The direct consequence of this is that PLHA are frequently faced with the problem of a lack of access to medication, which in many of the cases leads to the development of drug resistance that can become a significant problem because doctors have to change the combination of medications; over time, the patient slowly gets to the point in which no antiretroviral can help the patient to resist the advance of the virus in the patient's body.

The shortage of antiretrovirals and medications for HIV is probably the most severe and harmful effect of the deterioration of health care services in México, but it is not the only one. The second major problem we could see is regarding the lack of access to last generation antiretrovirals and laboratory testing to determine the levels of viral load in the blood and any resistances, a process which is fundamental for monitoring the effects of the therapy in the patient.

Another problem is manifested in an almost generalized lack of rooms and beds for hospitalization, particularly in what is denominated the third level of attention, which is

the level where people who experience serious illnesses are submitted to chemotherapies, surgeries and other treatments that require the patient to be in the hospital for several days. This fact directly affects PLHA since they belong to a sector of the population that requires frequent hospitalization for severe illness or check-ups and monitoring (CNDH 2009).

Finally, *poor working conditions and heavy workloads* should be mentioned as other severe forms of harm generated toward people living with HIV in the context of neoliberal reforms to the health care system. This fact has been analyzed in detail by various researchers of the school of social medicine at *Universidad Autónoma Metropolitana* in México City. Sergio Sánchez and Gabriela Montoya (2003), for example, have analyzed in detail the ways in which the process of cutting budgets for the *Instituto Mexicano del Seguro Social*, the institution which provides health care to more than 40 percent of the Mexican population living with VIH, produces a severe crisis in the quality of services. These reforms have organized an employment regime that can be characterized by heavy workloads due to the fact that an insufficient number of physicians and nurses are hired, particularly for first and second level of medical attention. This has caused physician-patient relationships to reach a high degree of deterioration, which has materialized in tensions, authoritarianism on the part of the physician, lack of attention to detail, lack of respect for the time and necessities of the patient and, as the CNDH has documented, the denial of medical attention. One of the consequences of this in the field of HIV is that this deterioration of the physician-patient relationship has been directly affecting the patient's capacity to adhere to prescriptions. The consequences of this have already been analyzed widely-that is, ultimately, the health of HIV positive patients deteriorates.

One of the main problems facing people living with HIV is the lack of adherence to treatments, a fact that leads to the development of opportunist infections in approximately 50% of cases. Around 25% of these patients die (Vásquez Gómez 2011). Although there is not much research on this topic, emergent pieces of research with people living with HIV in the north of México have shown that the lack of adherence to treatment is due to



structural barriers patients face in the hospitals where they receive medical treatment. For example, research carried out by specialist in at the *Universidad Autónoma de Tamaulipas* has shown that more than 50% of patients abandon the treatment with antiretrovirals<sup>17</sup>. From this quantity, more than 40% do that after not having received antibiotic prophylaxis in the hospitals or have been denied their access to medicines due to a supply shortage. In addition, some of the activists who were interviewed said that some patients who are experiencing a hard time without a job decide to sell their medicines or drop intake of medicines due to the fact that they do not have healthy and sufficient food and fear developing problems related to ingesting medicines without eating first. The researchers we just mentioned in the lines above mention that they attribute all these problems, in the end, to the lack of access among patients to integral treatment plans and specialists, such as nutritionists, psychologists and people who really educate and motivate the patient to take their medicines. This is another factor that can be attributed to the lack of infrastructure and integral medicare generated by the scarcity generated by the neoliberal project to promote lean institutions.

The other characteristic of this neoliberal employment regime is a lack of instruments or infrastructure that prevents health care providers at all levels of attention (ie. walk-in clinics, as well as hospitals where the surgeries are performed) from providing quality services and attention to the patient. Frequently, research conducted by CNDH on these matters reveals that in many of the cases in which medical attention or consultation has been denied to patients living with HIV is a lack of sterile gloves, syringes, and other basis instruments doctors require in order to attend their patients (CNDH 2009).

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<sup>17</sup> “Factores que influyen en la no adherencia al tratamiento antiretroviral en personas con VIH en Tamaulipas, México”, interview conducted by Jéscica Vázquez Gómez with the researchers M.E.C. Florabel Flores Barrios, M.E.S. Elva del Ángel Rivas, M.C.E. Nora Hilda González Quirarte, Dra. Isabel Peña Nieto de Córdova, Médico Ana María Rivera Peña y Lic. Norma Martínez Padrón, from the Cuerpo Académico de Enfermería Comunitaria de la Facultad de Enfermería de Tampico, UAT. In: Revista CienciaUat, April 16, 2011. Retrieved on April 15, 2011 from: [www.revistaciencia.uat.edu.mx/articulos.php?subaction=showfull&id\\_fixed=1238530141&archive=&start\\_from=&ucat=2&](http://www.revistaciencia.uat.edu.mx/articulos.php?subaction=showfull&id_fixed=1238530141&archive=&start_from=&ucat=2&)

#### **d.ii) Unemployment, homophobia and the lack of medicines**

In addition to the direct impact of neoliberal reforms on people living with HIV, there are a number of other factors that have indirectly affected the health of PLHA. The most important of them, in my view, is related with the changes in the structure of work, a fact that, together with homophobic ideologies and violence in the workplace against homosexuals, which are widespread throughout Mexican territory, organizes a regime of health vulnerability for PLHA.

As we discussed earlier in this text, health care is an individual right in México by constitutional mandate. The terms and modalities of this right depend upon the labour status of the person, however. According to the *Ley General de Salud* (General Health Act), people who have a formal job contract with the government or a private company must be attended at *Instituto Mexicano del Seguro Social* (IMSS) or at *Instituto Mexicano de los Servicios Sociales de los Trabajadores del Estado* (ISSSTE). For its part, the *Secretaría de Salud* has the mandate to provide with health care services to unemployed people or those who are self employed or do not have formal employment. The first institutes mentioned are the ones that offer an integral package of medical care, whereas the *Secretaría de Salud* only offers first level of attention, which means only basic medicines and basic medical consultation without hospitalization, etc. This fact results in a big disadvantage for PLHA since, according to the *Centro Nacional para la Prevención y el control del VIH/SIDA* (CENSIDA), most of them are unemployed because of the occupational violence against homosexuals, a sector of the population that has the most cases of HIV have in México (CONAPRED 2005). In effect, according to the *Secretaría de Salud*, men having sex with men (MSH) is the group of population most affected by the HIV infection (SSA 2003). Six in ten infections are concentrated among homosexuals or bisexuals. Although there is no research on sexual orientation, employment and HIV, it is very well known that a high number of gay men, above all if they have ‘feminine mannerisms,’ tend to choose self-employment and/or employment in the informal sector as a strategy to avoid workplace discrimination due to the high degrees of violence and intolerance that characterize most workplaces in México (CONAPRED 2005).

### **d.iii) The shortage of medication for HIV and the deterioration of the provision of health services**

In this context of unemployment, PLHA are prevented from receiving health care from the IMSS and ISSTE, institutions that, by law, provide this service only to working population. Therefore, they are directed to the *Secretaría de Salud*, an institution that is obligated by law to provide services to these populations even though it can only do so in a very limited way because the institution cannot offer more than antiretrovirals (ARV) and partial medical attention, which excludes, for example, laboratory testing and other important services required by PLH.

The main and most dramatic consequence of this whole matrix of institutional outcomes that has displaced people from their right to medicines and treatments in public hospitals is the permanence of mortality rates. According to data elaborated by the Mexican government, despite the universal health coverage reached in México as of 2004, as well as the efficacy developed by antiretrovirals during the last decade, the mortality rates of PLHA have not diminished in any significant way. In México, each year around 2,500 people die, a rate that has remained at the same level for the past 5 years. This data starkly contrasts with the Brazilian or Argentine experiences, which have seen important decreases in mortality as these countries guaranteed treatment for all (CENSIDA 2010; Cruz Martínez 2009). This situation is due to limited regular access to medication, as well as to a lack of access to punctual follow up and monitoring in hospitals. It must also be added that the factors that play a powerful role in this dramatic consequence are still broader than that. The mistreatment people face in the hospitals, along with the permanent shortage of medicines, lack of access to laboratory proofs, monitoring and permanent check-ups, the less than ideal relationship between patient and physician, the lack of jobs that allow sick people a guaranteed income and in turn the good and healthy food necessary for the efficacy of medicines -all of this related, as we have seen, with the permanent deterioration of the health care system under neoliberal policies.

## **Representations, HIV and stigma in México: The symbolic structures of oppression experienced by people living with HIV or AIDS**

A sociological emphasis on the ways in which the Mexican state's moves toward the dismantling of health care services in the neoliberal era, and the parallel labour structures and processes, help us to understand how the diverse forms of precariousness resulting from this new socio-economic structure directly affects people living with HIV. It increases their risk of not receiving medication on time, not being able to adhere to treatment, and therefore, developing various kinds of opportunist infections, which diminish their possibilities of increased life expectancy. This account, however, does not help us to understand other forms of institutional violence and displacement to which people living with HIV have been subjected in México and which are not dependent on the economic structure organized by neoliberalism. These diverse forms of violence that are not related with the economic structure and that, according to the data provided by *Comisión Nacional de los Derechos Humanos (CNDH)*, *Consejo Nacional para Prevenir la Discriminación (CONAPRED)*, *Centro Nacional para la Prevención y el Control del VIH/SIDA (CENSIDA)* and various NGOs, include arbitrary dismissals in the workplace; mandatory testing without consent; involuntary withdrawals from schools; segregation from student populations in schools, quarantine in hospitals and being placed in isolation in prisons; being subjected to offensive treatment in the hospitals for the supposed 'immorality' which caused their HIV-infection; as well as state intervention which prevents PLHA from caring for their children (ie. foster care).

All of these cases that we have referred to, as we said already, cannot be related to the economic structure. Rather, they should be considered as a product of institutional dynamics and individual practices that have been historically shaped by a structure of representations about HIV and AIDS.

According to the chronicles and analyses of activists, writers and researchers who specialize in social sciences in México, it is possible to locate three fundamental pillars which have underpinned this set of stereotypes and prejudices which shape this cultural

structure and organize the violence against PLHA. These are: 1.) The role played by the Catholic Church in México in the representation of HIV as a homosexual illness, as well as its understanding as a divine punishment; 2.) The role played by scientific discourses at the beginning of the pandemic in the generation of a representation of AIDS as a ‘pink cancer’; 3.) The role played by the media in the production, circulation or justification of incorrect information concerning AIDS and the infusion of fear among the population at large, and 4.) The active role played by the *Cruz Roja Mexicana*, *Pro Vida*, *Asociación Nacional de Padres de Familia* and other right-wing groups that have traditionally sought to prevent the distribution of condoms and the production and dissemination of scientific information about AIDS in the media and in public schools by the institutions of the Mexican state (González Ruiz, 1996 and 2002; Rivas Sanchez 2003 and 2004).

Juan Carlos Hernández Meijueiro, theologian from the University of Castengandolfo, Italy, and perhaps the most influential sexual educator and advisor of sexual politics and AIDS activists in Mexico since 1985, points out that the role played by the Catholic Church in the production and circulation of hate discourses against homosexuality must be considered as the most important source of stigma for people living with HIV/AIDS in Mexico. To exemplify this, he describes the very first public reaction of the Catholic Church when the Mexican government announced the first cases of HIV in Mexico: In 1985, he says, the representative of the pope in Mexico, *Gerónimo Prigione*, declared that “El sida es el castigo de Dios para quienes quebrantan la ley de la naturaleza” (AIDS is God’s punishment for those who break the law of nature).<sup>18</sup>

He also mentions that, even though some sectors of Catholic Church (fundamentally led by liberation theologians) have been progressive in matters of struggling against poverty, for example, and even have sometimes supported social insurgences such as the *Ejército Zapatista de Liberación Nacional* in Mexico or the struggles in El Salvador, Nicaragua and Guatemala in the 1970s and 1980s, in matters of sexuality, their role has not been progressive at all. Their opposition to the interruption of pregnancy, same sex marriage and AIDS has not changed substantially, he says, even amongst the most progressive

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<sup>18</sup> Interview with Juan Carlos Hernández Meijueiro, June 1, 2011

sectors.<sup>19</sup> This fact affected public policies regarding such issues in Mexico with the arrival of Carlos Salinas de Gortari to the Mexican presidency and then Vicente Fox. This happened due to the fact that these two presidents generated a close relation with Catholic Church in the design and implementation of public policy as a strategy for overcoming the instability generated the dubious legitimacy of the triumph Salinas de Gortari, and the commitments Fox acquired with the Catholic hierarchy during his presidential election campaign.<sup>20</sup> The Catholic Church, Juan Carlos Hernández explains, became active in the fight against AIDS at the end of the 1980s when they created shelters for persons who were labeled “victims of AIDS” and included women and children; this contributed to the generation of even greater stigma against those who were not considered victims but rather generators of AIDS, which, according to the narrative of the Catholic Church, were gay people.<sup>21</sup>

## **Conclusion**

As we have seen throughout this chapter, the structures that organize the precariousness and the violence that PLHA experience in México are powerfully conditioned by the material structures that have organized the Mexican state’s moves to dismantle health services. It is also related and mutually reinforced by a symbolic structure that is relatively independent from the economic structure and that justifies, underpins or reproduces the individual or institutional violence that PLHA experience in their face-to-face relations day in and day out. The mutually-dependent and reinforced character of the material and symbolic structures, such as those which have been described here, is possible to observe quite clearly in the health services, in particular, although this is not the only context. It is exactly these institutions where we can observe how the scarcity of medicine, the lack of material to attend HIV patients, and the moral structures that imagine AIDS as a product of an immoral sexual conduct or as embedded in a body

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<sup>19</sup> Interview with Juan Carlos Hernández Meijueiro, June 1, 2011

<sup>20</sup> For a more detailed explanation of how and why Carlos Salinas de Gortari and Vicente Fox co-governed with the Catholic Church during their respective presidential periods, see Carlos Monsiváis “‘No sin nosotros’. Los días del terremoto 1985-2005”.

<sup>21</sup> Interview with Juan Carlos Hernández Meijueiro, June 1, 2011.

which is weak, vulnerable and unable to care for itself leads to a series of attitudes on the part of individual medical personnel or on the part of the medical institution as a whole which tend to justify or deny the situation (in the best of scenarios), leaving the person exposed to the most infamous situations of abandonment and exposure. For example, in the stories of the activists we interviewed, as well as in the recommendations elaborated by CNDH, which present tales of the victims themselves, it is possible to observe how the absence of adequate medical services and professional treatment on the part of medical personnel almost always goes hand-in-hand with institutional discourses that tend to blame the patient for their situation. They say, for example, that the patient is in poor health because of their irresponsibility and lack of discipline with medical treatment and because of their inability to prevent re-infections (ie. this is when an HIV-infected patient is infected by another STI). In other cases, and in the worst scenarios, the authorities tend to minimize the problem by questioning whether or not it is worth investing so much in AIDS, as it is an incurable disease, or they justify forms of isolation and mistreatment by considering HIV positive patients as dangerous subjects whose irresponsible actions led them to contract HIV and become a threat to society.

This context has, of course, transformed over time and it has been subjected to important transformations that have been promoted by the very people who live with HIV/AIDS. The following chapter describes the forms in which the PLHA have responded and transformed this context of exclusion and precariousness organized by neoliberal forces and the symbolic structures which have been historically configured in Mexican society.

**III**  
**CONTENTIOUS POLITICS:**  
**THE EMERGENCE AND TRANSFORMATION OF MEXICAN AIDS ACTIVISM**  
**AND ITS REPERTOIRES OF CONTENTION**

Why, when and how did AIDS activism emerge in México? Which organizations led these efforts? What are their repertoires of protest and how have these transformed over time? What is the relationship between these changes and the structure of political opportunities? The objective of this chapter is to answer these questions.

According to the information shared by the activists interviewed for this study, as well as the information found in the documents written by civil society organizations dedicated to the fight against AIDS, the diverse forms of collective action carried out by people living with HIV or AIDS have experienced several transformations since they emerged. In a simple schemata we could say that these forms of collective action have fundamentally aimed to: 1) Create self-help groups which, through acts of solidarity, aim to deal with the devastating consequences of the illness and the process of stigmatization attached to it; 2) Gain social recognition and respect for people living with HIV AIDS through educational activities, the changing of normative frameworks and influencing institutional practices via lobbying and street protests; and 3) Attain the redistribution of public resources for HIV treatment, medical attention and prevention through street protest, the petitioning of authorities and lobbying.

Since the discovery of the first case of HIV in México, AIDS activists have been engaged in the three types of collective practices mentioned above, but the stress placed on one type of politic or another and its repertoires of protest has changed regularly in response to the structure of political opportunities available at different moments in time. This research helped us to understand that, since the emergence of the first AIDS organizations in the mid-1980s, the struggle to eliminate stigmatization and the attainment of social recognition and respect for people living with HIV were particularly stressed. After the nineties, the contentious politics, and its repertoires changed in a way that the struggles



for redistribution were more present. This idea of underlining the type and characteristic of AIDS activism within the limits of the continuum recognition/redistribution elaborated by Nancy Fraser (2004) is important because it can be helpful to understand how and to what extent the political activism carried out by people living with HIV has shaped the institutional processes and dynamics of transformation generated by the project of neoliberal social formation in México. This theoretical distinction deserves to be explained briefly. For Nancy Fraser, the demands for social justice ideally have two dimensions: one which stresses issues regarding misrecognition as the main problem faced by diverse social groups; therefore, it demands cultural recognition as the best way to overcome the related social exclusion and oppression. The other dimension emphasizes that the main problem facing social groups concerns issues generated by economic exploitation therefore, it demands diverse forms of redistribution as a way of overcoming the exclusion and oppression this lack of distribution produces. In the post-socialist era, she states, demands for cultural recognition have tended to predominate over the demands over redistribution, even though in reality the forms of cultural misrecognition (generated by the structure of representations) generate forms of distributive injustice (lack of access to good jobs, housing and other public goods) and, vice versa: the lack of access to redistributive justice generates forms of cultural misrecognition (Fraser 1997:17-54). I will locate the demands generated by AIDS activism in Mexico within this context of demands for social recognition - which implies demands for parity in political parties and policies, the modification of laws to guarantee respect for cultural differences and put an end to diverse forms of stigmatization and disrespect- and demands for redistribution which implies demands for equalitarian distribution of jobs, the redistribution of wealth demands which are typically associated with the socialist or welfare state.

The goal of the next part of this chapter is to offer a general and chronological overview of these three periods of AIDS activism in México, as well as the organizations that were established during these periods of time and their repertoires of contention. At the same time, the characteristics of such activism in terms of the recognition/redistribution continuum will be pointed out.

## **Phase 1: 1983-1985. Protecting the sick. Social solidarity and the struggle for survival**

The first type of reaction on the part of civil society was a reactive and self-protective one. The collective actions in this first phase the practice of collective and individual solidarity and the creation of groups to care for and assist the sick in emergency situations were given priority over efforts to make any broad social and political claims. Since this first type of activism was a protective response, it did not represent a contentious politic in the traditional sense of the word because their actions did not aim to affect the interests of other social actors or change the dynamics of the state, but rather, they sought to create networks of solidarity and to support the ill and their beloved ones. For this reason, it is difficult to identify phase one within the politics for either recognition or redistribution.

### **a) Altruism, spontaneity and solidarity**

In 1983, just two years after the first cases were reported by Centers for Disease Control of Atlanta in the United States, the first case of HIV was diagnosed in México. At that time, the institutional and social responses to the news were overwhelming. A variety of scientific, religious and political discourses with homophobic connotations that classified the new illness as a “pink cancer”, “divine punishment” or “homosexual illness” generated a hostile social environment that severely affected people diagnosed with HIV. The consequences were devastating: people diagnosed with HIV were dying on the streets without having access to hospitals; there were calls for quarantines, funeral services for those having died from AIDS were regularly denied; there were massive layoffs of homosexuals (the term “gay” was not used yet) as well as a health policy involving social isolation of infected people (Labastida 2009). At that time, religious discourses underpinned or provided a justification for the diverse forms of social punishment people living with HIV were exposed to. Juan Carlos Hernández Meijueiro provides two examples on this:

One day we received a message telling us that a friend of ours was in agony. We went to visit him at his house. His family did not allow us to enter the house

because they told us there was a priest taking his confession. We knew that he was an atheist and insisted that they allow us to see him. When the family finally allowed us to see him, we realized he had lost consciousness. We saw that the priest was telling him that he should accept the fact that the illness he had was a by-product of his sinful behavior; that he had to accept that if he had AIDS it was because he was a homosexual. (...) It was at that moment when our friend vomited on the priest and on the people around him. He never recovered consciousness. The family saw that as evidence that our friend was possessed by the devil. Since I knew my friend perfectly, it was very clear for me that my friend vomited on the priest because he was angry. That image became ingrained in my mind as the evidence of what the church has done with the issue of AIDS in Mexico, which is to blame the victims (...) to punish them.<sup>22</sup>

Then, in a second example, he says:

[One day] we received a phone call and somebody told us that one friend had died. I was very sad. Immediately we went to the funeral. It was a Jewish funeral. Our friend was placed with his feet towards the street, which is a symbol of humiliation, meaning that somebody had humiliated the family. His body was there, but nobody wanted to see him. (...) His partner was not allowed to be at the funeral. Some years ago, he sold all his belongings in order to travel with his partner (the one who had died) and lived in the house with him. He became homeless because the family of his dead partner took all the belongings away from him [la familia le quitó todo]. They went into his home and took away his CDs, electronics and clothing. His clothes were actually burned. He was separated from all his belongings. They pillaged him; it was a robbery (...) My partner and I brought him to our home to live with us. I remember that he cried and cried. We did not know why the family had done such a thing. I remember that he used to wake up during the night shouting in Hebrew: ‘Berele’ ‘Berele’. I used to help him and give him emotional support. Two months later, he died. Then, when my partner and I went to his funeral, and his family did not allow us to be there. They threw rocks at us until we left.”

Another case is the case of Oscar Alejandro. When he died, his family did not want his corpse. So, I had to carry him in my car for two days with permission of the municipal government. We put lime on the corpse and wrapped it [Lo vendábamos y le echábamos cal]. Society did not allow us to bury our dead because they were considered “infected dead.” I think they would allow only “healthy dead” or something like that [he said this with irony]. The funeral homes, such *Gayoso*, used to say that. In the cemetery, we were not allowed to bury our dead. That is why I was carrying Oscar around for two days in a car- in my mom’s pick-up truck, actually. She never knew that. We had his funeral in the car. Then we brought it to a professional service to have him embalmed. On the second day of the funeral in the car, a carpenter finally took pity on us. We were with the

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<sup>22</sup> Interview with Juan Carlos Hernández Meijueiro, March 1, 2011.

body on the street and the carpenter saw us, made a wooden box and gave it to us. We put our friend's body in the box and continued our funeral in the street.<sup>23</sup>

Parallel to these forms of social punishment, those people living with HIV and their allies organized diverse responses in order to survive and to cope with the violence they experienced. Friends, relatives, lovers, partners, left-wing intellectuals and artists, most of them who belonged to the gay and lesbian communities, created communities and networks of care aimed to help those who were facing the consequences of having received an HIV-positive diagnosis. Private houses were spontaneously transformed into shelters where sick friends were cared for permanently; parties and other private events were organized in order to collect money and send the sick to the U.S. for medical treatment; private funerals were organized to mourn the new friend, lover, partner, relative or comrade who had fallen victim to AIDS and was not accepted in a funeral home or; information and emotional support were provided to deal with the pain and survive the environment of symbolic castration, stigmatization and social rejection stemming from a life lived with HIV<sup>24</sup>. Juan Carlos Hernández Mejuero, a central protagonist in the creation of these networks of care, says:

Our friends, our ex-lovers, and our leaders were dying. I was very young. I was 21 year-old and the men I admired -handsome, savvy, intellectual and creative activists of 30, 40 years old- were all becoming skeletons; they suddenly started to dry up [a secarse], to disappear, to die. Most of them were our partners, lovers or our boyfriends. We lived with a lot of fear (...) and I felt as though gun shots were whizzing by me one after another. We lost 7 or 8 friends per year. We used to go to 7 or 8 funerals for our friends, ex-lovers, or ex-partners each year. It was like a massacre.

The institutions did nothing. We, the gay community, were the ones who reacted. We collected money and food etcetera. For example, with the toilet paper, we used to say: 'One roll of toilet paper is for you, one for me and one for our other friend'. Then, we used to bring all the stuff we collected to the house of our friend who was sick. We also used to bring canned food, money, and clothes. And we also used to bring our sick friends to our houses to eat, to have showers, to sleep, or simply to take a walk. We created community.<sup>25</sup>

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<sup>23</sup> Interview with Juan Carlos Hernández Meijueiro, March 1, 2011.

<sup>24</sup> Interview with Juan Carlos Hernández Meijueiro, December 9, 2009.

<sup>25</sup> Interview with Juan Carlos Hernández Meijueiro, March 1, 2011.

Due to the fact that these primary responses and efforts to face the consequences of HIV were created spontaneously according to immediate needs and aimed to solve the more immediate problems facing friends and relatives, the repertoires of action (taking care of the sick, providing emotional support, money, food and medicines, mainly) did not have a rational programme design or a political interlocutor. They were, therefore, not contentious politics in the strict sense of the word, but rather spontaneous and altruistic acts of care and solidarity with the affected and oppressed population.

### **b) Grassroots pedagogies and community-based projects**

It was during this context of effervescence of solidarity, however, that important community-based projects emerged. Such grassroots initiatives would play a very important role in the contentious politics of AIDS activism in the near future, principally in México City, Tijuana, Guadalajara and Ciudad Juarez. In 1983, for example, Juan Jacobo Hernández, a former militant of the group *Frente Homosexual de Acción Revolucionaria*, a gay organization linked to anarchist and Trotskyist political praxis which initiated lesbian and gay activism in México in the seventies, founded *Colectivo Sol* in México City<sup>26</sup>. Since the social and institutional rejection always implied isolation and a lack of all that was necessary to live (communication with others, recognition, food, and all sorts of infrastructure to access these items), this organization represented the very first effort to organize visits to homes or hospitals where the sick were located. It took food and mealtime company to the ill, cleaned their clothes, blankets and living quarters, gave them baths and provided compassion and encouragement. It also organized funeral events to the ones who were denied access to formal services once the owners of the funeral homes realized that they had died of AIDS.

Soon, the activities carried out by *Colectivo Sol* grew in number, and they expanded their work. In 1985, organizations such as *Cálamo*, *Colectivo Sol*, *Discoteque El Vaquero*, and others, started to coordinate and disseminate information regarding AIDS to provide the care we mentioned above, but also to provide scientific information aimed at educating

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<sup>26</sup> Interview with Polo Gómez, January 15, 2011.

people living with HIV and the gay and lesbian communities, the populations that, according to all elemental observation, were those that were primarily affected by the pandemic. They also provided information and training to the general public and to health care personnel at public hospitals. They began to offer free shelter, psychological and clinical services, medicine for treating opportunistic infections, and food (Andrade, Maldonado and Morales 2010: 109), thanks to the volunteer work offered by professionals belonging to gay and lesbian communities. Fundraising events with friends, relatives, small business owners (most of them linked to gay bars and discotheques), and the general population were frequently organized to collect money and finance their activities.

### **c) Making sense of the political character of AIDS**

The altruistic and educative work carried out by these community organizations during the first two or three years after the pandemic began in México soon transformed into more political work. This shift occurred, according to Andrade, Maldonado and Morales (2010) in the second half of the 1980s when the volunteers and organizations realized that, in the voice of the legendary AIDS activist Arturo Diaz, the high volume and diversity of the demands of the people arriving at these small and elementally-structured organizations.

Interviewed by Andrade, Maldonado and Morales (2010), Arturo Diaz also mentions that this shift was also generated because of the enormous pressure generated by conservative organizations linked to the Catholic Church, which traditionally opposed sexual education and the promotion of condom use as a prevention method and frequently impeded state efforts to promote condoms, made the AIDS activists realize that their role should not be to provide health care services to all the infected population and substitute the state's obligation in this matter, but rather to demand better and more effective intervention from the state in relation to HIV prevention and AIDS treatment.

It was in this context that the organizations started to construct social pedagogies aimed not only at encouraging the necessary exercise of social solidarity with the sick, but also at making visible the fact that AIDS prevention work is immersed in a political context and that, if the battle is to go beyond the exercise of compassion, it must also take place in the political arena. According to their rationale, this battle should involve: 1) combating and demystifying homophobic and sexophobic myths about AIDS and the etiological causes which were concocted and disseminated by the Catholic hierarchy and its organic intellectuals and organizations (They fundamentally argued that AIDS was generated either by God's will to punish the sinners, or as a consequence of a promiscuous and non-heterosexual sex life) and: 2) demanding that the government take action on the health and human rights issues implicated in AIDS and the stigmas attached to it.<sup>27</sup>

Two types of action were important for deconstructing the myths which had been built around AIDS: public education and journalism. With regards to the public education approach, Juan Carlos Hernández Meijueiro pointed out in our interview that, after the second half of the 1980s, they started to prepare themselves and organize workshops, talks and formal courses in public schools, neighbourhoods and organizations. In these courses, they informed the general population, fundamentally, about HIV prevention and transmission a strategy that helped to reduce stigma, he says, but that also progressively generated a public opinion of respect for homosexuals. He mentions that the fact that people saw gay communities educating people to take care of themselves in matters of sexual health made it possible to generate some sort of respect and recognition from the community. It also contributed to making visible the importance of sexual education in public schools as strategy for reducing rates of HIV infection.<sup>28</sup>

Regarding the journalistic work they carried out, Antonio Medina mentioned:

Our organization was founded by gay activists. They had the goal of using journalism to make visible the problematic situations faced by people living with HIV or AIDS. They also aimed to reflect on other problems occurring around the

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<sup>27</sup> This insight was shared by Roberto Guzmán.

<sup>28</sup> Interview with Juan Carlos Hernández Meijueiro, March 1, 2011.

issue of HIV in Mexico. And the idea was not necessarily to focus on the medical issues, but rather on public policy and its effects on the life of the ill. At that time, we experienced great stigma and a lot of discrimination in the institutional spaces that attended the people living with HIV. That is why *Letra S* was paradigmatic. It has been important not only for the issues it presents in its pages, but fundamentally because it has been defying a very conservative, machista and homophobic society that had fed from the discourses of the Catholic Church, a very conservative discourse on issues regarding sexuality.<sup>29</sup>

Such political work and insights, which later inspired the rest of the newly-founded organizations, configured the emergence of the contentious politics of AIDS activism, that is, a set of episodic, public and collective interactions with the state and its institutions whose goal was to make changes or to defend one's interests (McAdam et al. 2001). I dedicate the rest of this chapter to explain the formation and transformation processes of the contentious politics in Mexican AIDS activism and the manner in which its repertoires of action occur.

***Phase 2: 1986-1992. Self-reflexivity, political formation and protest: From isolated self-help groups to national networks of resistance and confrontation***

On June 11, 1986, Luis González de Alba, a famous writer, gay activist and former leader of the 1968 students' movement, announced the launching of his bar *El Taller* in gay magazines (Hernández Victoria 2010). When *El Taller* started, it was a unique project, and it constituted the very first institutional project which progressively provided incentives for the creation of self-help groups in México City. It was a space operating under government license as a community project (*asociación civil*) which in the evenings and nights operated as a pub that was exclusively for gay men with a masculine aesthetics, and in the mornings, it offered legal, psychological, and medical service to people living with HIV (González de Alba 2006). This second kind of community service, coordinated by *Cálamo, AC*, successfully operated with the participation of public health practitioners and volunteers from grassroots organizations and was soon moved to another location. This new concept gave birth to another very important

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<sup>29</sup> Interview with Antonio Medina, February 27, 2011.



organization in the fight against AIDS: *La Fundación Mexicana de Lucha Contra el Sida* (Hernández Victoria 2010); it also generated the emergence of self-help groups, a form of collective organization which created new forms of political praxis and stimulated the emergence of the AIDS insurgency.

**a) Self-help groups, collective reflexivity and the formation of political consciousness: “Let’s overcome mourning and fight for our rights”**

It is within these spaces created to take care of those affected by HIV AIDS, as well as to train people in the self-care of their health, stimulated by *El Taller* and concretized and managed effectively by *Cálamo* and *La Fundación Mexicana para la Lucha Contra el Sida*, that people living with HIV developed a political sense of collective indignation and a will to challenge the order of things. This was made possible basically through a process of reflexivity and the development of political consciousness in those spaces used to provide for people living with HIV or AIDS. According to some of the interviewees, it was in these spaces that they met people and realized that the grievances they experienced in public hospitals, whether as a relative or friend of a person living with HIV or as a PLHA, were, in fact, a collective experience organized by the state’s practices or omissions in protecting the sick. Finally, as a by-product of such reflexivity, they arrived at the conclusion that something should be done. So, they progressively transformed from being groups for mourning to groups for mourning, caring, thinking, protesting and demanding the right to be free of exclusion, discrimination and to receive treatments and adequate care from health professionals in the public institutions.

The story of Gina exemplifies very well the history of how the self-help groups were created, how they politicized their members and how their members transformed these spaces from self-help groups into activist groups through the extension of the sole practice of solidarity and compassion to the practice of the defence of their rights. Gina became part of the ‘AIDS world’ in 1988 after her partner was diagnosed HIV positive in the ISSTE. She says that, despite the fact that since the beginning she and her partner experienced all sort of grievances, which ranged from attempts to convince her to leave

her partner to die, to submitting to non-consensual HIV testing and gynaecological explorations, she never tried to do anything beyond individual and face-to-face confrontations with the health practitioners. She says that this happened partially because of her lack of strength in such a moment of mourning and sadness (conformist attitude that for herself is very surprising since she was raised in a family with a long tradition of workers' rights and union militancy and she herself had been very politically active in México since the end of the 1970s)<sup>30</sup>.

One day, she continues, all this attitude of tolerance and submission to mistreatment and grievances in the hospital changed radically when she was asked by a nurse to bring a sleeping bag for her partner at the hospital. Although she reacted with surprise to this petition, the day she brought the sheets to the hospital she realized, after seeing several patients sitting down on the floor, that they were used to denying the HIV-positive patients use of the chairs located in the waiting room, having them sitting down instead on the floor using the sheets, sleeping bags or pillows as cushions to avoid 'infecting' others. After observing this spectacle of what she considered violence and segregation, she complained to the nurse in charge of the patients at this place. After being told that nothing would be done about it, she started yelling at the nurse and asking patients to stand up and use the seats of the waiting room. Although some of the patients did not follow her call to rebel, arguing that some of them had already tried to do something about it several times and it had not worked, slowly, and without hesitation, they suddenly started to stand up and take the chairs of the waiting room.

When I asked Gina why she thinks this happened, her answer was very straightforward:

First, when I saw the group of people lying down on the floor, I realized that I was not the only one experiencing grievances. Second, I realized that the fact that we were many experiencing the same, we could do something about it. Then, when we did something and nothing wrong happened to us; we experienced power and will to keep doing the same<sup>31</sup>.

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<sup>30</sup> Interview with Georgina Gutiérrez (Gina), February 13, 2011.

<sup>31</sup> Interview with Georgina Gutiérrez (Gina), February 13, 2011.

This act of rebellion marked the emergence of the first self-help group in ISSSTE, and probably the first one in México in a public hospital. Encouraged by such a positive experience, they decided to have periodical meetings to talk about their experiences as HIV positive patients in the hospital. One of the patients who participated in the act of collective disobedience we mentioned above offered his private house to host the periodic meetings of the newly-formed group. This group, which gathered once a month in the member's private house, discussed their experiences of discrimination at the hospital, issues regarding their health, economic and family situations and other concerns in their everyday life. Together, making sense of the collective character of their individual experiences, they soon identified allies and opponents in the hospital and started to get involved in politics as patients, and they designed strategies to take care of each other and protest when it was necessary. They successfully protested collectively when some member were mistreated or in order to make proposals on how to improve the services provided by health professionals and the hospital, according to Gina.

According to my interviewees, this same mechanism of creating groups, promoting personal empowerment and improving health practitioners' treatment of patients through collective surveillance, mutual care and protest was repeated in almost every self-help group created in Mexican hospitals. Magda Padilla, a pioneer and leader of another self-help group created at the end of the 90's at IMSS, said that:

These spaces created a sense of community, a sense of mutual care and, above all, a sensation that things can be changed when people come together and protest when it is necessary to do so<sup>32</sup>.

It was through these groups that they made sense of the basic fact that grievances were actually shared experiences by the members and created mechanisms of defence and protest against such grievances not from the society as a whole, but rather from specific perpetrators of oppression. And this can be thought of as the starting point of AIDS activism's contentious politics, in the strict sense of the word, because their actions aimed to negotiate and protest for institutional changes. However, it is a very basic form of

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<sup>32</sup> Interview with Magda Padilla, January 13, 2011

contention that seems to be closer in appearance, characteristics and limitations to those forms of protest created by groups of individuals who defend their interests via localized actions which don't always aim to make broader changes, but rather to solve immediate problems faced by the collective which holds and carries out such acts of dissent (Staggenborg 2008: 3).

### **b) Opening windows for the subsequent AIDS insurgency**

The repertoire of collective action of the self-help groups consisted fundamentally in diverse forms of face-to-face confrontation through an attitude that in México is known as the 'kicking doors attitude'. This is a confrontational attitude that it is based on the supposition that the authorities' doors will be closed anyways and your job as interlocutor is to open the doors by using diverse of techniques of confrontation in order to vanquish the closed, intransigent and rigid positions held by your interlocutor. The targets of these forms of confrontation were mainly hospital health workers and health practitioners, and their actions mainly aimed to improve the treatment provided at the hospital by the health practitioners and to demand access to one medicine or another or timely access to hospital beds, clean clothes, food and baths. These forms of protest were very limited in the sense that they did not seek broad institutional changes, nor did they question the structural dynamics behind the deterioration of the health services. Instead, they sought to obtain immediate benefits. During our conversation, Magda Padilla offered this testimony:

Our main goals were to ensure that my friend could have access to medicine, or that he or she could have access to a hospital bed, and all those things. We did not have time to worry or to think about all those big things happening around us<sup>33</sup>.

Although these actions seem to be limited in light of what must be considered a contentious politics aiming to make big changes, the confrontational actions of the people who formed part of the self-help groups were enormously beneficial in a number of ways. First, and most importantly, they contributed to saving lives in contexts of immediate

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<sup>33</sup> Interview with Magda Padilla, January 13, 2011.

necessity. Second, they helped to improve the quality of medical attention in hospitals. Finally, and most relevant for the purpose of this chapter, these actions contributed significantly to cultivating the idea among the people living with HIV, and the groups which were forming at the time, that things can be changed by confronting the authorities and people holding positions of power. This aspect was absolutely fundamental and pedagogically transcendent for a politically shy civil society that had traditionally been incapable of carrying out acts of organization, resistance and transformation due to the authoritarian monopoly the *Partido Revolucionario Institucional* (PRI) had had on all political activity since the end of the 1950s.

In short, they changed clinical attention; politicized the marginalization and punishment of the sick and their friends, relatives and families; configured scenarios which made social changes possible for people who did not know changes could be made and; by doing all of this, they cleared the way for the emergence of a more effective and transformative form of AIDS insurgency, which emerged in the nineties.

### **c) The spaces and the politics against misrecognition**

During the nineties, human rights discourse started to form part of the public discussions. The first human rights organizations, created by organizations linked to critical movements, including Jesuits, Liberation Theologists and former secular militants of the new social movements of the 1960s and the guerrillas of the 1970s, had opened spaces which provided advocacy, legal defence for victims of state violence and popular education on human rights to the general population.

The self-help groups created in the bars and in the hospitals we mentioned previously started to make contact with such organizations or open spaces to discuss AIDS issues. For example, the self-help groups which belonged to *La Fundación Mexicana de Lucha Contra el Sida*, *Acción Humana por la Comunidad*, and other organizations created during this period of time started to provide training to their members on issues of human rights. The groups consolidated, taking on with formal spaces and infrastructure and

becoming more involved in public discussions which linked the issue of HIV and AIDS to the human rights agenda. With particular emphasis, they become involved in the first localized campaigns against HIV-related stigma and discrimination, particularly making the link between homophobia and sexophobia as main sources of HIV-related oppression, as was mentioned by Georgina Gutiérrez and Antonio Solis two of my interviewees. The politics against misrecognition and against stigma were born decisively during this period of time. The discussion which linked access to health care and human rights also began here.

#### **d) The factors of change**

What factors led these groups to change from politics based on solidarity and self-defence to politics based on solidarity and belligerent contentious politics?

1. - The first factor which must be mentioned is the reflexivity and collective insights those groups provided to formerly isolated individuals who had previously understood their experiences as separate and isolated from the broader context.

2.- The second factor is that they received training in human rights issues by groups and organizations that had a long story of activism in issues of human rights in México. These groups were part of a community of activists, liberation theologians and political dissidents who had come to organize in human rights organizations to denounce the lack of democracy and the diverse forms of violence and authoritarianism carried out by the Mexican state since the 1950s in order to colonize and expropriate the legitimate exercise of politics.

3. - Several of the AIDS activists were themselves people who had been raised in left-wing families or who had participated in those social movements which have long influenced the struggle for democracy in México; these movements include the students' mobilization in the 1960s (Carlos Monsiváis, and Luis Gonzales de Alba are examples of these mobilization's leaders), and the struggle for democratization and against electoral

frauds, which were very common since the 1970s in México. So, they had a rebel and revolutionary *habitus* in itself or were people that had learned that it was necessary to organize independently from the government to change the order of things. Most of these activists were sons and daughters of unionists and revolutionary peasants who taught them the values of solidarity, the capacity to feel indignation when faced with injustice and the disposition to act in consequence.

4. - The existence of grievances in and of themselves was a very important factor, but grievances not as an abstract element. In their narratives, the participants interviewed in this study mentioned that the very act of conversing with other people during the self-help group sessions made them aware of the fact that the grievances experienced by each of the participants in public spaces were a shared experience.

5. - There was also a prevalent political frame shared by the activists that represented human rights as a universal set of prerogatives that must be respected by the state. Likewise, radical contestation was seen as a way of transforming these prerogatives into a reality (without negotiation or conciliation because authoritarianism closes the doors); this made possible the emergence of this repertoire of protest.

### **Phase 3: 1993-1996. The emergence and strengthening of AIDS insurgency, and the creation of resistance networks**

Although this is a chronological account that intends to give attention to processes that helped to configure a heterogeneous social movement, such as the one we are studying, it is difficult to ‘discover’ a definitive and foundational specific moment that signals its precise emergence. Nevertheless, it is possible to locate its shifts by looking at the forms they used to protest. By doing this, we were able to easily figure it out the emergence of a particular type of activism. Following this logic, it can be argued that in 1993 a new type of AIDS activism was born which utilises a variety of forms of protest and claims-making of state authorities and which can be denominated a politic of contention in the strict

sense of the term. The reasons and the process by which this emergence was possible will be explained briefly.

#### **a) The rise of the AIDS movement and its stimulus factors**

Along with the important role played by the self-help groups and the mobilizing structures they generated through the creation of spaces, collectives and ideological political formation of people living with HIV, in the nineties important transformations occurred in Mexican society that strengthened AIDS activism and enriched its repertoires of protest. At the social and political level, civil society had started to participate in massive demonstrations against an electoral fraud involving the PRI in federal elections, and it started to organize massively in NGOs; the hegemonic political party had experienced several fractures and divisions in its interior. At the same time, the human rights discourse came to form part of public discussion, citizenship agenda, and state policy. In the economic sphere and in social policy, the process of dismantling public institutions in where AIDS was concerned had led to the enormous deterioration of health care services. Although AZT had arrived in México at the end of the 1980s, its availability was limited to two institutions which suffered chronic problems of shortage, as we mentioned in the previous chapter.

In this context, the AIDS movement made use of a variety of forms of protest at the same time that it experienced an exponential growth. The reasons for this can be understood by looking at three structural factors which were present at that time. On one hand, this structural context provided a progressive deterioration of the material conditions of working class people, creating poor quality in the provision of the public services, generating chronic shortages of medicines in public hospitals, and limiting the governmental intervention in regards to HIV, all of which was generating an increment in the number of grievances experienced by people living with HIV, that is, people who normally survived on low-paid jobs, or as self-employed or unemployed workers without access to medicine and good health attention. On the other hand, there was a context in which civil society and a variety of social movements had been progressively emerging,



partially out of necessity due to the lack of governmental action (as in the case of the earthquake of 1985), and partially because the struggles led by activists who were firm believers in democracy and were demanding democratization of society. Finally, there was a legacy of spaces and organizations composed of people living with HIV in civil society and public hospitals, generated by the work carried out by the pioneer gay and lesbian activists and their organizations, as well as by the self-help groups we mentioned in the lines above.

In this structural context, which provided a quantitative increment in the number of grievances experienced by people living with HIV and an encouraging political context which provided hope, courage and stimulus to civil society in terms of organization and a push for social changes, the self-help groups suddenly experienced a process of political and ideological formation. This situation soon transformed them into spaces for education in human rights and the formation of groups of activists that soon become leaders and guides of the episodes of contention generated by AIDS activism, which now included among its primary demands respect for the human rights of people living with HIV and the recognition of health care as a constitutional right.

#### **b) Addressing the state**

In this process, AIDS activism became stronger and started to make national politicians and federal institutions its subjects of interlocution and negotiation. In effect, the strength, presence, and combative capacity developed as a by-product of the growth in the number of its members and the stimulation generated by the above-mentioned factors made AIDS activism strong in the political arena and deserving of the ears of national politicians. This made possible the important advancement of their group interests and the strengthening of their negotiations with the institutions of the federal state. For example, in 1988, Francisco Estrada Valle and *Mexicanos Contra El SIDA* convinced the federal institutions National Commission for Human Rights and CONASIDA to endorse the first declaration ( which to this day is still valid) of the human rights of people living with HIV. Most importantly, however, was the fact that they had gained the role of legitimate interlocutor

of the state in the matter of HIV-related issues, and they had finally gained access to the political elite, which included both political allies and foes. The political tactics included lobbying, street protests (although limited) the organization of communitarian forums with the participation of government officials and confrontational, as well as formal, petitions.

### **c) The human rights agenda and the creation of the national resistance networks**

In 1991 the movement started a process of expansion as part of their strategy to become stronger and gain influence in the public sphere. As such, it founded the first national network of people living with HIV under the leadership of Arturo Diaz Betancourt. The name of this organization was *Mexicanos Contra El SIDA* and it consisted of 14 organizations from the regions of Netzahualcoyotl and Distrito Federal. Then, in 1995, the *Red Nacional de Sistemas de Apoyo en Sida* was created, comprising 18 organizations.

The organization started to frame their demands in terms of human rights. The right to no discrimination, the right to health care, the right to equality, etc. was the justification of all their demands and included in their protest strategies the acts of juridical defence by way of denouncing institutional forms of negating rights or through the impugnation of laws through the figure of '*juicio de amparo*'. Some of their leaders participated in the *Primer Encuentro Internacional de Personas que Viven con VIH Sida* in Paris, France (UNAIDS 1998).

### **d) The repertoires of protest**

In the mid-90s, several of the AIDS activists started to gain access to institutions as advisors or even as public servants of institutions, such as the governmental program *Centro Nacional para la Prevención y el Control del VIH/SIDA* (CONASIDA). They also

started to generate great stimulus and influence within the movement and to place their demands to decisions in the state.

In this phase of expansion and fortification of AIDS activism, the number of groups grew at the national level and their repertoires of protest diversified. In the south of México, several activists, most of them former members of basic Ecclesial Communities linked to Liberation Theology transformed private houses into shelters which provided food, housing, emotional and legal support to the people who were mistreated by family or local authorities, or for those who had been expelled from their communities and denied access to health care attention and medicines due to their serologic status of HIV positive.

In addition to this altruist work, these shelters become actively involved in processes of critiquing public health institutions and local authorities for their lack of support for the sick; providing information on HIV prevention and the human rights of people living with HIV with the hopes of reducing the diverse forms of prejudice and ignorance related to HIV, which they believed were the basis of such forms of mistreatment and marginalization. They provided this information on a face-to-face basis and by visiting house-to-house throughout rural and urban communities. They also organized hunger strikes as a way of requesting that authorities provide medicines or open specific programs aiming to protect HIV-positive patients.

The clearest example of these new formidable grassroots efforts, which aimed to protect the sick and to involve the government in protecting them, is the *Albergue Oasis de San Juan de Dios*, a community project created by Carlos Benavides. This organization, in addition to providing all the medical services we already mentioned to the communities of people who lacked basic social and institutional protection due to their HIV positive condition, pushed big and transcendent positive changes in social and institutional policy with the objective of providing protection, health, housing and counselling to the sick. Two of the main measures they were also providing to the vulnerable population were the monitoring of public hospitals to ensure that patients were receiving treatment, medicines and quality medical attention, as well as the persistent pressure placed on the local

Commissions of Human Rights to ensure that the state was involved in this task of protecting the human rights of the people living with HIV. Not only were their interventions important and transcendent in terms of ethics and human compassion, but they were also very effective. In 2002, for example, after *Instituto Mexicano del Seguro Social* (IMSS) stopped providing medicine and health care to 192 patients living with HIV in Yucatan, arguing a lack of money to provide such expensive treatments (Medina 2002b), the *Albergue Oasis de San Juan de Dios* started a series of mobilizations aimed to convince the Institute not to implement such a ‘criminal measure’. The pressure was so effective that the local director of IMSS soon announced that the institute would interrupt such measures and all of the 192 patients were quickly re-incorporated (Indignación, A.C. 2002: 3-4).

As evidenced by this example, which can be seen as a representative case of the forms of local activism carried out by the newborn organizations in diverse states of the Mexican Federation, the politics of protest were aimed to eliminate stigma and the forms of exclusion generated by this form of degradation of identity (Goffman 1963) as well as to make the state activate its actions to protect the affected and displaced population. The organizations were not looking for redistribution or for forms of identity-based politics but rather for making the state work in the protection of such displaced and mistreated populations. However, the mobilizing structures, fundamental to starting and finishing successful episodes of redistributive and pro-recognition politics of contention were set in this period of time.

#### **Phase 4: 1996-2010. The diversification of contentious politics and the cultural, political and redistributive transformations**

##### **a) The emergence of FRENPAVIH, the first national AIDS network**

In 1996, another twist in the repertoires of contention, perhaps the most important one in the history of Mexican AIDS activism, occurred. This shift occurred when the creation of

antiretroviral therapies was announced at the International AIDS Conference in Vancouver; these therapies promised to be highly effective for reducing mortality related to HIV and increasing the life expectancy for people living with HIV. What happened is that after such conference Dr. Angel Guerra, a Mexican delegate at that conference and a health practitioner who was long-recognized by AIDS activists as one of their allies,, organized a meeting with the AIDS activists to inform them about the news released in Vancouver, particularly regarding the antiretroviral. According to Gina, he concluded his report with the sentence:

Well, in conclusion, there are medicines available on the market now. The coin is in the air. The question now is: What are you going to do, guys, to have access to them?<sup>34</sup>

Aware of the transcendence of the existence of antiretrovirals for the well-being of people living with HIV and the extremely positive change they could make if they could obligate the state to universally distribute these in México, the activists present at that conference decided to have a meeting to plan what actions to take in order to reach this goal. At that meeting, which was organized at a popular chain of restaurants called VIPS, they decided to call all people living with HIV in México by using as a guide the directory of self-help groups available at CONASIDA and with information of contacts. The goal was clear: To create a national network of people living with HIV and affected populations (by which they meant relatives, friends, partners, etc whose lives had been shaped by AIDS in one or another way) whose only and specific goal would be to demand at the national level and by diverse means that the Mexican state guarantee universal access to treatment in México.

The people who were called on to integrate into this network were practically all the people who, at that time, were participating in self-help groups in almost every big city of México (state capitals, at least). It is in this way that the self-help groups, already activists in some way, became almost entirely transformed in advocates of the universal access to medicines. In the process, they created very empathic strategies based on confrontation

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<sup>34</sup> Interview with Georgina Gutiérrez (Gina), February 13, 2011.

and pressure on authorities, and they did not discuss any forms of negotiation. The name of the group *-Frente Nacional de Personas Afectadas por el VIH-* was born as a consequence of this national coalition, and its motto is “*Acceso Universal a los Medicamentos*”.

#### **b) FRENPAVIH and redistribution. Health and antiretrovirals for all**

In 1996, FRENPAVIH is constituted as a civil association and engages in several strikes, petitions authorities and call authorities to action. In 1997, FRENPAVIH become fractioned in two groups: the *protocolarios* (stigmatized because it wanted to engage in formal dialogue and formal petitions of the government), and another faction which emphasized the labour of confrontation and pressure measures. In February 1997, the first faction sued the *Secretaría de Salud* and CONASIDA for violations to Art 4 of the Constitution, which refers to health as an individual right. In April 1997, the confrontational faction took advantage of the organization of a congress on infectology, organized by the *Secretaría de Salud*, to engage in the first massive demonstration to demand health authorities guarantee access to antiretrovirals to all. Their demands also included launching the *Programa Nacional de Prevención y Control del Sida*, which had been planned by AIDS activists and organizations, as well as by the government but which had been delayed for starting.<sup>35</sup>

This public protest constituted the very first public demonstration with important impact on the public opinion at a national level. This was due basically to two factors. The first factor is that it was the first really big demonstration in numbers on the matter of HIV. For the first time, people living with HIV took the streets in massive numbers and that shocked the public. The second factor was their incredibly successful idea of appearing in public wearing balaclavas to hide their faces and avoid stigma but also to show sympathy for the Zapatista movement, a political movement started by indigenous communities of Chiapas which entirely had transformed left-wing politics of movements in México and shook the media just three years before.

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<sup>35</sup> Interview with Juan Alfonso Torres, October 12, 2009.

### **c) The diversification of the repertoires of contention**

In this process of making their claims public and addressing the state in the advancement of their group interests, FRENPAVIH incredibly expanded the repertoire of AIDS activism in México. In their national conferences, they organized workshops to train people in the art of making public petitions attractive to the public; organizing press conferences; preparing formal petitions for health authorities; applying coping strategies for conversations with angry drivers (the massive strikes filling the streets made drivers angry), police officers (who tended at that time to repress the strikers) and the general public to gain sympathy and public support for their demands.<sup>36</sup> Putting in practice such tactics radically improved the visibility of AIDS activism and its demands.

#### **c.i. Education through performance: The *Condonmovil* and the struggles for preventive education**

During this phase of intensification and strengthening of AIDS activism, creative forms of making public claims and educating populations emerged at the same time as the emergence of a population and a governing class which was reticent not only to the demands and claims made by AIDS activists, but also to public discussion about sex education and the distribution of condoms.

The most innovative project in this respect, and one which had probably the greatest impact on the general public, authority and right-wing organizations opposed to their claims, was the *Condonmovil*. As a project that emerged in 1998 as part of *Colectivo Sol*, the pioneer organization in the struggle against AIDS which we have mentioned lines above, *Condonmovil* was led by Polo Gómez, a young gay activist who was a recognized left-wing militant involved in street art and a leader of neighbourhood associations in México City. *Condonmovil* is a Volkswagen which travels around México supplied with condoms and material for promoting respect for people living with HIV, as well as for promoting diverse methods of sexual practices which prevent getting infected with HIV.

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<sup>36</sup> Interview with José Cruz Guzman February 21, 2011.

In each city visited by this singular and exotically coloured car, which also wears a big condom as a hat, Polo Gómez stopped in strategic places, most of the time in the plazas located in downtown's cities. Dressing as a drag queen, he and other "condoneras" (the self-description in feminine is part of their activism) carried a wooden box full of condoms and informative pamphlets about AIDS and safe sex practices, and they distributed the material to the people who they attracted in the central plazas through their exotic appearance and tactics.

Due to the 'dangerous information' that Polo Gómez and his *Condonmovil* distributed among the population, the *Condonmovil* has experienced several attacks from conservative groups linked to the Catholic Church in Querétaro and in México City; they have also been severely criticized by the Government of the State of Sonora. In 2000, for example, when he was distributing information regarding AIDS, discrimination and condoms in a public plaza in Querétaro, a group of people armed with knives destroyed the giant condom he put in the places where he carried out his educative meetings. Worst of all, however, they tried to kill Polo Gómez and *Las Condoneras*. This has not discouraged Polo Gómez in his educative labour. "It actually means," he says, "that my work is necessary"<sup>37</sup>, and recently he has started to extend his educative labour beyond national borders. He has made several tours to Honduras, Panama, Guatemala and El Salvador and his presence has become even more popular and useful for the AIDS activism. The existence of this innovative technique of making public claims through performance has led to increased access of rural and marginalized population to condoms and information regarding HIV prevention, as well as AIDS activism and its claims.

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<sup>37</sup> Interview with Polo Gómez, January 15, 2011.



**c.ii. A militant journalism. *Letra S*, the nationalization of AIDS activism and the art of making demands public<sup>38</sup>**

AIDS activism in México experienced a radical strengthening and diversification of its repertoires of protest in 1994 with the emergence of *Letra S, Salud, Sexualidad y Sida*, a journalism project and supplement of the left-wing national newspaper *La Jornada*. This project was created in 1993 by the initiative of the Mexican intellectual Carlos Monsiváis.

As a journalist committed to the struggles for democracy and for the rights of marginalized populations, such as the indigenous, gay and lesbian, and religious minorities, and after having documented for years the catastrophic effects of discrimination against people living with HIV and the diverse forms of disinformation and lack of capacity of the government to take action and provide medicines to the sick, in 1994 Monsiváis decided, along with Alejandro Brito, Carlos Bonfil and Arturo Diaz, all of them recognized gay activists, to create a journalistic project whose goal was to: 1) provide information and analysis about the situation faced by people living with HIV in México, particularly in regard to access to medicines and institutional mistreatment, 2) educate journalists on how to cover or produce positive or non-stigmatizing information about HIV and avoid the media coverage which tended to represent HIV in association with homosexuality, death, irresponsibility, and so on, and 3) to cover and promote the claims made by AIDS activists and civil initiatives to protect people living with HIV.

According to Antonio Medina, current General Coordinator of *Letra S*, Carlos Monsiváis and Alejandro Brito invited Arturo Díaz, the pioneer AIDS activist mentioned some paragraphs above, to collaborate on the project because of his strong skills on how to make changes at the level of society, as well as at the institutional level.

In 1994, publication of *Letra S* began as a supplement of *El Nacional*, a government newspaper that, despite its lack of independence, was recognized for the important

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<sup>38</sup> The history of the emergence, tactics and strategies carry out by *Letra S* was reconstructed based on the interview was carry out with Antonio Medina, coordinator of this newspaper on February 27, 2011.

cultural information it provided on its pages. This would be the first supplement in México to exclusively cover AIDS, sexuality, gender, and sexual minorities' rights issues. Since then, *Letra S* has been the most important source of information for debating and discussing issues regarding HIV AIDS, combating the prejudices in Mexican society about AIDS, promoting human rights and respect for people living with HIV and criticizing the incapacities and inefficiencies of government and public servants regarding HIV policy. Antonio Medina describes the role this journalistic project has played in the struggle against AIDS in Mexico:

When the *Suplemento Letra S* started, we were dealing with the stigma generated by the Catholic Church, its machismo and homophobia. Fifteen years ago, we knew about the existence of HIV in Mexico, but the society was fearful and ignorant in matters of sexuality. Therefore, AIDS had a very negative connotation, a connotation of death. There were two equivalences, I would say. The equivalence 'HIV is equal to homosexuality,' and the equivalence 'HIV is equal to death.' That is why at *Letra S* we always analyzed all the cultural processes of discrimination and denounced them. That is, *Letra S* became a space of political, social and even ideological discussion around issues related to HIV. We denounced the factors that were responsible for the fact that the HIV pandemic was not being stopped. We denounced the fact that the government was not creating public policies to stop AIDS, nor was it designing and implementing national strategies to stop the impact of HIV.<sup>39</sup>

The influence of *Letra S* in the public debate has been fundamental not only because of its journalistic contributions, but also because they have provided training to journalists and AIDS activists on how to make changes through public campaigns organized in the media, likewise, they practice what they call a 'militant journalism' committed to democratizing society and making human rights possible.

In 1995, *Letra S* launched a series of contentious politics in order to: 1) denounce through journalism the abuses public institutions committed against people living with HIV, 2) inform the public and eliminate stigma through informative news reports, and 3) invite civil society to debate, mobilize and transform activism from protest and resistance, as

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<sup>39</sup> Interview with Antonio Medina, February 27, 2011.

was commonplace, into an activism based on generating influence in institutions to politics.

According to Antonio Medina, one of the main tactics used by *Letra S* was to create news reports denouncing the government or making public the infamous mistreatment some people were experiencing in public institutions, as well as the lack of medicine in public hospitals. These reports used to appear on the main page of the newspaper. Then, after this news was reported, they published an extended article on the topic written by a recognized figure or expert that, by using his or her position as an expert, analyzed the topic and gave legitimacy to the discussion of the topic. Then, they invited civil society to organize and change the conditions generating such grievances. As a product of these debates generated in the news and in the population, Arturo Diaz, the political strategist, lobbied with the grassroots organizations and convinced them to organize and denounce such abuses in the streets and to lobby key political figures. They organized events to discuss these issues with allies, most of them left-wing politicians, feminists, gay and lesbian activists, and to generate public debate around the issues they were denouncing previously in the newspaper. Then, they again covered the event, organized press conferences, invited specialists to write specialized articles; they maintained alive the debate and they wanted to emerge in the public opinion. It was through this act of journalist activism that they made possible not only the circulation of the debates in the media and civil society, but also convincing politics.

This last part was also very important. They stressed very much the fact that in order to make real changes, they had to ‘penetrate the networks of power’ and make changes possible. In order to do this, *Letra S* provided a space to educate and train journalists in covering news regarding HIV issues from a liberal and progressive perspective. But also they formed activists that opened spaces in the institutions and dedicated themselves to defending people living with AIDS and educating public servants from inside. They created, for example, a group of gay and lesbian youth groups dedicated exclusively to discussing the problems of discrimination associated with sexual orientation, homophobia, and the link between homophobia, discrimination and HIV. By doing this,

they educated themselves on issues regarding HIV-related discrimination and with regards to the direct defence of people living with HIV who were treated in the *Clinica Especializada La Condesa*, a clinic established by the local government and dedicated exclusively to providing medical attention to people living with HIV. If they saw something wrong, they denounced or advocated in favour of the patients.

Operating in these ways -educating journalists, opening spaces in institutions and educating the public they radically transformed the politics of contention carried out by activists. So, with the emergence and consolidation of *Letra S*, AIDS activism changed from an autonomist and reactive activism whose purpose was resistance into an activism based on proposition, positive critique and reform of culture and institutions. They started to do politics by other means.

In our interview, Antonio Medina said also that another very important factor that led to the creation of *Letra S* was the denouncing of the role played by right-wing politicians and groups in the configuration of diverse forms of stigma and violence against people living with HIV. That's why they started this kind of mobilization.

With the emergence and successful activism carried out by *Letra S*, a number of organizations were created not only in México City, but also in diverse parts of México, such as groups of fathers and mothers of gays and lesbians against homophobia, groups of gays and lesbians to end sexism and homophobia in hospitals; groups of men against sexism and for gender equality, among others. In addition to their work educating populations and defending the rights of people living with HIV, these organizations had a space in *Letra S* to denounce what they considered should be denounced and changed. Antonio Medina tells us:

*Letra S* gave a privileged space to the civil organizations so that they could denounce all the issues related to the shortage of medicines, discrimination, and so on. So, *Letra S* soon became a space for the struggle and social denouncement based on an organized discourse and a plan aiming to create political incidence in all social sectors and institutions. We also always promote public and collective reflections on the necessity of creating policies to eradicate discrimination and

exclusion against populations traditionally affected by the HIV pandemic: homosexuals, gays and men who have sex with men, as they have been labeled lately. (...) Since the very beginning, *Letra S* has been denouncing how discriminatory discourses become public policy and how they have been affecting the ill population.<sup>40</sup>

#### **d) The structure of political opportunities**

What is the structure of the political opportunities which stimulate the transformation and diversification of AIDS activism in this last stage of struggle? Following the responses and insights provided by Antonio Medina<sup>41</sup>, member of *Letra S*, we could partially answer this question. When he was asked the reasons why *Letra S* had become so important and influential for AIDS activism around México since the second half of the nineties, he answered that their emergence and consolidation as an organization, as well as their successful and transformative intervention in culture, institutions and AIDS politics in México, was made possible as a consequence of several factors: 1) Access to funding provided by international organizations, such as *Fundación McArthur* and *Levi Strauss Foundation*. With this funding, they created spaces, and they trained activists and journalists in issues of HIV, 2) The existence of allies, such as famous feminists and high-profile intellectuals like Marta Lamas, Carlos Monsiváis and Elena Poniatowska who had public recognition, access to power structures and the media. 3) The arrival of PRD to power at the México City's municipal government was also very important. Medina pointed out that it was with this party that they had access to the power structures, and the organization of public events. And they received the support and recognition from the citizens who were left-wing and close to this party. With this party they also had access to funds and resources as well. 4) Another important factor Medina also mentions is that there was a political environment, a political language that already recognized the importance of talking about diversity, gender equality, and non-discrimination based on sexual orientations that was made possible by EZLN and its discourse around diversity and rights for homosexuals, the necessity of combating racism, sexism, and attaining a

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<sup>40</sup> Interview with Antonio Medina, February 27, 2011.

<sup>41</sup> Interview with Antonio Medina, February 27, 2011.

society which recognizes diversity and dignity for all oppressed people. They mobilized Mexican society and made it possible to create dreams of equality. 5) He said that the emergence and consolidation of a discourse of non-discrimination made it possible for society to see their actions as legitimate. They stopped being seen as the '*loquitas*' who struggle for minorities by society; instead, they were seen as freedom fighters, activists who were aiming to attain a society that recognizes rights already outlined in constitution. 6) The last point, he stressed, was the arrival of AZT. When they saw that AZT was saving lives, they decided to organize and struggle for access to medicines.

Other points that were always present are the aperture of spaces in public places. Also, according to Carlos Monsiváis (2005), the struggle generated by the student movement in 1968 and the 1985 earthquake led to the emergence of a society which thought it was possible and necessary to organize and fight for rights in contexts of institutional abandonment and state authoritarianism that, by monopolizing the right over public sphere, did not allow the organized response to crisis and the participation of civil society in issues of public interest. This was not possible during the repressive regimes previous to 1968.

Antonio Medina enumerates the factors that were stressed by some of the interviewees. Among this list, the access to international funding was particularly stressed. In effect, the access to grants and scholarships from US-based agencies was a very important factor shaping and strengthening the emergence of activists and diverse forms of protest in AIDS activism. All of the activists were interviewed reflected on the fundamental role played by the grants they had access to in strengthening their position as activists and in the selection of forms of protest. The grant Gina received from *Ashoka* in 1998, for example, was fundamental in relieving her from the worry of looking for job while she was participating in activism. She could instead one hundred percent on learning about politics and human rights and participating in street-level politics and grassroots activism in the jail during all the tenure of 5 years. She actually mentioned that the money she received from *Ashoka* made her feel that what she was doing was not something incorrect, but rather something that was very valuable, important and transcendent. These

feelings motivated her desires to “continue fighting”, as she says, without feeling worried about looking for job to put food on the table. “My passion gave money and recognition. What else should I ask for?”<sup>42</sup>, she said.

Polo Gómez the director of *Condomovil*, on the other hand, testifies that the money he received from *Ashoka* in 2003 made him feel very happy and rescued him from his very difficult financial situation; it also made him feel that what he was doing was something important and valuable for the rest of the society. He mentioned, for example, that when the members of *Ashoka* asked him to put the quantity he needed per month as a grant, he mentioned a very low quantity (500 dollars), and the *Ashoka* representative told him with surprise: “500 dollars? That’s it! Oh, no, that is too little money. We recognize that your work is extremely important and valuable. Ask us for more money, please”. Polo, after several tries adding 50 or 70 dollars to the initial quantity was asked “please receive 1500 dollars per month”<sup>43</sup>. The result is that he started to feel how important and valuable his work as an activist was and that motivated him very much to continue traveling around the country to fight against AIDS.

The money not only helped them to feel their work was important and made possible their complete dedication to the act of learning, but also gave them the opportunity to build a basic infrastructure for making things happen, as they usually said during the interview. For example, *Letra S* hired office personnel; traveled around the country to provide workshops and train advocates; bought cars and office facilities that made their work easier and increased their capacity to influence the public in a short period of time. Polo Gómez bought a new and more efficient car to make the trips which are necessary to provide education to rural areas and increased enormously his visits and the quantity of educative actions in and around México. Finally, Gina dramatically increased her activism and trained thousands of prisoners around México on issues of HIV/AIDS,

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<sup>42</sup> Interview with Georgina Gutiérrez (Gina), February 13, 2011

<sup>43</sup> Interview with Polo Gómez, January 15, 2011.

prevention and human rights. She also created the first groups of prisoners advocating for human rights and health issues in prisons in México<sup>44</sup>.

As has been mentioned, access to funding has been a crucial element in strengthening the struggle carried out by several AIDS organizations, in general, and AIDS activists in particular. However, the access to resources has not been the only motor feeding the people's will to keep fighting or to 'mantenerse en la lucha' as they say. There are some AIDS organizations that have been extremely successful in making cultural, institutional and legal changes despite the fact that they have not had access to national or international funding. This is the case of the *Red Positiva de Quintana Roo*, *Identidad Saludable*, *Tabasqueños Unidos por la Diversidad y la Salud Sexual*, and *Conciencia para el Futuro*. In these cases, there are other non-material resources that had made possible the existence of a will to launch and sustain a transformative political praxis despite lack of funding, resources, and infrastructure. For example, after sharing his experiences dealing with the scarcity of money and infrastructure to carry out their activities as organization, I asked Roberto Guzmán -the president of a politically successful AIDS organization located in Quintana Roo, why then he is still an activist, despite the stress and complexities generated from working with few resources and lack of sufficient infrastructure. Although his answer was interrupted several times by sobs, he answered my question with a sort of pride in his words:

I am a leader and I am an activist because I find pleasure on it. I have engrained in my hearth a sense of duty that motivates me to do this (...) Something inside me tells me that I have to be a messenger of this cause, that I have to make changes so that things can be better for me and for people living with HIV (...). Two of my very beloved partners have died (...) Maybe because of this reason I am still fighting. I am still fighting, and will continue to do so (...) Somebody has to do it! I have the courage to do it (...). It has not been an easy task, though.<sup>45</sup>

Similarly, Arturo Marin, president of an organization which carries out its activities in the south of Mexico, shared with me that for several years he and his collaborators have been carrying out their activism under stress due to the problems generated by the scarcity of

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<sup>44</sup> Interview with Georgina Gutiérrez (Gina), February 13, 2011

<sup>45</sup> Interview with Roberto Guzmán Rodríguez, January 27, 2011.



funds. As a consequence, some years ago he transformed his modest apartment, shared with his partner, into an office for the organization. He also, uses the spaces of his apartment to provide counselling and training to people living with HIV, and local activists. He mentions that he actually uses around 40 percent of his income as a public defender in the municipal government to cover the expenses generated for the organization. As in the case of Roberto Guzmán, when I asked him why he is still an activist despite the enormous weight and stress it puts on him, he answered:

I am doing this and I will be doing this forever because I live with HIV (...) Several of my friends have died. I am witness to all the pain and suffering it implies living with HIV in this so difficult and challenging context full of homophobia and lack of respect for people living with HIV. I am proud of my work as an activist and I will continue doing it forever, unless things change for the better<sup>46</sup>.

In these two cases, which well represent the case of the other two activists who were interviewed, what maintains the will to be an activist is the courage, the sense of duty and the feelings of pain, and indignation generated by having lost loved ones due to AIDS-related problems. The emotional resources, then, seem to be equally important factors in maintaining an individual and collective disposition to keep fighting against death and the tragic and painful consequences of living with HIV in a country lack of institutional, cultural and legal protection towards the people living with this illness.

### **e) The redistributive politics of AIDS activism**

A very important part to consider in this chapter is that during this period of time, the AIDS activism has become increasingly focused on making redistributive politics a priority for the Mexican State. Its repertoires of contention - based on debates generated at press conferences, the use of mainstream and alternative media, massive strikes, education through street performance and other formal petitions to the government- aim most of the time to convince the government that their prerogatives as a group should not

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<sup>46</sup> Interview with Arturo Marin. The name was changed at his request.

been seen as prerogatives which are separate from those of the rest of society. They stress that the constitutional principle of equality should be the basis and the horizon of the public policies created by the Mexican state in regards to health care and other public policy aims to improve the living conditions of the Mexican population.

At the same time, their public discourses, demands for people living with HIV, and their public campaigns invite people living with HIV to show their faces and not to feel shame for being diagnosed as HIV positive. They stress that these feelings are induced by the interiorized stigma generated by the feelings of guilt and shame which stem from and are shaped by the homophobic prejudices that attribute HIV to a homosexual and 'perverted' sexual practice. Then, the invitation and encouragement to elaborate politics based on the recognition and social inclusion of these identities, which have been deteriorated by the dominant discourse of exclusion, are becoming part of their activism. To follow Adam (2002), the politics of contention carried out by AIDS activists in México have been based on a struggle to attain social recognition and respect from mainstream society and state institutions and to attain public policy and state interventions which redistribute the resources which they have been denied as a social group, at the same time.

## IV

### FRAMING PROCESSES AND THE OUTCOMES OF AIDS ACTIVISM

After describing the process in which AIDS activism emerged, as well as the ways in which particular social and institutional conditions led to the emergence and expansion of its repertoires of contention, let's move on to describe and analyze the main outcomes generated by AIDS activism. Some of the questions that will guide this intellectual exercise are: What are the main outcomes generated by AIDS activism and to what extent have these contributed to enriching the well-being of people living with HIV? What are the institutional scopes and limitations of such collective outcomes? What are the episodes of contention and the methods used by AIDS activism which led to the successful concretion of such collective outcomes? What was the structure of political opportunities that stimulated and facilitated the episodes of contention of AIDS activism? And finally what is the meaning of such outcomes in the context of neoliberal policies in México, or to what extent do they contribute to their weakening or strengthening? The outcomes described in this part will put particular emphasis on how the frames used by the movements have influenced the episodes of contention and its outcomes.

#### **Introductory note: Political frames and collective outcomes**

As has been mentioned in the first chapter of this thesis, the outcomes generated by a social movement are always the result of diverse factors that shape and structure the horizons, as well as the limits and scopes of what a social movement wants to change. In addition to the obvious limits and possibilities that the structural and external factors in a particular social formation impose on the collective action, the ideological structures used by the leader of determined movement, or the entire movement itself, to frame the causes and consequences of a problem and the ways it must be addressed, challenged and transformed play a fundamental role not only in the ways a movement utilises particular repertoires of protest, but also target the institutional arrangements that must be changed. Empirical research has shown that liberal frames used by some social movements tend to determine a collective action which is oriented to lobbying and whose main target is the

transformation of the law in order to address and solve the problem which led to the emergence of the movement. In the same way, when a movement sees culture as the cause or origin of the problem they want to change, it tends to target particular cultural forms as points of their contentions.

For heuristic reasons, legal and institutional outcomes generated by AIDS activism are divided into two parts here. The first set of outcomes represents the outcomes generated under the stimulus of a liberal framing. This will be called “the liberal framing”. The second set of outcomes, generated under the stimulation and influence of anti-capitalist or radical leftist movements, will be called “the radical democracy framing”. In both cases, the political process and the structure of opportunities that led to the episodes of contention will be mentioned first to better inform the context and the stimulating factors in which the episodes of contention and their outcomes took effect.

### **The liberal frame and its institutional and legal outcomes: Medicine, institutional programs and the broadening of right to health**

#### **a) The first outcome: Medicine for all in a context of neoliberal scarcity**

One of the most important and meaningful outcomes generated by Mexican AIDS activism is the access to medicine and antiretroviral therapies for people living with HIV, as well as the enrichment and expansion of the right to health care for the Mexican population as a whole. What is particularly fascinating about this case is that this outcome was generated precisely in a context of scarcity generated by the neoliberal process of dismantling of public services, including the health care system, and its consequent chronic and cyclical shortage of medicines.

Although the struggle for medicines and better treatment in public hospitals, led by people living with HIV, started right after the creation of the first self-help groups, the episodes of contention carried out by AIDS activism as social movement, which aimed to

gain access to medicines and health care in public hospitals, only started at the beginning of the nineties, right after the introduction of low quantities of AZT to public hospitals in México. This process was carried out via two episodes of contention, which will be described in the following paragraphs.

**a.i) The first episode of contention: Toward access to medicine for people living with HIV or AIDS**

In 1991, *Mexicanos Contra El SIDA*, the first network of social organizations fighting against AIDS (14 in total) in Estado de México and México City, led by the legendary activist Arturo Díaz, organized the first national encounter in which civil organizations discussed the problems generated by the permanent shortage of medicine. They also discussed ways in which to act in order to demand that the Mexican state solve the problem, as well as possible ways in which they could promote the initiative nationally and effectively implement it. After this and other several encounters, *Mexicanos Contra El SIDA* and other organizations which did not belong to this network, started to demand that the federal government, particularly through *Secretaría de Salud* and CONASIDA, the federal organism created at the second part of the 1980s to face the problems AIDS had generated, implement a policy that would guarantee that medicine be covered for all people living with HIV. They made this possible through radio programs, where these issues were discussed, and through having discussions with the government at public events and on the radio programs themselves. By doing this, the organization reached the goal of putting the issue on the public agenda (UNAIDS 1998).

**a.ii) The second episode of contention: FRENPAVIH and access to ARVs for all**

In 1996, after realizing that antiretroviral drugs were available on the market, as it was reported at the Vancouver Conference, the first National Front of People Living with HIV made it their main goal to guarantee access to medicines for all HIV positive people in the country.

The main form of protest, as it was analyzed in the last chapter, was the organization of street protests. The first protest was carried out in April 2007 during a congress on infectious diseases organized by the *Secretaría de Salud* and attended by elite public servants who worked in the area of health. Dramatic manifestations in front of such an event with slogans demanding to stop killing people living with HIV by denying their access to free treatment, as well as the use of balaclavas filled the main pages of the local and national newspapers around México. The result of such events led to the first agreement with the IMSS. The IMSS authorities promised to eliminate the shortage problems and demand more money from the government so that they could include antiretroviral therapy of last generation to their basic list of medications<sup>47</sup>.

Empowered and fascinated with the results of the first mobilizations, FRENPAVIH expanded its activities and protests in various states of the Mexican Republic and, in November 1997, they made another agreement, this time with the *Secretaria de Salud*, which would provide them with public funds and allow them to broaden their influence in México (González Ibarra 2006). In 1998, they participated in several protests and the first legislative forum organized by *Letra S* and the Federal Parliament where forms of funding for increasing antiretroviral and other HIV-related medicine coverage was discussed. This last exercise started a series of mobilizations and protests in the Chamber of Deputies each year, where they asked the deputies to raise the funds so that the expansion of medicines for all people living with HIV would be possible.

In 1998, this organization expanded its repertoires of protest and started to send complaints to the National Commission for Human Rights. They started framing the problem of lack of access to medicine as a human rights problem. Although the response from this institution was not always positive and encouraging for the group, it created important precedents and made possible the visibility of their cause in the public opinion. In response to these actions, in 1998, *Secretaría de Salud*, along with the *Universidad Nacional Autónoma de México* (UNAM), created a public fund specially designed to

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<sup>47</sup> This information was shared by Polo Gómez, Georgina Gutiérrez, Antonio Solis and Antonio Medina.

collect private funds for providing medical attention to people living with HIV who were without access to treatment (González Ibarra 2006). Although this victory was partial and very limited, the impact on the public opinion was important. The public discussion on the issue was augmented and the issue remained relevant for the general public.

In 1998, as a result of the activism and pressures created by FRENPAVIH and other AIDS activist organizations, the Chamber of Deputies organized the Forum: “VIH/SIDA: Reto Social y Desafío Legislativo”. In this event, the issue of how to raise the public funds invested in health and antiretroviral was seriously discussed. The *Declaración de San Lázaro*, a commitment produced as a result of this event, proposed that it was fundamental to prepare and guarantee the allocation of resources for prevention programs integral medical attention and the defence of the human rights of people living with HIV AIDS” (Saavedra 1988: 113).

The deputies and public servants did not do very much to assign the money needed to attain this goal, however. In response, FRENPAVIH radicalized its positions. After organizing large and short national and local mobilizations, they managed to have PRI deputies agree to allocate a historical quantity of resources for HIV medicines. Based on a calculation elaborated by several specialists, amongst them Jorge Saavedra and future director of the Mexican Government’s National AIDS program (CENSIDA), the Chamber of Deputies assigned 73.4 million dollars to HIV-related expenses. From the total of this money, 65.7 million were allocated to ARV, 3.3 million were allocated to laboratory tests, 1.3 million to training health personnel in public hospitals, and finally 2 million to buying medicines fundamental for the treatment of opportunist infections related to HIV (Saavedra 1998: 144-145).

After this first great victory for people living with HIV generated by the effective mobilization by AIDS activists at the street level and at the level of lobbying with deputies that are allies, traditionally from the *Partido de la Revolución Democrática* (PRD), the money allocated to HIV has faced several steps forward and backwards and the victory has not been achieved definitively. In 2002, for example, at the height of the

neoliberal reforms in the fiscal area imposed by the deputies of *Partido Acción Nacional (PAN)*, the conservative party which arrived to the power in 2000, the members of this party severely reduced the money allocated to AIDS, arguing a lack of public money generated, according to them, by the lack of structural reforms that did not allow the government to have money for medicine (Medina 2002).

However, thanks to the tireless fight carried out by FRENPAVIH and its allied organizations, in 2003 the Mexican state started to use a reserve of money borrowed by the World Bank for catastrophic expenses, to finally guarantee universal antiretroviral therapy for all people living with HIV in México, regardless of their employment status. Even though the shortage of medicines continues to be a relevant issue that impedes people's formal access to their medicines, the institutional transformations carried out by AIDS activism has constituted one of the most relevant victories generated by social movements in the last 50 years.

Key to the successful mobilization that generated this outcome was the existence of mobilizing structures generated, first, by the self-help groups and the spaces they provided, which generated political reflexivity and the development and formation of future AIDS activists or sensitive people who showed up during the manifestations organized by FRENPAVIH and its allies.

Another key element was the existence of *Letra S, Salud Sexualidad y Sida* and its set of militant journalists that not only made possible the existence of a social movement struggling for their right to health care and medicines, but also the public debate in itself through the papers of their supplement and by organizing forums and public debates with key political actors and allies of the movement<sup>48</sup>.

The act of framing the problem as a human rights issue in a moment in which human rights become part of the public agenda was an strategic and fundamental choice. It was possible to put the issue on the political agenda and overcome the idea, promoted by

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<sup>48</sup> Interview with Georgina Gutiérrez and Antonio Medina.



right-wing intellectuals and some newspapers, that the issue was only pushed by strident homosexuals.

## **b) The second outcome: Changing laws and institutions**

Parallel to this street-level activism that opened up access to antiretrovirals for all people living with HIV, AIDS activism also began to successfully change laws, establish specialized programs in public institutions and win important legal battles that, in addition to solving cases on a case-to-case basis, have created precedents which expand and enrich the content of the constitutional right to health care to the benefit of the whole of the sick and needy sectors of the Mexican population. Three primary cases exemplify this.

### ***b.i) The Supreme Court and the constitutional right to health care***

The first case refers to the recognition of health as a constitutional right. In 1996, José Luis Castro Ramírez, a haemophilic man who was severely affected by HIV and who had been denied health care at the *Instituto Mexicano del Seguro Social* “due to the lack of availability of retroviral therapies”, turned to the Supreme Court to seek legal protection and start a constitutional appeal against the health institute for what he considered to be a violation of his right to health protection, a guarantee established by the Mexican Constitution. In this constitutional appeal, Jose Luis Castro was asking that IMSS provide him with all the medications needed to protect his life from the devastating effects of HIV. In response to the request made by the Supreme Court, IMSS answered that, although the medicines were available in México, they were not included in the “Cuadro Básico de Medicamentos” of public health institutions, a mandatory list that includes all the medications that by obligation all health institutions must provide. AZT was not included on such a list, which is why IMSS did not feel obligated to provide it to Jose Luis Castro. In first resolution, the Supreme Court determined that, in effect, IMSS was not obligated to provide such medicine.

Since there weren't any antecedents of sick people looking to the Mexican Supreme Court for protection from a federal health institution, the case received very little attention from the public and the NGOs did not apply any pressure. Nevertheless, after a second appeal, in 2001, the Supreme Court ruled in his favour and established that Mr Castro's constitutional right to health had been violated and that he had the right to receive his medicine even though they were not included on the mandatory list of medications. This victory in the Supreme Court constituted the first victory and a precedent on the long road to the recognition to the constitutional right of all Mexicans to receive medical treatments needed to protect their health. In 1997, AZT and other medications to treat opportunist infections related to HIV were included on the list of mandatory medicines for health institutions. Although José Luis Castro Ramírez had already passed away by the time the Supreme Court gave its verdict, the case created an important precedent that allowed people living with HIV and all other people who suffer from illness to receive medical treatment because it was their constitutional right.

After this case, two additional cases established another important step forward. In 1997, the lawyer Pedro Morales Ache took on the case of a group of minors who experienced growth hormone deficiency (*GHD*), and these cases were also won (Ramírez 2009). This established a very important precedent in the Supreme Court. In the Mexican judicial system, law can only be changed once three consecutive cases have returned similar legal decisions. After these three cases, all Mexican institutions would be obligated to provide the medical attention and therapies available in the health care system to treat those suffering from HIV or any other illness. It is for this reason that the movement led by people living with HIV has not only made access to antiretroviral drugs possible for all people living with HIV , but it has also made all medicines available to whomever needs them for treatment and protection when suffering an illness, regardless of the type of illness. So, the generation of legal precedents and jurisprudence in the Mexican tribunals, along with the street-level protest targeting authorities has changed laws and moved institutional structures that are beneficial for the whole of the Mexican population.

### ***b.ii) The case of military personnel living with HIV***

The second case refers to the recognition of the right to health care for military personnel living with HIV. On September 27, 2007, a similar legal decision was made by the Supreme Court after the analysis of seven constitutional appeals presented by HIV-positive soldiers who had served in the Mexican Army and, due to their HIV-status, had been discharged without receiving medical treatment. Because of the Supreme Court decision to rule in the soldiers' favour, the Mexican Army is now prevented by law from discharging HIV-positive military personnel. It must also provide integral medicare to all personnel that experience chronic health-related problems, a right that was not recognized by martial law before these constitutional appeals were put forth.

### **b.iii) Making specific laws to protect people living with HIV**

Finally, the third case is related to the creation of laws aiming to protect the PLHA's rights. On December 25, 2008, the Chamber of Deputies of the State of Veracruz, one of the states most affected by HIV, and one which had a reputation for having government official who held conservative positions regarding sexuality and the rights of sexual minorities and people living with HIV, promulgated a law specifically oriented to protecting the rights of PLHA. Although the new law criminalizes the transmission of HIV, it establishes a series of governmental duties regarding the protection of PLHA, sexual minorities' and sex workers' rights to medicare as well as educational programs and protection from violence and discrimination. This law was made possible due to the activism and political work carried out by a multi-sectoral organism composed of activists, such as Nicté Aguilar, academics, such as Patricia Ponce Jimenez, and health institutions. In terms of human rights, this law constitutes a significant advancement in the recognition and protection of PLHA in this part of México. It is also, one of the most important precedents in matter of legislation regarding HIV in México.

It is important to point out that in all these cases, the role played by *Letra S*, and, particularly those articles written by Antonio Medina were fundamental for illuminating

and giving relevance to themes that were quite marginal in the public debate in México. For example, in 1997, they started to publicize the discussion around the importance of including AZT and medicines to treat opportunistic infections in the *Cuadro Básico de Medicamentos* by inviting specialists, such as the lawyer Pedro Morales Ache. In the case of military personnel, the discussions generated by Antonio Medina in *Letra S* and by Guillermo Núñez Noriega, a recognized public intellectual on issues of sexual politics in México, were fundamental in making public and relevant an issue that had appeared in mainstream media as irrelevant.

Another important factor was the way in which AIDS activists made contact and petitions with key public figures in parliament and with public servants who were traditionally allied with the AIDS cause. This access to key public figures and allies made public discussions possible, which in turn made these issues relevant when, otherwise, they might not have had any impact on public opinion and, therefore, no relevant institutional outcomes. For example, in order to make the law happen in Veracruz, the wise decision of Patricia Ponce to make contact with public servants at the National Commission for Human Rights and CONASIDA, led to the organization of a public event to discuss the law with local authorities. This event played a very important role in convincing the reticent local authorities. After the forum and after elaborating the law itself (with the help of such federal public servants who were traditionally allied with the cause), officials in the local congress passed the law without any problem. The public mobilization in other cases was also a very important factor in making such changes possible.

### **The radical democracy frame and its outcomes: Expanding communities, defending local autonomies and making radical anti-capitalists part of the AIDS cause**

Led by the Mexican state and local economic and political elites, the process of crafting (Wacquant 2010) the neoliberal social formation at the national level has created a double movement (Polanyi 2001) in Mexican society. On one hand, a set of legal, economic and political reforms have led to the configuration of diverse forms of geographical,

institutional, economic, and symbolic displacements. These forms of exclusion have, in turn, created higher levels of poverty, homelessness, unemployment, and massive forced migration from the rural to urban areas, as well as an ‘elitization’ of politics, meaning that entire communities are excluded from political participation and access to the outcomes linked to participation. On the other hand, as a consequence of these processes of exclusion, the communities of displaced persons have tended to organize from the bottom up around diverse communitarian and political projects, sometimes as a self-protective defensive measure to deal with the consequences of exclusion, and other times as a offensive measure aiming to transform the structures that exclude them from economic and political participation.

In this context, radical forms of political thinking, political participation and protest that were subjugated, weakened, delegitimized, and which almost ‘disappeared’ during the 1970s and 1980s due to state violence (Montemayor 2010), re-emerged with particular strength in the 1990s as a via for democratization and as an anti-capitalist frame for political action. On January 1, 1994, for example, precisely the day NAFTA took effect, large numbers of communities composed of indigenous peasants displaced from their lands, intellectuals, students, union activists, environmentalists, and women’s associations, organized around the *Ejército Zapatista de Liberación Nacional (EZLN)*, declared a rebellion against the Mexican state; they invited the Mexican population, civil society and NGOs to launch a national movement in order to reconstruct and democratize México ‘from below.’ Their call to launch a democratization process in México found an echo and success among the Mexican population (and abroad), not only because they clearly proposed that these changes be made via pacific means, but also, and principally, because they utilized an inclusive discourse of democracy and change in which the recognition and strengthening of diversity was located at the origin and end of all political horizon. One of their more compelling mottos, and probably the most representative of their political project, was: (“*Queremos un mundo donde quepan muchos mundos*” (“We want to build a world where all worlds have a place”).

After the eruption of the Zapatista movement and several other episodes of contention that generated profound changes in the structure of the regime during the negotiation process with the Zapatistas, Mexican civil society, a heterogeneous mass composed of citizens associated around organizations, that was very weak, fragmented, dispersed and sometimes functional to the regime (which used their young existence to lie about a supposed existence of democracy and openness) experienced a process of growth, strength and definition. Civil society became empowered and began to dialogue through several encounters organized by the Zapatistas and its political organization, the *Frente Zapatista de Liberación Nacional*. The young people became politicized and defined themselves as left-wing, as Zapatistas or as people of 'democratic ideals'. The civil organizations' repertoires of protest diversified, deliberation around public issues and petitions to the regime returned to the streets again. Civil society's fascination for density as a way of showing strength and decisiveness of transformation became a reality in social movements: "*No somos uno, no somos cien, pinche gobierno cuéntanos bien*" (There is not one of us, nor is there one hundred, stupid government count us well). To sum up, it is not possible to understand the growth and fortification of civil society in México, the broadening of their repertoires of protest and their collective outcomes and successful struggles during the last 20 years without understanding the powerful role played by the emergence of the EZLN in Mexican politics.

AIDS activism, composed mostly of gays and left-wing intellectuals who had divorced from the radical and revolutionary orthodox Marxist movements of the 1970s and 1980s, suddenly felt attracted to the Zapatista call to engage in radical transformative politics from and for diversity. They were also drawn by their call to all the oppressed and marginalized populations of México to join a unified struggle (not necessarily in the name of or led by Zapatistas, but self-organized, at least) for their right to health, housing, autonomy, democracy and respect of their diverse ways of life. One of the organizations which was most influenced by the Zapatista uprising is *Brigada Callejera de Apoyo a la Mujer*. This group has created important outcomes in the struggle for the AIDS cause, and will be discussed in the next section.

### **a) AIDS activism, sex-workers and the expansion of resistance networks**

In 1992, a groups of sociologists from the National Autonomous University of México (UNAM), Elvira Madrid, Jaime Montejó and Rosa Isela, launched a project called *Brigada Callejera Brigada Callejera de Apoyo a la Mujer* to prevent HIV infection among sex workers whose main work space was downtown México City. At that time, the main problem facing these sex workers, according to them, was the high rates of STDs generated by the limited availability of condoms (due to high prices), as well as several forms of intimidation and violence on the part of clients and pimps. In that context, the main purpose of this project was to educate sex workers in HIV prevention and the care of their own health, opening up a free walk-in health clinic and providing them with educational tools so as to enable them to become “owners of their own bodies” and to know how to defend themselves from street violence and extortion. As a result of such work, the group became a NGO which advocates for the (mainly health) care of the sex workers who work in the downtown area of México City.

The altruistic and apolitical work of this community of sex workers ended when, in 2002, the *Fundación del Centro Histórico del DF* (FCH), a foundation created by Carlos Slim, the richest man in the world in 2010, according to Forbes magazine<sup>49</sup>, started a permanent campaign for the reconstruction and beautification of the historical downtown area. From that time on, the FCH has been financially supporting local governments in the implementation of four main policies: 1) Public security and combating delinquency, 2) Restoration and the conservation of World Heritage properties recognized by UNESCO, 3) Promotion of cultural activities, and 4) Promotion of people’s well-being.<sup>50</sup>

These campaigns have materialized into a regime of expulsion and silencing of the communities that have lived and worked in this part of the city for decades, including street vendors, sex workers, street artists and so on. There are several ways in which this

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<sup>49</sup> “Special Report. The World’s Billionaires,” edited by Luisa Kroll and Matthew Miller, 03.10.10. *Forbes*, [http://www.forbes.com/2010/03/10/worlds-richest-people-slim-gates-buffett-billionaires-2010\\_land.html](http://www.forbes.com/2010/03/10/worlds-richest-people-slim-gates-buffett-billionaires-2010_land.html)

<sup>50</sup> See the webpage of the *Fundación Centro Histórico* here: [www.fundacioncentrohistorico.com.mx](http://www.fundacioncentrohistorico.com.mx)

has occurred. One of the most important has been the use of a public security system called “*Zero Tolerance*”. This system is based on a set of recommendations made by Rudolf Giuliani (Davis 2007), former mayor of New York, and it relies on the use of public surveillance cameras and the police as the fundamental pillars of this beautification program.

The other forms of expulsion from the México City’s historic downtown have involved the use of public grants for poor people so that they can accept a pacific and “friendly” relocation to other parts of the city; the introduction of real estate developers who have contributed to a drastic increase in the prices of housing, food, and public services in the area, as well as the marginalization, sometimes enforced by the police, of public artists who, because they do not match the aesthetic parameters of “high” art which is deserving of expositions in the prestigious galleries and museums located in this part of the city, are becoming classified as street beggars, an activity defined by municipal laws as illegal.

In this context, the sex workers working in this part of the city, instead of being targeted by local authorities for condom distribution, education on HIV-prevention or protection from sexual extortions, have been targeted as problematic elements that must be relocated and persecuted. Particularly, the sex workers which organized the *Brigada Callejera de Apoyo a la Mujer* have been targeted by laws and the municipal government as problematic elements that obstruct the possibilities of the beautification of the city. For those reasons, they have been subjected to a process of progressive displacement and expulsion from their territory. Several times, local politicians and lawmakers have launched campaigns oriented to the modification of municipal laws in order to regulate these places and the ways in which they can carry out their work in order to *illegalize* or criminalize their presence in strategic areas of the downtown core. These campaigns have failed thanks to the sex workers’ popular mobilization and capacity to create political alliances in response. Therefore, the governmental strategy has been to invent problems supposedly related to sex work in downtown México City. In the name of the protection and safety of sex workers, particularly for the minors that, according to the authorities, are at risk of sex trafficking and sexual exploitation, the local government has started a



process which persecutes sex workers' leaders, closes legal places for encounters between sex workers and clients and promotes a media campaign to discredit the sex workers involved in *Brigada Callejera*. In response, the sex workers have started a campaign called "La calle es de quien la trabaja" (the street belongs to those who work it). And this is precisely what connects *Brigada Callejera* to the Zapatista Army of National Liberation (EZLN) and to other communities of displaced persons.

### **b) Expanding community and political alliances**

On January 1, 2006, the EZLN announced the launching of "La Otra Campaña" (The Other Campaign), a national campaign oriented to the construction of a national dialogue among communities, individuals and social groups that, in the words of Subcomandante Marcos, leader of the Zapatistas, have been excluded and alienated from their land and dignity by the "democracy of the rich" and "the owners of the money". Thus, this was a call to unite all those who identified with the necessity of building an anti-neoliberal and anti-capitalist project from the bottom up.

One of the organizations that adhered to "La Otra Campaña" and actively participated in its promotion was *Brigada Callejera*, the group of sex workers that we described previously. They started to organize meetings, assemblies and other public events where they reflected their affinities and started to make links between their struggle and the EZLN's history of rebellion against displacement and exclusion experienced by indigenous communities in México. They realized that the history of displacement and violence they experienced had similar roots, with different faces. Then, they started to promote their struggle with the motto "*La Calle es de quien la Trabaja*" (the street belongs to those who work it) in clear allusion to the old Zapatista motto: "*La tierra es de quien la trabaja*" (the land belongs to those who work it). They also elaborated an educative program aim to promote gender equality, sexual health, and STD and HIV-prevention within the indigenous Zapatista communities of Chiapas; this campaign has been successful among indigenous people in general, and the Zapatistas, in particular,

with regards to issues of HIV and the forms of vulnerability and discrimination attached to it.

Led by *Brigada Callejera*, an additional 28 organizations of sex workers created a national network named *Red Mexicana de Trabajo Sexual* (National Network of Sex Workers), and joined *La Otra Campaña*. Soon, the sex workers of México adopted a new image of radicalism and solidarity like never before. Zapatismo, on its part, become represented as a more open and “humane” form of guerrilla.

Another group that adhered promptly to this national initiative was the *Comité of San Salvador Atenco*, a group of peasants which has been involved in struggles against displacement since 2006. Soon, it became common to see peasants and sex workers - some of them *travestis*- working together, shouting the same slogans in the demonstrations, smiling together, talking to each other, and sharing similar utopias in the streets or in the assemblies. The number of romantic relationships and the acts of friendship, camaraderie and love among members of these groups (peasants, sex workers and Zapatistas) that is possible to see in such events, in addition to being a wonderful aesthetic experience in itself, is a phenomenon which must be analyzed. The Zapatista leader Marcos and EZLN have also become adherents and promoters of sexual health and the struggle against AIDS in indigenous communities. For example, the condom made by the cooperative *Brigada Callejera* called “*El Encanto del Condon*,” which is distributed free of charge to all sex workers or sold at a very low price in the *condonerías* of México, has as a promotional photo of Subcomandante Marcos with a “El Encanto” brand condom in his hands. The peasants of San Salvador Atenco have also been promoting sexual health and *El Encanto del Condon* within their communities.

It is interesting to note that, from that time on, these three organizations, along with dozens of other groups and organizations throughout México have participated in the creation of national networks whose main characteristic is being part of communities that, for different reasons, have mobilized their members around territorial-based struggles. Some of these networks include the *Asamblea Nacional de Afectados Ambientales*

(National Assembly of the Environmentally Affected Populations) and the *Frente de Pueblos en Defensa de la Tierra* (Peoples' Front in Defence of the Land). These networks are composed of indigenous populations that have been alienated from part of their lands, movements of people who have been relocated to other parts of the historic downtown, former peasants who have sold their land, neighbourhood organizations that lost their properties to foreclosure as a result of unemployment, artists and street vendors that have been prevented from working on the streets where they used to make a living, and so on.

After seeing this example of community-building based on identified common causes, it is easy to argue that another of the main causes generated by AIDS activism, at least the line that bases its struggle on an anti-capitalist frame, has successfully highlighted the struggle against AIDS and its destructive effects on the health and dignity of people and expanded it to communities whose poor and marginalized character have traditionally excluded them from receiving this information. They have been successfully including these communities in the struggle against the forms of exclusion and violence generated by the positive serologic condition in México. The expansion of such networks of resistance is one of the other major outcomes generated by AIDS activism.

## V

### CONCLUSION

As was mentioned at the beginning of this thesis, the main research goals that guided this academic exercise were: 1) To understand how and to what extent the implementation of policies created in light of neoliberal structural adjustment programs in México have shaped the vulnerability of people living with HIV or AIDS in México, and 2) To describe and analyze the array of political practices that have, as a social movement, been exercised in order to transform the conditions that organize this vulnerability in México.

In regards to the first goal, it is necessary to underline some fundamental points that help us to understand the extent to which the neoliberal policies have been affecting people living with HIV in México. In Mexican society, most of the narratives and political diagnostics generated and circulated fundamentally by government programs specialized in HIV and AIDS, and reinforced uncritically by the alternative and non-corporative press, and even by AIDS activists and their CBOs, present homophobia as the main source of the oppression experienced by people living with HIV and AIDS. This narrative is only partially true. Contrary to this interpretation, a basic review of the policies of deregulation, which started in México in 1983 and radicalized after the nineties, shows that cuts to the general budget allocated to health care services translates into chronic shortages in antiretrovirals; a lack of specialized medical personnel and infrastructure and a deterioration in the relationship between patient and health professionals which ultimately has had a very negative impact on the health of people living with HIV. Particularly stressed was the fact that these diverse forms institutional deregulation and the participation of private enterprises in the health services, reinforced by the progressive deterioration of services, led to a stagnation rather than a reduction in HIV-related mortality rates and an increase in the number of cases in which the patient developed several resistances to antivirus due to the permanent shortage in medicines.

These material structures, which organize the vulnerability to which people living with HIV or AIDS are exposed, operate in a mutually-reinforcing relationship with the

symbolic structures underpinned by the discourse generated by the Catholic Church and a conservative Mexican elite organized around interest groups, such as *Asociación Nacional de Padres de Familia*, *Asociación Nacional Pro Vida*, and other militant right-wing groups. These symbolic and mental structures of representation organize and justify the violence against PLHA by imagining AIDS as a ‘homosexual disease’ or as an illness stemming from God’s punishment of the immoral people.

Relatively independent from the economic structure, these symbolic structures justify, underpin or reproduce the individual or institutional violence that PLHA experience in their face-to-face relations day-in and day-out. The effects of the mutually-dependent and mutually-reinforcing relationship between the material and symbolic structures, such as those which have been described here, are possible to observe quite clearly in México’s health services. It is exactly in these institutions where we can observe how the scarcity of medicine, the lack of material to attend HIV patients, and the moral structures that imagine AIDS as a product of an immoral sexual conduct (or as embedded in a body which is weak, vulnerable and unable to care for itself) leads to a series of attitudes on the part of medical personnel or on the part of the medical institution as a whole which tend to justify or deny the situation (in the best of scenarios), leaving the patient exposed to the situations of abandonment and exposure.

The aforementioned context has been subjected to important transformations which have been promoted by the very people who live with HIV/AIDS since the disease emerged in México. As discussed in this thesis, the emergence of AIDS activism, its repertoires of protest and the outcomes generated as a consequence of this struggle began with the progressive creation of self-help groups. These spaces, which were originally designed for dealing with the psychological effects of living with HIV AIDS or for coping with processes of mourning, generated spaces and networks of people living with HIV as well as processes of collective reflexivity and the formation of political consciousness. This latter was generated by two factors. One was the contact with and training received from human right organizations, and the other was emergence of political opportunities that

stimulated their organization and design of political strategies which would promote institutional transformations.

Among the set of factors that stimulated the transformation and diversification of AIDS activism in its different stages are: the access to public and private funding provided mainly by international organizations; the existence of allies (intellectuals, an diverse sectors of the left-wing party, and progressive public servants) who provided the social organizations with contacts, access to funding and public visibility; the emergence of the EZLN which made possible the existence of public discussions about justice, democracy, and stimulated political participation of civil society, and, finally, the invention of AZT first, and then of the antiretrovirals later, which stimulated AIDS organizations' mobilization to demand access to them.

The existence of these factors (particularly access to resources, infrastructure, political allies, and the emergence of a transformative social struggle which provided openness in polity) are consistent with what the Political Process Theory (the main theoretical approach used in this thesis) points out as some of the most important factors which stimulate the emergence of social movements and diverse forms of social protest. In this sense, this approach was very useful to detect, describe, and analyze a list of factors that appeared to be shaping Mexican AIDS activism since its emergence until the present. However, it was also possible to detect another important factor which provided stimulus to the struggle led by some AIDS organizations that does not appear among the list of factors traditionally stressed by the Political Process Theory. I refer to the role played by emotions in the emergence and permanence of the social struggle led by some of the individuals who were interviewed. In effect, as it was pointed out by some of the activists who participated in this study, the emotional factor is an important resource which have been stimulating and feeding the individual's will to launch and to maintain mobilizing strategies aimed to create social changes, despite the precariousness they face as a consequence of their lack of access to funding and infrastructure. Some of the activists interviewed, and its organizations, have been extremely successful in making cultural, institutional and legal changes despite the fact that they have not had access to funding. In

such cases it was possible to detect non-material resources that had made possible the existence of transformative political praxis. According to these activists what sustains their struggle is the courage, the sense of duty, and the feelings of pain and indignation generated by having lost loved ones due to AIDS. These emotional resources, then, seemed to be also very important factors in the development of AIDS insurgence and the creation of individual and collective dispositions to keep fighting.

This said, it seems quite evident that a materialist and structuralist theoretical approach, as the one was utilized here to read the data which was collected during this research process is insufficient to the understanding of other non-material and non-rational factors that have been also underpinning in a very significant way the emergence and permanence of the transformative political praxis carried out by some individuals and organizations that are part of Mexican AIDS activism. The emotional turn that has recently appeared in the sociology of social movements, then, is an approach that must be taken very seriously in the study of social movements, if the social movement scholar wants to be able to grasp the complexity of the social phenomena under scrutiny. This is perhaps one of the most important lessons I learned during this research.

Another point I consider important to mention in this conclusion also concerns theory. Throughout the text I tried to show that since its emergence, the PLHA movement has focused its political efforts on the transformation of the cultural sphere and the symbolic structures that sustain it in order to attain recognition and respect from the Mexican population and put an end to the stigmatization and marginalization they experience. They have also been applying transformative politics in order to force the government to design and implement redistributive politics that have been beneficial for protecting the sick and the needy in Mexican society. These struggles for redistribution that went hand-in-hand with the efforts to attain recognition call into question the recognition/redistribution dichotomy advanced by some scholars.

Based on the theoretical categories elaborate by Nancy Fraser and Axel Honeth (2004) regarding the characterization of contemporary struggles in the post-socialist era, it can be

said that, in globalized contemporary México, with the exception of some cases, the main characteristic of the struggles led by the current social movements is a struggle for *recognition*. From the political struggles led by gay and lesbian people to promote sexual diversity, to marginalized young people's (such as "emos", punks, "cholos", "darketos", and so on) cultural wars to claim the "right to be different," to the indigenous population's defence and claim of their "traditional laws and customs" (*usos y costumbres*), to the gender equity claims of feminists, the main claim which unites these struggles could be summarized in terms of asking for 'Respect for my way if being' and non-discrimination ('*respeten mi forma de ser, no me discriminen*').

Without wanting to diminish the importance given to these legitimate demands, it seems quite evident that these struggles have not merged by coincidence but as a by-product of the centrality given to the *individual* and its identity in the context of the advancement of liberalism as a dominant epistemological regime in the post-socialist era.

Yet, it is interesting to observe the way in which the social movement organized by people living with HIV, started by a group of persons whose demands were focused on achieving respect for the individual identity (this is, on the achievement of its recognition, respect and non-discrimination related to health condition and sexual preference), has transformed into a social movement that demands the establishment of a mode of justice based on *redistribution*, to continue using the categories put forth by Nancy Fraser. And we say 'redistribution' because the most important claim of PLHA, as a social movement during the second half of the 90s, was, as stated previously, "access to medications for all". In addition to the access to medications for all as a redistributive outcome generated by AIDS activists, we should highlight other important outcomes which have had redistributive characteristics. For example, the successful territorial appropriations generated by the alliances created by AIDS activists, sex workers, Zapatistas and peasants against the processes of gentrification in downtown Mexico city and peasant lands, discussed previously, has been fundamental to the conservation of spaces which have been fundamental for those who make a living in such territories by producing on the



land, making a living out of sex work, and developing grassroots health care programs for those who need it, as in the case of *Brigada Callejera de Apoyo a la Mujer*.

It is even more interesting to see that the shift of the PLHA from the recognition paradigm to the redistributive one occurred precisely at liberalism's height as a dominant political philosophy in México and exactly during a period characterized by scarcity caused by the application of SAPs that undermined the health institutions and severely affected the Mexican labour market. If this appreciation is correct, then this means that the material conditions generated by these new dynamics of a neoliberal mode of government in México have had greater impact on the individual and popular mobilizations than the ideological set of values promoted by people who directly benefited from the SAPs, including passivity, competence, absence of solidarity and individualistic indifference. Moreover, it is interesting to observe that what in reality has been generated by the economic liberalism is a sequence of effects directly opposed to those that have been promoted by the economic elites looking to consolidate their hegemony. What we refer to are the acts of solidarity, resistance and insubordination to the "invisible hands of the market" that have been carried out by people who are most affected; in this case, the people living with HIV. In this sense, it is not overly adventurous to say that the movement of PLHA is, in fact, a post-liberal movement whose practical effects have been the defiance, the dispute and the obstruction of the destructive effects generated by the dynamics of neoliberalism on its path toward "liberty."

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## APPENDIX A: Interview Guides (English version)

### ABOUT THE ORGANIZATION

#### I.- Profile and characteristics

- **Let's talk about general aspects of this organization**

(Explore: ¿When it started? ¿How was the context in which the organization started? How was the situation of the people living with HIV in terms of their access to Medicare, antiretroviral, discrimination, etcetera at the moment the organization was created? Who started it? Why? How the participants were recruited?)

- **What are the organization's objectives?**

(Explore: What were the goals when the organization was started? What are they now? How have they changed? Why?)

- **What are the main activities you carry out? What kind of services do you offer? What is the targeted population?**

(Explore: What were the activities when the organization was started? What are they now? How have they changed? Why?)

- **Who are the bases of the organization?**

(Explore: Which was the base when the organization was started? What kind of people supported you? What kinds of people support you today? How has this changed? Why?)

- **What kind of work do you carry out? What kind of activism do you carry out? Does it include political activities? If so, what kind of political activities?**

(Explore: What was the work it was carried out when the organization started? What kind of work you do nowadays? How it has changed? Why?)

- **Who are the leaders?**

(Explore: Who were the leaders who started the organization? What were their characteristics? Who are the leaders nowadays? What are their characteristics? How they have changed? Why?)

- **Let's talk about how the organization is funded**



(Explore: How the organization used to get funding when it started? How do you receive funding nowadays and from whom? How the funding you receive affects the work carried out by the organization? How do you use the funding you receive?)

## **II.- Networks, Spaces and Resources**

- **Let's talk about the allies you have in your work fighting against AIDS. What kind of relationship you have with them?**

(Explore: Social organizations, funding agencies, politicians, institutions, programs of government, etc.)

- **What kind of international/national/regional networks do you belong to?**
- **What kind of activities do you carry out in such networks? How do you collaborate with them?**

(Explore: How this has changed since you started as organization? What kind of allies, collaboration, etc.)

- **Let's talk about the opponents you have in your work fighting against AIDS. What kind of relationship do you have with them?**

(Explore: Opponents, organizations, funding agencies, politicians, political parties, institutions, programs of government, etc. Have they been always the same? If not, how this has changed throughout the time?)

- **Let's talk about the infrastructure and the spaces of the organizations.**

(Explore: Describe location, history and activities you carry out there? How this has changed?)

- **What kind of infrastructure does the organization has?**

(Explore: Office(s), cars, bedrooms, etc. How the infrastructure has changed through the time? Why?)

- **What kind of human resources the organization has?**

(Explore: Volunteers, waged workers. How this has changed since the organization was started?)

- **What kind of economic resources does the organization has?**

(Explore: Without talking specific amount of Money, explore the changes in income/funding the organization has received since it was started. Private and/or public funding? How this has changed since the organization was started?)

### **III.- Emergence**

- When the organization started?
- Who created it?
- Why the organization was created?
- What was the social context in which it was created? I.e. What kind of problems/challenges people living with HIV were facing at that time?
- How the activism and profile of the organization has changed throughout the time?
- How the members of the organization were recruited?
- How did you find/create the spaces of the organizations?
- What kind of services did you offer at that time? Why?
- What kind of activities/tactics did you put in practice? Why?

### **IV.- Achievements and obstacles**

- What are the main achievements of this organization since it was started until today?
- What are the main obstacles this organization has faced since it was started until today?
- What are the main challenges this organization has faced since it was started until today? (Financial, political, infrastructure, human resources, etc.)
- What are the scopes and limitations of the activism this organization carry out since it was started until today?

### **V.- Vision and political rationale**

- According to this organization, what are the main problems faced by people living with HIV in Mexico?
- According to this organization, what are the best ways to face these problems in terms of tactics, strategies, and ways of collective action? Why?

## **ABOUT YOUR PERSONAL HISTORY IN AIDS ACTIVISM**

### **I.- Personal identity**

- Could you tell me a little bit about you?

(Explore: Where you were born? Where did you study? Level of studies, Social class, Political background, etc., Do you belong to a political party or any other social/political organization?)

### **II.- Personal history of activism**

- When did you start your social/political activism?

(Explore: Age, specific reasons for involvement)

- What is your political education?

(Explore: What kind of political education you have received? There was a specific moment/circumstance/personal figure that inspired you to get involved in activism?)

- When your participation in the struggle against AIDS started?

(Explore: Age, specific reasons, etc. There was a specific moment/circumstance/personal figure who inspired you to get involved in activism?)

- What have been your main achievements since you started your participation in the fight against AIDS?

### **III.- Role in AIDS activism**

- What is your position in the structure of the organization?
- How did you become member of this organization?
- What kind of activities do you carry out at the organization? Since what time? How your role has changed within the organization?
- What is your position of Leadership you have in the fight against AIDS in Mexico?

### **IV.- Political rationale**

- In your opinion, what are the main problems people living with HIV face in Mexico? Could you give some specific examples?  
(Explore: Stigma, discrimination, access to medicines, medicare, education, political rights, and so on)
- In your opinion, what are the best ways to face these problems in terms of tactics, strategies, and ways of collective action? Why?
- In your opinion, what are the scopes and limitations does the AIDS of the activism this organization carry out since it was started until today? Can you provide specific examples of this?

## **VITA AUCTORIS**

Héctor Eloy Rivas Sánchez was born in 1973 in Tala, Jalisco, México. He graduated from the Colegio de Bachilleres del Estado de Sonora in 1993. From there he went on to the Universidad de Sonora where he obtained a B. A. in Sociology in 2007. He is currently a candidate for the Masters degree in Sociology at the University of Windsor.