Centro de Estudios y Programas Interamericanos

INSTITUTO TECNOLÓGICO AUTÓNOMO DE MÉXICO (ITAM)
Río Hondo 1
Colonia Progreso Tizapán
Delegación Álvaro Obregón
México, D.F. 01080
México

Teléfono: +52 55 5628 3926
Fax: +52 55 -5628 4092
Correo: interamericanos@itam.mx

CEPI WORKING PAPER
No. 4

The Double-Edged Nature of Transnational Networks: The Case of Mexico's AIDS NGOs

Nielan Barnes

March 2006

ITAM

The Double-Edged Nature of Transnational Networks: The Case of Mexico's AIDS NGOs

Nielan Barnes
nbarnes@csulb.edu

California State University, Long Beach

March 2006
Paper No. 4

Summary

This paper is part of a larger comparative case study of the local and transnational nature of networks possessed by organizations in Mexico City and Tijuana. The project combines qualitative (in-depth interviews, participant observation and archival document analysis) and quantitative (social network analysis) methods to examine both 1) how and to what effect local AIDS organizations in Tijuana and Mexico City strategically employ transnational networks to resolve local problems; and 2) the effect of transnational networks on organizational outcomes. Previous research (Barnes 2002; Fox 2002; Bandy 2004; Barnes forthcoming) has shown that certain types of transnational networks have paradoxical effects for local CBOs and the AIDS service sector. The dilemma is that transnational networks convey much-needed resources to facilitate the work of local organizations, but they also exacerbate or (re) creating North-South inequities, and local-level inter-CBO elite regimes and competitive divisions which can significantly compromise organizational sustainability and service provision capacity at the local level. This project provides insight into these problems and outlines several health policy and practice recommendations for coordinating AIDS services.

Significance

This project shows how qualitative aspects of transnational networks (that is, whether the ties are formal or informal; convey funds, goods or information; are close, dense and strong versus distant, thin and weak) can move CBOs toward (or away from) formal institutional structures, goals and practices, and toward (or away from) closer and more cooperative CBO-public health sector alliances. The significance of the project is multifold in that it:

- reveals whose interests are served by transnational networks and activities; and shows how such networks and activities affirm, reconfigure or destroy existing power relations between different organizational actors;
- shows how transnational networks intersect with local organizational contexts to shape key structural, cultural and social network aspects of CBOs and local organizational fields;
- illuminates how transnational networks affect sustainability of local community-based organizations and service delivery models.

Outline of Paper

This paper is a discussion of the data from the Mexico City site. So far, the paper is heavily descriptive and loosely organized based on the analytical categories generated from analyzing the qualitative data. The task of weaving in the social network data remains to be done.

I. AIDS in Mexico

II. AIDS organizations and service delivery
- A. Emergence of service structure and major providers
- B. Medication access and transnational networks
- C. Shifting of Service needs in Neza

III. Organizational Cycles
- A. Transition points in the epidemic
- B. Old Organizations & Leadership burnout
- C. Organizational expansion and retraction
- D. Organizational Flexibility & Hybrid Organizations

IV. Field-Level Dynamics
- A. Organizational cohesions - Formal Networks
- B. Organizational divisions
  1. Activist versus Professional organizations
  2. "Alternative" organizations
  3. Population-based focus
  4. AIDS vs. Sexual Health focus
- C. Institutionalization - Working with the State
  1. State Funding versus "Autosuficiencia"
  2. The A.C. and organizational accountability to the State

V. Transnational Influences: NGOs as organizational brokers for the state & international agencies

VI. Network Observations
- A. Formal Networks and Boundaries
- B. Informal Networks and Flexibility
- C. Quantity vs. Quality of networks

VII. Methodological Challenges
- A. Getting the data – resistance to being a research subject
- B. Quality of data
- C. Data Analysis

I. AIDS in Mexico (notes from Project Hope visit)

By 2001, estimates of total cumulative AIDS cases in Mexico ranged from 45,133 and 67,700. Estimates of HIV infection are considerably higher - approximately 150,000 individuals were estimated to be HIV positive by 2001 (USAID 2001; UNAIDS/WHO 2004).

In Mexico city, 1/500 Mexicans has HIV/AIDS. (There are 20 million residents in Mexico City.) 25% of people living with AIDS (PWAs) live in the metropolitan area. In DF, AIDS is the third leading cause of death for men and the sixth leading cause for women ages 24-35[1].

Mexico ranks third in numbers of reported HIV/AIDS cases in Latin America and the Caribbean, (WHO states it is now second, behind Brazil) and ranks thirteenth globally (USAID 2003). The first AIDS case was diagnosed in 1983, although the presence of the virus in Mexico can be traced back to 1981. Between 1988 and 1995, there was an exponential increase in HIV infections in Mexico; since 1996, the rate of new cases has stabilized, with an average of 4,000 new cases annually (USAID 2003). While infection rates have stabilized, the epidemic is "concentrated" in specific populations (see Table 3.6), in which seroprevalence rates range from 1% to 25% (the rate is .1% in the general population). However, with regard to mortality rates, Mexico's rates have not dropped as in industrialized countries, largely due to limited access to antiretroviral drugs. AIDS is currently the third most common cause of death among Mexican men, and the sixth most common cause among Mexican women, in the 25-44 year age group (the male female ratio is six-to-one) (USAID 2003).

Mexico's epidemic is characterized as "concentrated". The highest number of infections are among men who have sex with men (MSM; 53.6%), followed by heterosexual transmission (39.1 %), then perinatal (2%) and transmission via intravenous drug use (.9%). As of 2001, the highest rates of HIV among intravenous drug users (IDUs) were in the northern border states of Baja California and Sonora (USAID 2001). In general intravenous drug use is low in Mexico – there have been only 378 known cases (1.4%) of HIV attributed to drug use. The fact that the proportion of IDU cases in Baja California is 15.9% suggests that for Mexico's northern border-states, the epidemic is more similar to the US than central Mexico. Generally speaking there are two primary infection patterns: urban (observed in large cities of Mexico and the northern border with the US, where a larger percentage of males are infected and there are longer incubation periods of 18 months); and a rural pattern (observed in central and southern states among higher proportion of females, with a shorter incubation period of 8 months) (Uribe, 1998).

Cultural barriers to HIV/AIDS prevention and care:

In general, Mexico has been successful in reducing HIV infection due to blood transfusion however reducing the rates of sexual transmission has been difficult because of cultural barriers about discussing sexual topics. The greatest barrier to increasing condom use and HIV prevention and treatment in general is not lack of knowledge, but stigma, fear and discrimination that stem from cultural beliefs about HIV/AIDS as a gay (or IV drug-related) disease. There is a large degree of resistance around condom use in Mexico as it implies that someone might be either unfaithful or have an STD. The condom use image must be transformed from "disease suspecting" to "life affirming". Also, new trends that

[1] From: "A University-NGO Collaboration to Control HIV/AIDS in a Low-Income Region of the Mexico City Metropolitan Area" 2003. Poster Presentation.

represent challenges to HIV prevention are increasing number of infections among intravenous drug users, migrants and those living in rural communities.

II. AIDS organizations and service delivery

A. Emergence of AIDS organizations, service structure and major providers

Social movement scholars have written extensively about the ways in which the US AIDS activist movement was fueled by the previous work of gay rights activists in the US (Altman 1986; Epstein 1995; Treichler 1999). Similarly, the first community-based AIDS organizations emerged in Mexico during the early 1980's from the work of gay and human rights activists in Mexico City, Guadalajara and Tijuana (Hernandez-Chavez 1995). In the words of a long-time gay rights and AIDS activist who has worked with organizations in Mexico City, Guadalajara and Tijuana:

> The AIDS movement has its antecedent in the gay rights movement [which began] in the early 1980's and was concentrated in three cities: In Mexico City, where it started in a clandestine form in the late 1970's and came out into the open in 1979; in Guadalajara it started in the early 1980's; and in Tijuana, where the gay rights movement started in a clandestine form in the early 1980's (A G 2001).

Initially, AIDS prevention efforts in Mexico were limited because information about the "gay disease" was minimal. However, Alex G. explained that in the early 1980's AIDS CBOs in Mexico City activated networks with organizations in New York (the Gay Men's Health Crisis) and San Francisco to obtain HIV/AIDS prevention information, and translated the information into Spanish to disseminate to their community. According to Alex G. the first organization to do this was *Colectivo Sol* "because they were in communication with friends in New York and San Francisco".

Historically, activists and organizations in Mexico City and Tijuana have utilized transnational ties and networks to obtain the information and resources (both fiscal and in-kind) needed for organizational survival. Since the beginning of the epidemic, Tijuana and Mexico City's AIDS organizations established networks with a range of international actors including foundations, development agencies and community-based AIDS organizations in the US, Europe, Canada and other parts of Latin America. In particular, "access to treatment has become a global issue and has given rise to a new phase of global solidarity" among AIDS CBOs throughout the world (UNAIDS 1998: 5).

Given their active local response and transnational ties, AIDS CBOs and activists in Mexico City "played a decisive role in meeting the challenges of HIV/AIDS [in Mexico] since the epidemic began" (Zuniga, Rodriguez et al. 1998: 5), and that participation from civil society was essential to meeting HIV/AIDS prevention and treatment needs, especially among hard-to-reach populations (UNAIDS 1998).

As is commonly noted in social movement literature AIDS activists in Mexico City avidly borrowed various repertoires of contention (Tarrow 1998) from human and gay rights activists in Mexico, as well as from gay rights and AIDS activists in US centers of activism such as New York, San Francisco, Los Angeles, etc. to further their political agendas. The ideologies that informed Mexico City AIDS activism in the early days of the AIDS epidemic were drawn from the antagonistic stance of US activist groups such as ACT-UP. However, the strategies that emerged were less overtly public and disruptive than those employed by ACT-UP, as the social stigma around homosexuality and HIV/AIDS was much more

pronounced in Mexico. Consequently, activist efforts focused on disseminating information to other AIDS organizations and society in general.

The work of civil society (AIDS activists and CBOs) also included pressuring the state-sponsored public health sector to devote more resources to HIV/AIDS prevention and treatment programs in Mexico. Unlike in the US (and other parts of the world) where activists pressured the government to respond by staging large demonstrations in public places (sit-ins in the FDA offices, "die-ins" at St. Patrick's Cathedral), the pressure exerted by AIDS CBOs in Mexico stemmed from CBO participation in national and international conferences which gave visibility to their work as legitimate providers of AIDS information and services as compared to Mexico's public health sector. Table 2.a.1 presents a timeline of the "birth" if Mexico City AIDS NGOs in relation to key events, policies and state-sponsored public health AIDS initiatives.

Table 2.a.1 Mexico's AIDS Policy and Activism Timeline

	Date	**Agreement/Event Description**
1981	15-Aug-81	*Colectivo Sol, AC* formed
1983	1983	First AIDS case diagnosed in Mexico
1985	1985	First International AIDS Conference
1986		Mexico established a National Committee Against AIDS
		AIDS is added to *La Ley General de Salud* as an illness covered by state health services
1987	1987	Begin testing blood supply for HIV
	30-Nov-87	First National AIDS Congress in Morelos
1988	1988	National Council for the Prevention and Control of AIDS - CONASIDA – formed
1989	1-Jul-89	*Mexicanos Contra El SIDA, AC* formed
	23-Aug-89	*AVE de México, AC* formed
1991	21-Mar-91	First National Conference of NGO's and Civil Society in Tlaxcala
	6/23/91	*Amigos Contra el SIDA, AC* formed
1992	1992	*Ser Humano* formed
1993	1993	*Norma Oficial Mexicana para Prevención y Control de SIDA* is adopted
	21-Oct-93	*Acción Humana por la Comunidad (AMAC)* formed
1994	27-Oct-94	*Centro de Atención Profesional a Personas con SIDA, AC (CAPSIDA)* formed
1995	1995	*Red Mexicana de Personas que Vive con VIH/SIDA, AC* formed
	30-Jun-95	Confederation of AIDS NGO's (last activity of Mexicanos Contra el SIDA)
	11/25-26/95	First National Conference of PWA's in DF – *FRENPAVIH formed*

1996	23-Oct-96	Breakfast meeting between NGO's and Patricia Uribe, Director of CONASIDA
1997	30-Nov-97	First street information fair/condom giveaway in DF (Amigos Contra el SIDA and CONASIDA)
1998	1998	*FONSIDA* is formed by UNAM and CONASIDA to ensure access to medications for uninsured
	1-Apr-98	Second National Conference of AIDS NGO's in Tlaxcala
1999	5-May-99	Second meeting of AIDS Service organizations
2000	2000	CONDESA Clinic in DF established
	2000	Strategic Plan -*Programa de Acción para la Prevención y Control de VIH/SIDA e ITS* 2001-2006 by SSA and CENSIDA
	1-Sep-00	Third National Meeting of AIDS NGO's
2001		CONASIDA becomes the National Center for the Control and Prevention of AIDS – CENSIDA

In 1981, even before the first AIDS case was diagnosed in Mexico, *Colectivo Sol* formed as a response to the growing awareness of a "gay disease" spreading among men in the US and Europe. *Colectivo Sol's* primary strategy was to obtain key HIV/AIDS prevention information from the US and disseminate it to gay men in Mexico City. Like many AIDS CBOs in central Mexico during the early years of the AIDS epidemic, *Colectivo Sol* first looked to US organizations for transnational assistance. However, as the epidemic wore on, Mexico City's AIDS CBOs expanded their transnational networks to include ties with other CBOs and international donors and development agencies from across the globe.

Colectivo Sol's ability to secure international support was aided by participating in the annual international AIDS conference because such conferences provided many networking opportunities. In addition, the strong presence of CBOs in terms of both numbers and voice applied indirect political pressure on their government to act. For example, after the first international AIDS conference in 1985, a National Committee against AIDS was formed, AIDS was added to Mexico's General Health Law as an illness covered by public health services, and by 1987 Mexico began testing the blood supply for HIV. Also in 1987, Mexico had its first National AIDS Congress and shortly thereafter the president of Mexico formed the National Council for the Prevention and Control of AIDS (CONASIDA).

National networks between AIDS CBOs began to form (*Mexicanos Contra el SIDA*) in the mid-1980s because they were seen as beneficial for increasing CBO political visibility and service provision capacity and pressuring the state to direct more resources to HIV/AIDS, particularly with regard to providing AIDS medications to the medically indigent. In 1991 the (now defunct) confederation of CBOs called *Mexicanos Contra el SIDA* organized the first national meeting of AIDS service CBOs in Mexico. In 1991 *Amigos Contra el SIDA* was also formed, and a year later, *Ser Humano* began offering services. Over the next few years, a number of other key organizations formed and in 1995, the first national meeting of people with AIDS (PWAs) took place in Mexico City, forming the basis for another national network - called FRENPAVIH (*Frente Nacional de Personas con VIH*; National Front of People with HIV).

In 1996 FRENPAVIH and other CBOs met with the Minister of Health and the faculty of medicine at the Autonomous National University of Mexico (UNAM) to discuss the issue of getting medication for people with AIDS who did not have access to Mexico's social security health services. Dissatisfied with the lack of progress, AIDS CBOs demonstrated against the lack of AIDS drug supplies in April 1997 in front of the national medical center. This demonstration led to more dialogue between FRENPAVIH and the government public health service, and the forming of a joint committee to look further into the matter. Also in 1997, the first major street outreach campaign (an information-condom giveaway fair) was conducted in Mexico City. By 1998, the second national conference of AIDS CBOs took place, and the Mexican public health sector set up a fund called FONSIDA (*Fondos Nacionales para SIDA*; National AIDS Fund) to buy medication for uninsured AIDS patients.

Clinica Condesa:

Despite its initial success, FONSIDA was defunct by 2000. Access to medication continued to be a major issue that was taken up by the state-sponsored *Condesa* AIDS clinic which was established in 2000 largely due to pressure from CBOs to have a government-funded AIDS clinic. According to Dra. Carmen Soler (in a 2005 interview), the first year the clinic was in operation they had 300 patients. By 2005 they were treating 5,300 patients. Many patients come from outside DF to access care at *Condesa* (and they are not counted as part of the 5.300). (Dra. Soler commented that the clinic budget allows them to provide medical services, but not medication to individuals living outside the DF.)

In a 2001 interview, CONASIDA official Renata H. described how the CBOs pressured the CONASIDA to not only open a clinic, but establish a Chief of HIV/AIDS Programs, and include them in the process:

> The *Condesa* clinic came about because civil society was pressuring the government to do something specifically about HIV treatment, so the government says ok, let's put together a committee with representatives from government and civil society. So it was through pressure from civil society that the committee was formed. And we also have a chief of HIV/AIDS programs in DF at the *Condesa* clinic, which did not exist before, whose name is Dr. Carmen Soler.

The organization *Red Mexicana* was invited to work with the CONASIDA to establish a space in the clinic for their medication bank; they were "consulted" regarding the functioning of the clinic, and have benefited from their liaison with *Condesa* and the CONASIDA because they were able to establish an organizational space inside the clinic. The director of *Red Mexicana* explained that

> As an organization, *Red Mexicana* participated from the beginning in the project design. We were consulted with respect to how the clinic functioned, and we participated in the whole conception of the Condesa clinic project. One of the things that really benefited us was that we were able to negotiate that our organization would have a space inside the clinic. And what we decided to do was open a medication bank inside the clinic… [essentially] all the medication is managed by our organization, but within the clinic (they see about 200-250 clients a month in the meds bank).

This CBO director framed CBO-state collaboration as strategic for his organization and a "complementary" relationship that is necessary to fighting the complicated AIDS problem because neither the CBOs nor the state can do it alone. He also conceded that

despite being poor, the state can act as interlocutor between CBOs and international donors, which in turn is a motivator for cultivating closer state-CBO ties:

> As a strategy, our organization promotes intersectoral cooperation, so we are always looking to generate ties or make "partners" [sic] with the government, or with private initiatives. For us, it is strategic to establish cooperative ties with the government. We think the AIDS problem is very complicated and we can't handle it alone. For example, the medication bank is a form of cooperative effort with the government. What the government does is give us money, at times, very few times, and what they give us more is technical assistance, contacts, they link us up with the media, they give us referrals –but they don't give us money because the government is very poor, well, not poor, but they have their priorities. So there is not a lot [of money] – but they are going to get a loan – it seems that the World Bank – something that would improve how government relates to [*interactuar*] the CBOs.

Drawing CBOs into closer relationship with the state does have clear tangible benefits when international funding is available. However, not all CBOs are interested or able to develop good working relationships with the public health sector. For example, not all CBOs were invited (or able) to participate in forming *Condesa*. This is both a reflection and re-iteration of an ongoing division between "insider" organizations that want to collaborate with the state to provide services, and "autonomous" organizations that view the *Condesa* clinic as a duplication of CBO services already being provided. Max L., director of an AIDS CBO that provides a range of health and social services for people with AIDS, wondered why the government doesn't strengthen the infrastructure already put into place by CBOs. He said:

> The problem with the AIDS specialty clinic, *Condesa*, in my view, is that at times we duplicate efforts, and that there already exist places that are working in this area [providing AIDS specialty services in a clinical setting], so why duplicate services? Why not take advantage of and strengthen those that already exist? One of the policies of the government is to take advantage of the infrastructure of civil society organizations. If we already have personnel with experience, and a space dedicated to the care of this diverse population – a space that came about precisely because the government did not sufficiently respond to our needs – they should collaborate with us, no?

In response to this CBO critique Dra. Soler points out CBOs have the capacity to provide services for 5 or 10 people, and "have not evolved to serve the increasing volume of patients". She advocates offering all HIV/AIDS services through the *Condesa* Clinic. But the local CBOs say "no, you are leaving us without work". The irony is that *Condesa,* in responding to CBO demands that the state fulfill its responsibility to provide all necessary health services to citizens, is putting those very CBOs out of business.

Table 2.a.2 Core AIDS CBOs in Mexico City	
Organization	**Year Established**
Acción Humana por la Comunidad AC	1993
Amigos Contra el SIDA, AC	1991
AVE de México	1989
Centro de Atención Profesional a Personas con SIDA, AC (CAPSIDA)	1994
CITAID	@1985
Colectivo Sol	1981
FRENPAVIH	1995
Red Mexicana de Personas que Vive con VIH/SIDA, AC	1995
Ser Humano	1992

From the beginning of the AIDS epidemic in Mexico to the present, several "core" insider CBOs have been central to organizing symposiums, conferences and workshops throughout Mexico to promote and disseminate HIV/AIDS prevention and treatment information. These CBOs (listed in Table 2.a.2) (only nine of more than 140 AIDS CBOs in Mexico City) were instrumental in pressuring the Mexican government and public health sector to direct more resources to AIDS prevention and treatment, and to allow CBOs and activists a seat at the decision-making table when it came to developing and implementing AIDS programs and policies. This core of CBOs has evolved into a civil authority that has successfully negotiated a seat at the table with the Health Secretariat. The 2001 chief of the Department of NGO programs for CONASIDA explained in an interview:

> *Ave de México, Colectivo Sol, Amigos contra el SIDA, La Red de Atención y Asistencia* – make up the organizations that form a civil authority and pressure us [to act]… one of the achievements of civil society has been to have direct contact with the Health Secretaries (R H 2001).

The achievements of "civil society" rest on the ability of activists to become scientifically credible and lay-experts in politics (Epstein 1995; Epstein 1996; Kaufert 1998) in order to demand more funding and more effective research for their respective issue area. In the case of Mexico City AIDS CBOs, their work in developing credibility and lay-expertise in science and politics indicates that they saw solutions in working within, or reforming, rather than conducting a revolution against the state-sponsored bio-medical system.

B. Medication access and transnational networks US-Mexico Medication Networks

Despite a 1997 Seguro Social policy to offer free AIDS medications to its HIV+ clients, the reality is that medication still remains unavailable through the state due to its high cost. A decade prior to the state policy, a number of CBOs established informal networks with US counterparts to obtain supplies of antiretroviral medications needed by their clients. For example, from 1986 through 1995, Dr. Goyos of CITAID worked with other CBOs to get AIDS medications into Mexico from international sources. Mostly, medication was donated from the US, or bought at a reduced cost and imported into Mexico

by various CBOs. Dr. Eduardo Catalan of CURAS also followed suit. From 1989-1994 Dr. Catalan lived and studied in San Francisco, where he became involved with many SF HIV/AIDS organizations. He helped establish a network between Mexico City and SF AIDS CBOs (RAMP, the Positive Humanists and Friends and the Andrew Zeigler Foundation in SF, CA) that collected unused medications (recolecta) in the US for use in Mexico. By 1996-97 he was importing so much donated medication that there was a 'surplus' and his organization was able to donate medication to other service organizations in central Mexico. CURAS also provides a service by which one can get their viral load tests done less expensively – reduced cost of $210 USD – via an arrangement Dr. Catalan has with a laboratory in Santa Monica, CA.

Legal loopholes for importing medication donations (CURAS):

The transfer of large amounts of medication, medical supplies and even condoms, from the US to Mexico is extremely problematic. CBOs are required to obtain legal documents approving the importation of large donations of in-kind goods into Mexico from Mexican public health and immigration authorities. Unfortunately, these documents are notoriously difficult to obtain due to government politics and bureaucracy.

Frankie R, long-time AIDS activist, explained in a 2001 interview that the main problem with obtaining goods from the US in general is the "government officials on both sides, but mostly the Mexican government, are not available to sign agreements and participate in meetings and events – they are traveling elsewhere in the country. It is not a priority for them." So CBOs end up waiting indefinitely –sometimes years- for signatures from government officials.

Dr. Catalan says it is a matter of "interpretation of law" and that doctors can use their licenses to import medication. There is a prior precedent set by a ruling for a legal case in San Fransciso-DC that allows donations to "third world countries in need" as long as it is clear that is it not a business, the medications are a necessity, and are not contraband". The donations also have to come from a legal non-profit organization in the US. In this way, several legal North-South networks have been established between organizations in the US and Mexico as well as Chile, Peru, Africa.

C. Shifting of service needs to the south - Neza

A number of respondents in Mexico City noted that the AIDS epidemic is "moving south", specifically to the city of Netzahualcoyotlz in the Zona Oriente, or "Neza". The reasons for the movement of the epidemic to Neza are numerous: this area is characterized by low socio-economic status, social and economic isolation from the rest of DF, poorly developed urban and social infrastructure, and higher rates of rural-urban migration, crime, alcohol and drub use, and sex work. According to Dr. Catalan, 42% of women in Neza have Human Papiloma Virus; 25% have uterine cancer; and 15 of 18 women have an STD. Finally, according to Project Hope International, in 2000 Neza had the second highest incidence of HIV in the country, next to DF.

In response to the movement of the epidemic further south, Dr. Catalan stated that he was considering moving CURAS' office and base of activities to "Neza" in order to "follow the epidemic where there is more need". From 2003-2004, CURAS worked on a project (on sexual health, reproductive health, HIV prevention, diagnosis, treatment) with 21 municipal health centers in this city in which they provided information, medication and condoms. The project also involved the Hospital San Jose, where they see 110 people with HIV/AIDS

monthly. CURAS provides the medications and additional funds are provided by the Fundacion San Jose (monks). (Project Hope International has a major project in Neza.)

III. Organizational Cycles

Organizational Cycles coincide with (and must find a way to survive) historic medical, social, economic events of various types. This section will explore: What events mark these cycles or shifts in the philosophy and strategies of AIDS organizations in Mexico City?

Organizations are required to "follow the epidemic" in several ways – by state funding mandates; the market forces of service delivery (i.e. must meet a demand and need to have "clients") – both of which follow shifts in HIV transmission patterns.

A. Transition points in the epidemic

The pre-medication environment of the 1980's (in which AIDS seen as death sentence) was characterized by CBO demands to "die with dignity", the fight against discrimination and for the human rights of PWAs and the fight for prevention and AIDS research/treatment. By the mid-1990's more information was available on the internet for activists and organizations. It was no longer necessary to wait for someone to "bring back" information from an international conference or site visit to another organization in the US (and/or Europe).

In 1996 the discovery of highly active anti-retroviral treatment (HAART) shifted CBO focus to access to AIDS medications. The emphasis went from fighting death to fighting for medication (life). In 2002 free medication was declared the right of all with HIV, but medication is still not available in state health sector (per Julio Frenk). However, by this time local CBOs were successfully importing donations of medication and there actually exists an over supply in some cases, so CBOs are now helping other CBOs in rural Mexico and Central Mexico. During this time we also begin to see "deeper" culturally focused campaigns against homophobia and more programs to improve quality of life for PWAs.

As the state health sector begins to finally strengthen its service capacity, CBOs face loss of clientele and service demand. Those that persist are able to offer things the state sector cannot – specialty services (meds and viral load testing), focus on specialty populations (sex workers, drug users) and geographical areas (i.e. Neza), and better quality care in general (i.e. less discriminating more welcoming setting, offers a wider range of services in one setting).

B. "Old" organizations & Leadership burnout:

A major problem for many "older" CBOs is how to survive transitions in the epidemic (whether demographically or policy-based) and leadership burnout. Organizations deal with both problem in a variety of ways: via changing organizational personnel/internal restructuring, downsizing/moving locations, scaling down operations (going to exclusively volunteer personnel, operating out of homes), etc. Some of the most "challenged" organizations I observed were AVE de Mexico and Albergues de Mexico.

C. Organizational expansion and retraction cycle:

What factors are the cycles of organizational expansion and retraction "attached" to? What (internal) organizational, social (networks) and environmental/structural factors

trigger and temper organizational expansion and retraction? Expansion/retraction is clearly linked to shifts in the AIDS epidemic. But it is also linked to organizations providing redundant services/duplication and to limited and unpredictable state and international funding.

D. Organizational Flexibility & Hybrid Organizations

To survive, organizations must have a degree of flexibility. In the case of some organizations flexibility is achieved by "multi-tasking" by situating an "income-earning" business within the CBO. For example, CODECOI offers office space inside their CBO for an optometrist (who provides prescriptions for HIV patients) and an internet café (source of revenue for the organization). CAPPSIDA, in addition to providing a wide range of HIV/AIDS services, has an on-site café.

Organizational flexibility is also achieved by forming a combination of *informal and formal networks* with other organizations at the local and national level respectively. The CBO Brigada Callejera (BC) is perhaps a good example of the use of both informal and formal networks. Locally speaking, the BC exists on the "outside" of the DF organizational field in terms of network centrality (they have fewer formal linkages and networks with other CBOs and none with the state). However, the BC is the head of the National Red Mexicana de Trabajo Sexual, which works with two organizations in DF and seventeen organizations nationwide to promote condom use, provide technical assistance to organizations (building leadership and helping administration), and providing goods and prevention information. In this case, maintaining a limited number of informal local networks preserves CBO autonomy, and makes the organization less formally accountable so it can have a more instrumental ("means to an end") or "product over process" orientation. At the same time, involvement in a national-level formal network established organizational legitimacy, particularly for the state and international donors.

"Flexibility" is also achieved by combining grass roots and professional organizational structures and strategies. For example, the BC is an entirely volunteer run "activist" organization that also provides medical services in a professional setting. (The BC runs a 'micro-clinic' for women and sex workers where they provide some forms of medical care). The BC is a very successful grass roots organization that has many 'formal elements'. They obviously keep good records (from the financial books I saw and from the way they wrote me out an itemized receipt). They also "multi-task" by selling sex education and sex toy items at the fairs they go to and from retail outlets – condonerias – to generate the revenue they need to accomplish their work.

Despite their grass roots nature and not being formally and well-networked at the local level this organization is successfully and consistently meeting the needs of a very vulnerable population.

This is an example of a flexible, multi-tasking organization with a 'hybrid structure' – a combination of formal/professional and informal/grass roots structures.

IV. Field Level dynamics

A. Organizational Cohesions - Formal Networks

During the course of the AIDS epidemic, there has been a proliferation of formal organizational networks between AIDS NGOs in Mexico (see Table 4.a.1). Currently, there exists several formal and well developed local "*redes*" (networks) of AIDS organizations that

are central to service delivery and activism. These organizations also have fairly well developed and extensive international ties with key donors (of both funds and technical information). In addition to forming a base for organizational and political solidarity, these networks represent an effort to develop and offer a coordinated and comprehensive array of HIV/AIDS medical and social services to a wide range of HIV/AIDS affected and infected populations.

These networks are comprised of the more established organizations that in addition to finding international support, have also managed to raise local revenue through their own fundraising projects and 'businesses' (i.e. several have coffee houses, bakery, or small restaurants/lunch counters that generate income). So in addition to developing their local and international networks to increase resources, these AIDS CBOs are engaging in practical, direct and immediate forms of revenue generation to cover day to day expenses. This is frequently necessary because even though adept at accessing international and local revenue sources, the size and scope of these revenues is often extremely small and limited (i.e. the Gates Foundation 'mini-grant').

Also key is the ability of an organization to expand its networks with other local, international and government agencies and organizations that are not strictly AIDS service organizations. In other words, create linkages that allow them to develop and expand organizational programs (training for working in hotel industry; women/men/youth general sexual health education programs; medical and social services that go beyond HIV/AIDS services; TB and STD prevention and treatment programs) that address issues only indirectly related to HIV/AIDS and that allow them to attract non-HIV/AIDS specific donors and other forms of support. The importance of formal networks will be discussed further below.

Table 4.a.1. Formal CBO Networks in Mexico City, 2005

Name	**Description**
Organizaciones y Mujeres Decidiendo frente al SIDA	Run by Margarita Andrade of the Fundacion Mexican Lucha SIDA – for women w/HIV/AIDS
Red de Attencion y Prevencion en VIH/SIDA, REDSIDA	Group of about 10 core AIDS CBOs
DEMYSEX – Democracy and Sexuality	Group of Sexologists
FRENPAVIH	Network of PWAs
VANMPAVIH - Vanguardia Mexicana de PVVS	Network of PWAs
LACASSO	UN sponsored group of CBOs throughout Latin America
Red Mexican de Personas Viviendo Con VIH/SIDA	Network of PWAs
Red Mexicana de Trabajo Sexual	Brigada Calejera + 19 organizations

B. Organizational divisions

1. *Activist versus Professional leadership and organizational focus*:

The division between (gay and AIDS) activists and (medical/social service) professionals is expressed in numerous ways. First, it can be seen in the service focus of an organization; that is, whether an organization (and its leadership and staff) engages in

strictly providing medical and social services, or if it also participates in "politics" (i.e. political events and policy committees; information dissemination, etc.).

According to the "professionals" it is difficult to work with activist organizations because they are "always fighting" and very political. For example, Dr. Catalan states it is "difficult to work closely in *Redes formales*" with other HIV activist organizations, because "egos get involved" (it is political). It is easier and more common to work with health care professionals in informal, practical networks (i.e. service focus) because they are more practical and focused on service delivery.

Occasionally you find an organizational leader who is both a professional (i.e. is a medical doctor or psychiatrist) and an activist (in a number of key cases, these individuals are also HIV+) and therefore can incorporate both perspectives and approaches. In these cases, the organization and its leadership have credibility on both fronts.

Frequently, "professional" organizations express a specific ideology in which there is no space for political activism. For example, Profin states that a "socialist ideology, professional health experience and epidemiology" inform their work as service providers. In addition, the directors of Profin distinguish between their organization, which was "created by male and female medical and health professionals" and organizations that were "formed by a dominant group of male and homosexual activists and/or PWAs". According to the Profin directors, medical professionals and activists speak two entirely different languages. Medial professionals speak the technical language of medicine and research, whereas activists speak the activist language of rights and preferences and personal interests.

As the AIDS service sector becomes more about managing a chronic illness (more medicalized versus politicized) "professional" organizations with a service focus are "taking over the field", giving rise to resentment from the activist organizations which have a *"nivel de medicalizacion muy bajo"* (low level of medical proficiency) according to Profin.

2. *"Alternative" Organizational Focus*

Some organizations identify as "alternative spaces" where activism and medical professionalism is de-emphasized in favor of addressing the emotional, spiritual and physical well-being of the patient. These organizations largely focus on providing "alternative therapies" (such as acupuncture, magnet therapy, homeopathy, etc.) to people with HIV/AIDS (and other illnesses). There are fewer of these types of organizations and they are frequently not taken seriously by either professional or activist organizations; in many ways, the "alternative" space provided by such organizations is a marginal space.

3. *Population-based Focus*

A division (based on shifts in the epidemic?) that has recently emerges is one between organizations that focus on men who have sex with men (MSM) versus other affected populations (i.e. women, children, families, etc.). According to some informants, there is "a lot of money" out there for MSM programs from state/national and international sources. This focus excludes organizations working with other more marginal populations. In particular, CONASIDA has been accused of being "*amafiados*" with organizations that have an MSM focus.

Organizations make a distinction between having an AIDS vs. "population" (i.e. street children, women, gay) focus. Those with a population focus are often able to extent networks to a wider range of donors interested in the population.

4. *AIDS versus Sexual Health focus*:

Another line of demarcation between CBOs is whether they have a focus exclusively on sexual and lifestyle practices associated with HIV/AIDS versus sexual health more widely defined. Civil society organizations working on "sexual health" view sexual health issues (such as HIV/AIDS, homophobia, among others) to human rights and the formation of a true democracy. A key to organizational sustainability may be branching out into the larger 'sexual health' arena as an exclusive focus on HIV/AIDS is limiting.

C. Institutionalization & working with the state – To be (autonomous) or not to be?

1. *State Funding versus "Autosuficiencia"*

Many NGOs decline to work on a formal basis with the State because it limits their autonomy in various ways. In general, AIDS NGOs view government funds (specifically referring to SEDESOL) are "*manejadas*" (managed) very closely by the state. By this, respondents mean 1) that the application process is very time consuming – a lot of paper pushing for very little funding; and 2) the money is often highly 'managed' in that its use is mandated for very specific purposes (which may not necessarily be central to the organization's mission). Also because the state is very bureaucratic, obtaining state funds requires that CBOs spend a lot of time filling out forms and doing paperwork (for very little money or support) instead of running the organization and its programs. For many NGOs, obtaining financial resources from the state is viewed as a waste of time; the preference is to remain "autosuficiente" to avoid the bureaucracy and demands of the government.

On a more political note, some of the more activist organizations view the state as an "enemy" and so avoid working within the institutional sphere. For example, the Director of CODECOI states that there are two powerful enemies: the local and federal government. From his perspective, the local government is very conservative and right-wing (and avoids working with AIDS NGOs), and the federal government only supports PRD organizations in the traditional patronage system.

2. *Working with the State. The A.C. and organizational accountability to the State*:

Regardless of how anti-state NGOs might be, for many, a symbol of organizational formality, fiscal accountability, and organizational legitimacy lies in obtaining the A.C. (*Associacion Civil)* status. When an organization becomes an A.C., it means that the organization has formalized its structure in order to become fiscally responsible and accountable to its clients and the state (via the tax system). The law for becoming an AC states that the organization has to report all income and expenses to the government. This process requires a formal audit; to pass the audit, organizations almost always hire an outside accountant to manage their records, oversee and complete the audit. In addition, all ACs must have a formally constituted Executive or Advisory Committee consisting of a president, treasurer, secretary, vocale, etc. It is interesting to note that some NGOs, in a strategic effort to remain more autonomous, choose to become IAPs (*Institucion de Assistencia Privada*) rather than an AC because IAPs are subject to less government scrutiny and paperwork.

V. Transnational Influences: NGOs as organizational brokers for the state & international agencies

Major international donors often look to government officials to provide recommendations for working with local NGOs. Those organizations that have their A.C. status, and that have a track record of "working well" within government structures are often first in line to make connections with international agencies. (Additionally, membership in a formal network as discussed above is also helpful in obtaining such recommendations.)

To help manage their investments in local NGOs, and to "spread the wealth" more evenly, international agencies often identify "stronger" (in terms of organizational capacity and political legitimacy) local NGOs that are given lead roles in project/program development, implementation and evaluation. In addition to providing leadership and direction to local projects, these NGOs act as "umbrella organizations", which administer funds (and information) from international and state sources to other smaller, less established NGOs included in the project.

For example*, La Manta* (The Names Quilt Project) heads up the CD4 program, and so administers funds to Colectivo Sol, AVE de Mexico, CECASH, CAPPSIDA, and several organizations in Cuernavaca, Morelos.

Another example is provided by the work of Alianza Internacional and Fundacion Positive Action, which have selected *Colectivo Sol* to head up an external evaluation committee to administer funds to other CBOs in Mexico City, Vera Cruz and Merida for a "self esteem and discrimination" project funded by these two international agencies.

VI. Network Observations

A. Formal Networks and Boundaries

Formal networks (at local, national and international levels) are frequently described as "*frente politicas*" (political fronts) through which "insider" NGOs obtain the connections and legitimacy to enable them to work more closely with international organizations (such as the UN) and with their own state. These networks provide a "*frente de negociacion*" (negotiation front) that can be particularly useful for NGOs attempting to confront or contact organizations in the context of international and national conferences.

International agencies and the state tend to prefer working with organizations that are members of formal networks, rather than with "outsider" NGOs, because in the context of formal NGO networks, the work of 'frame alignment' between the organizations has already been accomplished (they are all more or less in agreement to work together) and so the international organization or the state does not have to deal with NGO conflicts or disagreements. The formal networks minimize the cost of frame alignment for the state and international orgs.

A problem frequently identified as endemic to formal networks is that they exist in name but do not tend to 'work' in practice, that is, at the local level in terms of providing services or practical results.

Formal networks have a way of delineating the boundaries between organizations in a number of ways. First, formal networks establish boundaries between NGOs that are 'inside' and 'outside' the international donor-state-NGO nexus; that is to say, membership in formal networks tends to facilitate access to the state and international agencies (and their resources). Second, formal networks establish boundaries around "service jurisdictions"

and "political turf" in a variety of ways. For example, in the case of *Red de Attencion y Prevencion en VIH/SIDA, REDSIDA* only organizations that have an exclusive focus on providing HIV/AIDS services can be members. In the case of DEMYSEX, organizations that work in the area of "sexual health" (i.e. those that do NOT have an exclusive HIV/AIDS focus) are members. Other formal networks establish turf boundaries between organizations working with sex workers, women w/HIV/AIDS, people living with HIV/AIDS (PVVS/PWAs), etc.

B. Informal Networks and Flexibility

Informal networks are the most common kinds of ties between organizations. Such networks largely consist of the day-to-day interactions and exchanges between personnel in different organizations, as they enact their daily organizational tasks. These interactions and exchanges can range from a simple phone call for information or referring a client to another organization, to sharing a table or marching together at an AIDS prevention event or protest. Informal networks are looser and more flexible than formal networks and are constantly 'open' to new contacts and exchanges; therefore they do not have the same kind of boundary-making function as formal networks. However, informal networks do form cliques (See **Diagram 1 below)** which indicate organizational clusters (and divisions) around service jurisdictions. A detailed comparative clique-to-formal network analysis comparison (that is, comparing informal clique relationships to formal 'nominal' network relationships) would shed light along the lines of *both* organizational division and cooperation. Such an analysis would also provide practical help with coordination of service delivery.

C. Quantity vs Quality of networks

Evidence from some organizations (such as Brigada, CURAS) that are "less formally networked", that is have fewer institutional links with other organizations at local, national or international levels, indicates that these organization may be more effective in their work. They spend less time "networking" and more time on practical activities. They also have to deal with less bureaucracy created by formal networks (i.e. especially those involving the state).

IV. Methodological Challenges

A. On getting the data

The strategy I pursued to contact the organizations was to contact the organizations in a series of "waves". The first major wave consisted of organizations that have email addresses, as I determined that those with email capacity were going to be easier to contact and more 'networked' in general, as email access is a signifier of and organizations orientation toward being "connected" with other organizations. Of the 200 organizations in the directory I was working with, about 140 of them had email addresses. Since I did not want to be overwhelmed with too many responses to my initial letter of invitation to participate in the project and risk delaying my own response to organizations, I separated these organizations into four separate "sub-waves".

The first sub-wave consisted of the organizations that I had contact with during summer of 2001. The consecutive sub-waves were simply the rest of the organizations divided into three additional groups of about 35 organizations. The letter of invitation was sent to each group, beginning in late February, about two weeks apart. So far, the

response from the organizations has been positive, but not as great as anticipated or needed to fulfill the objectives of the project. In total, so far I have had 8 positive responses for interviews and 2 negative ones (stating they do not offer HIV/AIDS services). Also, many of the emails have been returned with the email address no longer valid, so I have had to do web searches to find valid addresses and resend the letter.

I anticipate that it will be necessary to make follow up calls to many of the organizations, to request their participation over the phone. It is a lot more difficult to ignore a live person on the telephone than to ignore or put off responding to an email. Other reasons for the limited response are that organizational personnel have limited resources and are busy with the work of their organization and their own lives; there also exist few immediate or direct incentives to participate in the project.

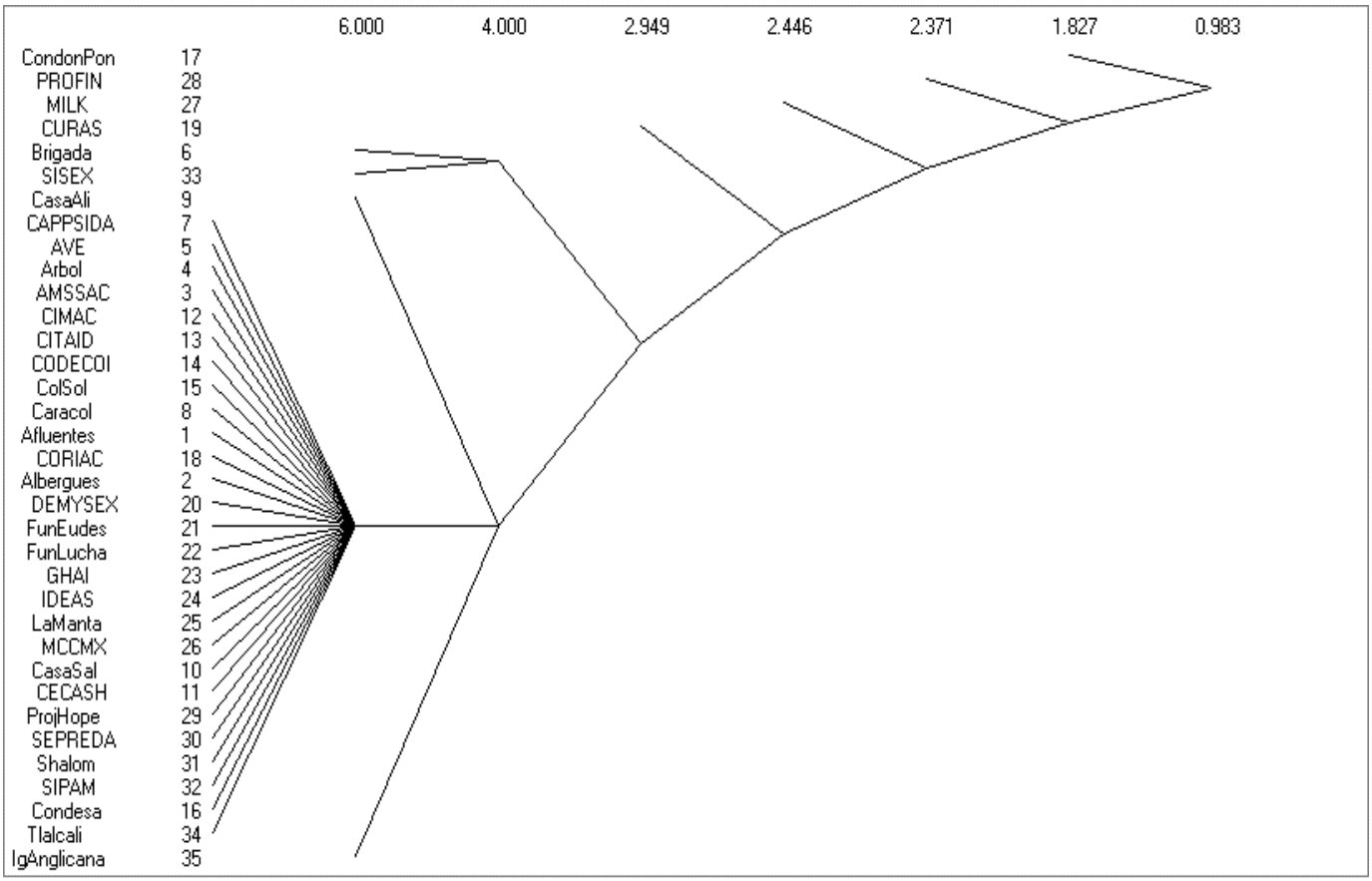
B. Thoughts about the quality of the data

In terms of the quality of data I am getting through the interviews and using the network survey guide, it seems that the organizational representatives that I have spoken with so far are extremely knowledgeable about the existence and type of local and international networks they possess. I am able to get respondents to recall from memory most of the organizations that they work with locally and internationally, and they are able to describe the nature (information, service, funding, goods, etc.) and frequency of the ties with little hesitation and great clarity. When shown the list and guide, respondents are able to recall additional organizations and fill out the guide with ease and usually within a period of less than 5 minutes. Often, they are helpful in adding organizations to the list, or telling me if an organization is no longer operating. Finally, getting information about the organization itself in terms of accounting procedures, number of staff and existence of executive boards has also been very easy, as all the organizations so far are highly formalized, with well organized records, administrative capacities and 'professional' accounting procedures. Of course I am aware at this point that the organizations I am talking to are going to be on the more professional and formal end of the spectrum by virtue of having email capacity and by their availability and willingness to participate in the project.

Additional Methodological Challenges:

Additional challenges include the sheer size of the organizational field (there are over 200 organizations to survey and map) and the inability of one researcher to collect the data in a reasonable period of time. (Also the need to learn social network analysis and use new software presents a challenge to the researcher.) The politics of AIDS activism and service delivery is problematic, particularly when it comes to organizations with a resistance to being a research subject. Those organizations who did not wish to participate are largely absent from the data set. Resistance to participating in the project ranged from (Albergues) instances where the informant said he was "opposed to encuestas", to (Brigada) refusal to fill out guide or give information about networks, to (Amigos) refusal to participate outright.

Diagram 1: Tree Diagram of N-Cliques for Mexico City AIDS Organizations, 2005



Bibliography

Altman, D. (1986). AIDS in the Mind of America. New York, Doubleday.

Bandy, J. (2004). "Paradoxes of Transnational Civil Societies under Neoliberalism: The Coalition for Justice in the Maquiladoras." Social Problems **51**(3): 410-431.

Barnes, N. (2002). "Collaboration between the U.S. and Mexican HIV/AIDS Sectors: The Role of Community-Based Organizations and Federal HIV/AIDS Funding Policies in Creating a Binational Political-Organizational Field." International Journal of Sociology and Social Policy **22**(4/5/6).

Barnes, N. (forthcoming). Are Transnational Networks Good or Bad for Local Community-Based AIDS Organizations? The Case of Binational Collaboration between California and Baja California HIV/AIDS Sectors. Sociology. San Diego, University of California, San Diego.

Epstein, S. (1995). "The Construction of Lay-Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials." Science, Technology and Human Values **20**(4): 408-437.

Epstein, S. (1996). Impure Science: AIDS, Activism, and the Politics of Knoweldge. Berkeley, University of California Press.

Fox, J. (2002). Lessons from Mexico-US Civil Society Coalitions. Cross-Border Dialogues: US-Mexico Social Movement Networking. D. Brooks and J. Fox. La Jolla, Center for US-Mexico Studies, University of California, San Diego.

G, A. (2001). Founder, Board President and Clinic Director of Tijuana AIDS CBO and clinic; longtime AIDS and gay rights activist; founder Y QUE. Interview with author. Tijuana. **November 21**.

H, R. (2001). Director of the AIDS information line TelSIDA, for CONASIDA (May 2001-present); Current Chief of the Department of NGO programs for CONASIDA. Interview with author. Mexico City. **July 30**.

Hernandez-Chavez, J. J. (1995). "El Trabajo en VIH/SIDA de las Organizaciones No Gubernamentales Mexicanas." Salud Publica de Mexico **37**(6): 654-660.

Kaufert, P. A. (1998). Women, Resistance and the Breast Cancer Movement. Pragmatic Women and Body Politics. M. Lock and P. A. Kaufert. Cambridge, Cambridge University Press.

Tarrow, S. (1998). Power in Movement: Social Movements and Contentious Politics. Cambridge, Cambridge University Press.

Treichler, P. A. (1999). How to Have Theory in an Epidemic: Cultural Chronicles of AIDS. Durham, Duke University Press.

UNAIDS (1998). NGO Perspectives on Access to HIV-related drugs in 13 Latin American and Caribbean Countries, Joint United Nations Programme on HIV/AIDS (UNAIDS).

UNAIDS/WHO (2004). 2004 Mexico Update: Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Diseases, UNAID/WHO.

USAID (2001). HIV/AIDS in Mexico and USAID Involvement, USAID.

USAID (2003). Mexico HIV/AIDS Country Profile, USAID.

Zuniga, P. U., C. M. Rodriguez, et al. (1998). "AIDS in Mexico." J Int Assoc Physicians AIDS Care **4**(11): 29-33.