

THE POLITICS OF AIDS: INCLUSION AND EXCLUSION IN THE BRAZILIAN AIDS NGO POLITICS

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Introduction

The purpose of this article is to study the politics of AIDS in Brazil from a bottom-up perspective and to use the case of a national coordinating association called *Encontro Nacional de Organizações Não- Governamentais/AIDS* (ENONG) as an example of a network that is part of a sub-politics. The case study does not focus on the governmental AIDS politics (although this is obviously part of the analysis) but identifies other fields of practice in the AIDS governance where sub-political processes are developing. Part of my interest is in which subjects – storylines – that are on the agenda at the ENONG conferences, if there are tendencies to exclude certain organizations or specific themes, and the structural process of network building. This network, or umbrella organization, as one example of the AIDS governance in Brazil, illustrates tendencies of what used to be described as the *NGO-ization* of civil society and what João Biehl see as “a vanishing of civil society” (Biehl 2007:393–396). There is a worldwide trend of a growing identification between “civil society” and NGOs, and civil society is shrinking as a broader public force or as the “Third Sector” (Alvarez 2009, Avritzer 2002, Dagnino 2002:17). My decision to study ENONG is based on various reasons. It is an assemblage with a national reach in Brazil; and there is plentiful documentation of its more than 20 years of existence as an amalgamation, and its relations to government, International Organizations (IO), and to other NGOs. There are written sources and also an open debate about the events’ financing, representation, mobilization, and other relevant topics in articles, journals, minutes of meetings, and

websites written by researchers and activists. There have been and still are a broad variety of local and regional NGOs working with AIDS, which over the years have been involved in and still are part of ENONG activities. From my own research on the AIDS civil society in Brazil I have learned that ENONG, as a national assemblage including most of the participating NGOs, is recognized and has legitimacy among governmental,¹ public, and AIDS actors (Câmara da Silva 1998, Galvão 1997, 2000:89ff, Grangeiro et al. 2009, Nunn 2009). These reasons are the motivation for examining the public sphere created by the network and its influence on the national AIDS politics.

The German sociologist Ulrich Beck discusses in his book *Risk Society: Towards a New Modernity* (1992) the topic of sub-politics, a process whereby certain actors exert a strong influence on the political process. Sub-politics is in this context comparable with Foucault's concepts of power and power/knowledge, signifying forces or processes creating social change. This article uses a social scientific perspective to relate the production of knowledge on HIV/AIDS to issues of stigma, discrimination, sexuality, and denial and thereby to link it to the power of certain professions (e.g. medical doctors and the pharmaceutical industry). This means that throughout the history of AIDS, there has been a relationship between power and knowledge, which means a control over individuals as well as social bodies (Parker and Aggleton 2003). In this article, local and global civil society activities are seen as sub-politics, which due to vital networking, access to Internet, and social and political commitment have influenced the parliamentary politics of AIDS and implemented social and political changes nationally and globally. Sub-politics is also created in the interfaces and tensions between civil society and the market. Networking and negotiations with the pharmaceutical industry,

¹ On the Brazilian National AIDS Program website more than 100 documents on ENONG can be found (www.aids.gov.br).

and lobbying with other parts of society which are outside civil society, indicate a node of power/knowledge (Wogart 2007).

Brazil is an unequal society with a wide gap between poor and rich, and with a political culture historically characterized by social authoritarianism and hierarchical traits. These “excluding visions of society and politics constitute crucial obstacles to the constitution and functioning of public spaces” (Dagnino 2002: 3). But, what will be illustrated is that these structures have been challenged by a process of re-democratization. This had its beginning at the end of the 1980s and continued during the 1990s in what Amy Nunn calls the post-authoritarian era. One step in the process has been decentralization, the weakening of the military’s centralized authoritarian regime (Nunn 2009:15). The new Constitution from 1988 is one vital aspect of the post-authoritarian society. It states that health is a duty of the state and a right of citizens. The act has weaknesses in terms of issues of economic responsibilities, but is still a strong legal weapon for citizens to use to claim their right to treatment, not least concerning universal access to antiretrovirals (ARV) – the life-saving treatment for People Living with HIV/AIDS (PLWHA) (Grangeiro et al. 2009).

What will be presumed in this article is that Brazil has a dominant political culture – structure – in relation to, among other issues, “race relations” and social and gender inequality, but also concerning the right to health and health care reforms. Political culture is defined as the particular social construction in every society of what counts as “political” (Alvarez, Dagnino, and Escobar 1998:8). Governmental and civil society partnerships for health have a long history as part of the dominant political culture, but with resistance characterized by a social health movement that emerged as a reaction to the military regime’s failure to provide basic health care to the poor and rural population (Mello e Souza 2007, Galvão 2000, Nunn 2009, Follér 2005). These structures are challenged through

actions at the public level – sub-politics.²

If social movements purport to modify social power, and if political culture also involves institutionalized fields for the negotiation of power, then social movements of necessity wrestle with the question of political culture (Alvarez, Dagnino and Escobar 1998:8).

The concepts “political culture” and “sub-politics” are the tools applied to analyze how civil society AIDS organizations act as a driving force in the Brazilian AIDS politics and the creation of the *Programa Nacional de DST/Aids* – the National STDs (sexually transmitted diseases) and AIDS Program (hereafter NAP) – hosted by the Ministry of Health as a Health Ministry Agency since the mid-1990s. Since 2009 this is a Department of the Ministry of Health. Often social movements do not demand to be included in the dominant political culture, but rather seek to reconfigure it, and this issue will be articulated in this article when describing how civil society is changing its form into professional NGOs.

ENONG is seen as part of the sub-politics, a struggle for public space to influence the politics of AIDS in Brazil, and to a certain degree also part of the international arena through transnational networking and advocacy. The transnational interactions of activists, knowledge, and practices are part of a global civil society connected through an AIDS agenda. ENONG is dealt with as one collective actor, which between 1989 and 2009 organized fifteen conferences with civic organizations from all over the country representing regional and local actors and international interlocutors. The local/regional AIDS NGOs act independently in their own settings between the conferences and act with a mandate from the local/regional members during the conferences. This means that there are negotiations and controversies about the structure of the organization and political priorities, debates on specific

² Sub-politics is more or less synonymous with the concept “the cultures of politics” used by Alvarez, Dagnino, and Escobar (1998).

themes and which decisions that are taken over the years. ENONG is taken as a case study as a way to attempt to describe how citizens voluntarily seek to participate and shape the rules of politics and thereby influence the social life and rights of PLWHA. AIDS civil society groups constitute an arena, bringing citizens together non-coercively in deliberate efforts to mould the political culture – formal laws and informal norms such as traditions and public policies – that regulate social interactions in a country.

Globalization, the Brazilian re-democratization, and the international AIDS governance make up the context of the ENONG performance. As a part of civil society it acts in relation to the State, and together with other organizations (e.g. community-based), institutions (e.g. the Church, corporations), and media. This is what social movement researcher J. A. Scholte describes as a change away from *statism*, when governance came down to how civil society functioned in relation to the state (2004). This was the case for the few existing civil society organizations during the dictatorship. The only interlocutor was the military government, and social movements therefore became explicitly political – with the non-governmental organizations being a reaction or protest against the absence of governmental responses (Galvão 1997). However, when the framework of governance changes – as it has done with contemporary globalization – the character of civil society may be expected to change in tandem, and in today's more *polycentric* condition, civil society associations have redirected some of their attention from states to other sites and networks of governance, including global regulatory arrangements (Scholte 2004).

The NGO-ization and professionalization of civil society organizations and directions of future development will be elucidated. The assemblages of themes from ENONG conferences are described and analyzed as “storylines.” These are excerpts from texts, my own interviews, and participant

observations at conferences. The network construction of ENONG and the ongoing activities are part of the outcome of the national AIDS governance.

Background: A brief history of the global HIV/AIDS pandemic

The HIV/AIDS pandemic is one of the major political challenges of our time and has come to occupy a permanent place in media and on the public agenda over the past 30 years. It has been labeled the first disease of the era of globalization (Lieberman 2009, Altman 1999, Barnett and Whiteside 2002). In an early stage of the epidemic, AIDS-positive gay men in New York and San Francisco were portrayed in media as thin and undernourished and with typical characteristics of the disease, such as swellings on their backs and abscesses on their faces and bodies. Pictures in magazines and on TV explored how they mourned the death of their loved ones and buried them. During the first years of the 1980s, in the USA and also in Brazil, it was called the “gay disease” (Terto Jr. and García 2008).

Another dominant perception of the AIDS pandemic, during the years that followed, was emaciated, exhausted, and hollow-eyed African women, men, and children slowly dying of a virus that eats up the person from within. It is an image we have seen before; it illustrates victims – Africans starving to death in famines caused by droughts, floods, or civil wars. Most people’s thoughts go to sub-Saharan Africa, and South Africa in particular has been highlighted in media, due to former president Thabo Mbeki’s political moves, and as a result of the health situation, with one of the highest prevalences of people living with AIDS in the world. Sub-Saharan Africa has thereby become the face of AIDS. The pandemic has over time been included in two narratives – the political and the biomedical. The biomedical narrative is globally hegemonic, even if

counter-discourses exist. An AIDS-denialism or dissidents' discourse, advocated by, among others, the ex-president of South Africa, continues to exist. There is also a popular "alternative medicine" discourse with other explanations than the scientific (biomedical) ones concerning the origin of the disease and how to treat it (Nattrass 2007). The political and biomedical narratives on AIDS interact and take different forms depending on the social and cultural settings in which they are constructed. The knowledge about the epidemic is articulated differently depending on whether it is constructed by scientists, traditional healers, corporate actors, politicians, or activists, and also how it is represented in media. The construction of knowledge dealing with AIDS is multifaceted and often controversial.

During the early period of the epidemic AIDS was apprehended by heterosexual Westerners as a disease that above all affected "the other": Africans, homosexuals, intravenous drug users (IDUs) – but not us. These images might explain the slow and deliberate character of the reaction of numerous Western governments and public health institutions to the apocalyptic situation emerging, as it mainly affected marginalized groups in the Global South. But the situation has slowly changed, and from the end of the 1980s and during the 1990s various initiatives have been taken to respond to the epidemic. These reactions to the epidemic arose among governments, but also in research communities, international organizations, transnational collaborations, and the context of civil society.

One reason why the USA and actors such as the United Nations placed AIDS on the global political agenda with the goal of slowing down or stopping the epidemic was that it was seen as a security issue, as discussed in the Security Council in 1999 (Altman 2008, Fourie 2006). Today various donor organizations have increased their economic support tremendously. The total resources made available for HIV/AIDS globally increased from

1.6 billion USD in 2001 to 10 billion USD in 2007 (UNAIDS 2008) and they are expected to continue to grow. This inflow of money is affecting the global AIDS governance in a variety of ways (Hein, Bartsch, and Kohlmorgen 2007).

Consequently, AIDS politics, whether local, national, transnational, or global, must be approached as part of contemporary globalization, and thus as embedded in the power structures of present-day world society (Follér and Thörn 2008:1). The wave of increased AIDS activities in Brazilian civil society, and an emerging global civil society, are linked together and are part of globalization.

Globalization and the Brazilian AIDS governance

The AIDS epidemic is intimately connected to the process of democratization in Brazil (*abertura* – referring to the gradual opening of political institutions) that started during the 1980s, after more than twenty years of military dictatorship (Follér 2005, Galvão 2000, Nunn 2009, Terto Jr. and García 2008). To understand today's civil society AIDS activism, a health reform movement that originated in the late 1960s and early 1970s has to be mentioned. This was a new social movement comprising health professionals, bureaucrats, intellectuals, and civil society organizations known as the *Movimento para Reforma Sanitaria*, or the Sanitary Health Reform Movement (Marques 2003, Mello e Souza 2007, Nunn 2009). The participants were acting both for democratization and for improved health care for all. The movement called for a radical reformation and decentralization of the Brazilian health system. It thereby became part of the broader movement for participation, democratization, equality, and inclusion of which the AIDS NGOs have been a vital part since the 1980s. Participation and inclusion refer to health programs being designed by and accessible to the general public and using an integral approach, that is, integrating preventive and curative services in a basic package of primary

health care service (Nunn 2009:32). These concepts came to be highly relevant in the health care for PLWHA.

Different factors within the political culture have contributed to the “success story” of the AIDS situation in Brazil; and the broad, cross-sectional sanitary movement was one important component of the efforts in the late 1970s to develop new democratic institutions within the field of health care. The political culture emphasizes the role of political traditions in the country regarding forms of organization and mobilization, and modes of collective identification (Avritzer 2002). Apart from historical influences from the struggle for health reforms, the international and national AIDS agendas as well as global networking during the 1980s have affected the political culture in Brazil and become an important part of civil society sub-politics – a struggle for social and political changes in society.

An example of the new tendencies in global civil society is transnational networking between activists. Influences from the US gay movement concerning AIDS activism – how to create opinion, how to rely on and interpret knowledge related to the disease, and the importance of media contacts – were transferred to Brazil by gay activists who had previously been forced into exile due to persecution and discrimination during the military dictatorship. After a political amnesty and during the incipient democratization, they returned home with new knowledge, experiences, and contacts from the resistance (e.g. the work of Act Up³ and other organizations) and the promotion of human and sexual rights they had encountered in civil organizations abroad (Terto Jr. and García 2008, Epstein 1996, 2005, Parker 1997, Kulick and Klein 2010). In this way, the experiences of the US gay movement reached the Brazilian civil society and its activists, and created a vital network for future work. This is part of the emerging network society described by

³ Act Up – AIDS Coalition to Unleash Power, was formed in New York in 1987 (Epstein 2005).

Manuel Castells, a society where the key social structures and activities are organized around electronically processed information networks, which are influencing political organizations in different parts of the world (1996).

During the 1980s a public debate on AIDS also became visible in a rising civil society with movements such as women's organizations, church- and community-based organizations, among black movements, and among gays and lesbians and PLWHA.⁴ Also in the academic world, especially within the medical sciences, a search for new knowledge emerged, as new scientific data regarding the virus – its composition, epidemiology, and many other aspects related to the complex AIDS symptoms – were found (Bastos 1999, Camargo Jr. 1994). Also in the social sciences an emerging field opened up, connecting HIV/AIDS to studies on human and sexual rights, sexuality and sexual identities, discrimination, stigmatization, and other related questions (Parker 1991).

Discussions within the Brazilian AIDS governance – closely connected to the international agenda – on what were the main problems and how to solve them, were articulated differently depending on which discourse they were constructed in. The actors getting involved in the AIDS governance had diverse roles and motivations as well as social, cultural, and cognitive commitments, and acted accordingly. In Brazil, the initial reactions from the federal government and the health authorities were slow, which caused the civil society to take action in the face of the passivity. Many people had suffered and died before the state reacted and AIDS was treated as a national public problem by the health authorities. What was

⁴ Later on the *Associação Brasileira de Lésbicas, Gays, Bissexuais, Travestis e Transsexuais* – ABGLT was created with inspiration from the gay movement. It is a national network with more than 200 affiliated organizations, and was founded in 1995 to promote the citizenship and rights of these segments of the population. They have international consulting status for the United Nations Economic and Social Council (www.abglt.org.br).

debated – in the health movement, among the first AIDS NGOs in São Paulo and Rio de Janeiro – was the need for centralized political decisions and actions together with coordination at state and local levels to implement an integrated AIDS policy.

Transnational organizations and global AIDS initiatives

Brazilian civil society AIDS activism is the focus of this article, but social movements work in tandem with the state, foundations, donors, state-funded organizations, non-commercial transnational NGOs, and transnational corporations (Follér and Thörn 2005). Among the influential transnational actors in the context of AIDS politics are the World Health Organization (WHO), and later on UNAIDS and the Global Fund. One central figure and driving force in WHO during the 1980s was Jonathan Mann, the founding director of the Global Program on AIDS (GPA). He promoted partnerships between different actors in the Global South and Global North, initiated international conferences, and was a strong forerunner in emphasizing human rights as a key issue in the fight against AIDS (Bastos 1999:50–67, Mann et al. 1992, Parker and Aggleton 2003). The vigorous mandate by the WHO during the 1980s was strongly influenced by the US social AIDS movement with a special emphasis on human rights and social matters (Follér and Thörn 2005). Another event which has been vital for global AIDS governance was the creation of the United Nations special AIDS unit (UNAIDS) in 1996. UNAIDS emerged from strong civil society influences, using global actions, networking campaigns, and other forms of pressure, and is today's leading institution, a powerful actor in the global AIDS governance. The organization influences and affects the politics of AIDS at global, national, and local levels. One controversy in the politics of UNAIDS has been the question of viewing HIV/AIDS as "exceptional" (Whiteside 2009, Fourie 2007). This stance is questioned by many and remains a divide in the organization. Its opponents do not perceive it as relevant to treat AIDS as

exceptional and there are statements to the effect that “exceptionalism” should be abandoned and AIDS should be treated as just one of many health challenges (England 2008, Mistry 2008).

Two other essential International Organizations (IOs) with an impact on questions related to AIDS are the World Trade Organization (WTO) and the World Bank (WB). The WTO deals with issues related to medicines and patents. One example is the controversial TRIPS agreement, which has involved conflicts between the North and the South, including the transnational pharmaceutical industry on subjects related to patents and pricing of medicines (Chaves et al. 2008, Sell 2004). The WB is another strong global actor with abundant economic resources and power. Brazil took several loans from the WB during the 1990s, which affected the AIDS governance in various ways and became an important component in the Brazilian response to AIDS. The loans had impacts on the development of AIDS NGOs, the governmental politics, and the relationships between different actors in the AIDS governance. WB policies strictly forbade expenditures on antiretrovirals (ARV), which created a strong sub-politics of “treatment activism.”

Through political action, including public protests, social activism in the courts, media pressure, and by working within the NAP, the AIDS movement was able to strongly influence initial development of AIDS treatment institutions as well as help create an activist culture at the NAP (Nunn 2009: 70).

The concept of “storylines”

ENONG is interpreted as a narrative and the concept “storyline” is applied to elucidate the progress of the activities. The actors participating in the narrative construct categories and give meaning to specific physical, social, cultural, or political phenomena which are discussed during the

conferences and emphasized in texts, and referred to in interviews and questionnaires. The storylines are assemblages of themes which are highlighted as meaningful at the conferences and articulated in discussions and negotiations. They not seldom create controversies, as there are different opinions regarding which storylines that should be articulated (Câmara da Silva 1998, Galvão 1997, 2000, 2002, Lindner 2005). The participants, who in a complex way are producing the storylines, identify themselves as academics, activists, media people, policy makers, PLWHA, or a mixture of these characteristics. They have different backgrounds, ideologies, political opinions, and aims. The storylines are part of the agenda created, reproduced, and highlighted at roundtable debates, panels, and sessions, and also questioned in the corridors between the sessions. The outcome of the event can be seen as new assembled knowledge, which is documented in the proceedings and can be read in academic articles and obtained through interviews and questionnaires. The knowledge produced and reproduced in these settings is a partial knowledge conditioned by the activists' background, gender, race, class, and personal experience, and is a part of how they interpret the world. The knowledge is based on scientific, popular, and lived knowledge, and can be viewed in terms of Donna Haraway's definition of situated knowledge (Haraway 1988). The same phenomenon occurs with the texts referred to in this article; they should be understood in their own social and cognitive contexts, as a collective history describing the activities documented from AIDS NGOs between 1989 and 2009, with a special focus on ENONG documentation. It is not a coherent narrative that is told; ENONG is dealt with as one actor, but all the time there are voices interacting both inside and outside the conferences. Between the conferences, local NGOs are acting, just like other external actors, and through civil society, sub-politics are causing changes over time in the political culture.

The main text dealing with ENONG is *Construção de sonhos e lutas* (The construction of dreams and struggles). This is a document with one chapter for each of ENONG's conferences between 1989 and 2005 (Lindner 2005). I also use other articles, books and pamphlets dealing with the AIDS NGOs (e.g. Câmara da Silva 1998, Galvão 1997, 2000:89ff, Landim 1988, Terto Jr. and García 2008). Since 2003 I have conducted 15–20 interviews with AIDS activists from Rio de Janeiro, São Paulo, and Natal, and participated at ENONG 2009 with a small questionnaire

The storylines extracted from ENONG articulate vital questions raised in international and Brazilian AIDS governance, because the organization is part of the global and national AIDS governance and does not exist in a political vacuum.

The pre-history and institutional precursors of the AIDS NGOs in Brazil

The Brazil of the 1980s must be viewed in its political context; as a country it was slowly recuperating after twenty years of dictatorship, and its civil society was reemerging after repression. It was a period when media, newspapers and television still referred to the AIDS epidemic as gay cancer (Parker 1994, Terto Jr. and García 2008). During the 80s the civil society reaction was still defensive and came from emancipated gay groups mainly in the big cities, e.g. São Paulo, Rio de Janeiro, Salvador, and Belo Horizonte (Galvão 1997, Terto Jr. 1999). A broader engagement can be seen from 1985 onward, when alongside the gay groups other social movements – community groups, church groups, the national health sector, and the academic community – started to act. The first group to primarily work with AIDS was created in São Paulo, *Grupo de Apoio à Prevenção da AIDS* (GAPA/SP), and the next NGO to follow was *Associação Brasileira Interdisciplinar de AIDS* (ABIA or the Brazilian Interdisciplinary AIDS Organization). ABIA was

founded by Herbert de Souza (Betinho) in 1986 in Rio de Janeiro and he was the president until his death in 1997. Herbert Daniel⁵ recognizing the need for an organization focused primarily on the political dimensions of living with HIV/AIDS, decided to form the *Grupo Pela VIDDÁ* (GPV or Group for the Affirmation, Integration, and Dignity of People with AIDS) in Rio de Janeiro in 1989. Like many AIDS NGOs during this period, and as a result of the epidemiological realities (e.g. men who have sex with men were the largest category of people with HIV/AIDS in Brazil at this time), most of the participants at Pela VIDDÁ in its first years were gay-identified men (Kulick and Klein 2010). One important political step for Pela VIDDÁ was the active participation of PLWHA in the work and a strong stance against seeing themselves as victims. Nevertheless they worked for universal human rights and solidarity and did not exclude anyone.⁶ One important step was also to mobilize PLWHA, one example being the “buddy”⁷ project which provided practical and emotional support (Valle 2000). The AIDS NGOs of this period were inclusive in their approach; they worked with community workers, with and within women’s and gay groups, and spread information in schools and corporations. There were also new links with medical and social scientists and other groups. The concept of “inclusion” among the actors was important during this period

⁵ Herbert Daniel (1946–92) was a prominent activist during the 80s on human and sexual rights and member of the Brazilian guerilla. He lived in exile for seven years in Lisbon and Paris during the dictatorship. He was a charismatic leader of vital importance for the development of the AIDS NGOs especially in Rio de Janeiro (see more about his role in Kulick and Klein, this volume).

⁶ Later there are AIDS organizations which only accept participants carrying the virus and exclude others. Further information on exclusion and/or inclusion can be found on *Grupo de Incentivo à Vida* (Group for Life Incentive) – GIV’s website: <http://www.giv.org.br/index.php>. GIV was founded in 1990.

⁷ The Lawyer Ezio Távora Dos Santos Filho became affiliated with GPV in 1990 and was for many years the coordinator of GPV’s buddy project (interviewed in February, 2003).

and gave coherence to the work on prevention and intervention that was implemented (Galvão 1997:76).

ENONG – A case study⁸

The process of democratization that brought political freedoms to post-authoritarian Brazil allowed AIDS activists to organize openly and officially express their political opposition and opinions, as described above. How HIV/AIDS is understood within the ENONG network, how it is discussed and which power relations that can be mapped, and on what knowledge the practice is based are the core determinants of which storylines that emerge. In the Introduction I referred to the NGO-ization, not only among AIDS NGOs, but as a tendency among social movements all over Latin America including women's, feminist, and indigenous groups and environmental organizations. The earlier mentioned NGOs, GAPA-SP, ABIA, and Pela VIDDÁ are signs of this trend. Civil society organizations are becoming institutionalized, and in this part of the article I will reflect on the quotation "... have not just been co-opted by the powers they once criticized (such as the state and transnational capital and their agents)..." (Castro 2001:17). There are many discussions on the identity of the NGOs and one source of inspiration for me is Sonia Alvarez's *Beyond NGO-ization? Reflections from Latin America*. She discusses the hybrid identity of the feminist NGO boom and says that it is important to move beyond binary representations of the good and bad NGOs, as they are intertwined and interdependent (Alvarez 2009). The same process is relevant for the AIDS NGOs. There was indeed an increased and rapid expansion of AIDS NGOs during the 1980s and 1990s in Brazil (Galvão 2000, Landim

⁸ The conferences will not be analyzed as individual events, but instead storylines connecting the conferences will be constructed. A list with the year, place, and number of participants of the ENONG conferences from 1989–2009 can be found in Annex 1.

1988). By 1992, there were nearly 100 AIDS NGOs in Brazil (Galvão 1997). And today on the government website more than 400 AIDS NGOs are registered.

The first breakthrough in increased AIDS activities in Brazil was in 1989/1990 when a national AIDS political movement began to articulate itself through a series of semi-annual and later annual national meetings. This was a process of institutional maturity with strong influences from the global AIDS governance. The World Health Organization (WHO) had a meeting in Vienna in February 1987 at which a call for civil society participation in confronting the AIDS epidemic was stressed (Galvão 2000, Lindner 2005:12). The request attracted a great deal of attention and a first international AIDS NGO meeting took place in June 2-4, 1989 at McGill University in Canada called "Opportunities for Solidarity." The conference was held some days before the Montreal conference⁹ and was organized by Canadian civil organizations and ABIA from Rio de Janeiro. More than 300 delegates from 50 countries met to discuss how to respond to the AIDS epidemic. The topics or storylines emphasized in published texts and speeches from the conference were a call to work together and the importance of solidarity. The Brazilian activist Herbert Daniel gave the concluding remarks, stressing that AIDS is not a punishment of some groups in society; it is a disease and it takes a mental revitalization and new awareness to accept this reality (Lindner 2005:13). A global AIDS network became apparent from this period, based in regional and national AIDS organizations. New links for cooperation were strengthened, which opened up for innovative challenges (Parker 1997). The emerging global network resulted in the creation of the International Council of AIDS Service Organizations (ICASO) in 1991.

⁹ In 1985, the International AIDS Society (IAS) began holding annual conferences to share scientific discoveries related to HIV/AIDS. Starting in the 1990s, civil society activists and PLWHA were welcomed and the conferences became more participatory and more interdisciplinary by including additional social, epidemiological, and policy issues.

In Brazil, at the initiative of Herbert Daniel, the first AIDS NGO network was established and first joint articulation of several NGOs' overarching human rights objectives, entitled the *Declaration of Rights for Individuals Living with AIDS*, was published in 1989. The declaration outlined the movement's principles of nondiscrimination, social equity, democratic accountability, and participation of PLWHA in policy development (Galvão 2000, Nunn 2009:50, Lindner 2005:20). The intention was to create a political response to the government's inaction and to emphasize the responsibilities of different authorities and the compromises they had to make in relation to public health. The creation of ENONG in 1990 is a national political challenge stating that AIDS should be treated just like other diseases, and this happened in parallel with an emerging global AIDS governance. From the beginning ENONG assembled a collection of local and regional AIDS NGOs, social movements, and activists. The gay activists had been well mobilized for some years, and solidarity and democracy were vital concepts in the creation of the network. The first meeting took place in the city of Belo Horizonte. Among the 14 NGOs participating there was a broad heterogeneity of interests and later the same year a second meeting took place in Porto Alegre, this time with 38 organizations participating (Lindner 2005:16). From the beginning the idea of solidarity is a unifying thread in the discussions and an overarching approach for intervening in the politics of AIDS (Galvão 1997).

At the outset, some charismatic leaders of the movement can be identified. There are a number of, mainly male, individuals with power, eloquence, contacts in political parties and among political leaders, and an ability to unite people. Some of these have already been mentioned, such as Herbert Daniel and Herbert de Sousa, but there are more. In tandem with the planning of the upcoming ENONG meetings, further AIDS NGOs are established around the country. They are created and expand in a dynamic process in diverse environments and can

be compared to what feminist scholar Fiona Macaulay, with regard to the women's movement, describes as "trickling up, down and sideways" (Alvarez 2009:177). The AIDS NGOs are in various ways linked to health authorities, the government, and community and church organizations, as well as to international NGOs and international donors.

In parallel to the growing number of organizations participating in the ENONG meetings, the face of the epidemic changes. The epidemic first affected the group of Men having Sex with Men (MSM), but at the beginning of the 1990s the epidemic also reached the interior of the country, which was described as a process of pauperization, feminization, and "interiorization." But MSM are still the most numerous and vulnerable group. There is also evidence that more AIDS cases are seen among Injecting Drug Users (IDUs) (Follér 2005, Lindner 2005:24).¹⁰ What will be reflected on throughout this article is that ENONG does not include questions related to IDUs, drug use, and syringe exchange as prioritized areas or as parts of the storylines.

At the 3rd ENONG meeting, in Santos, there were discussions relating to which activities to carry out, and two upcoming storylines can be discerned. One is a human-rights-based and politically oriented storyline (supported by, among others, Herbert Daniel), and the other is more of what can be called the "service provision" or "assistant oriented" storyline (supported, among others, by the anthropologist and gay activist Luís Mott)

¹⁰ In 1998, Brazil hosted the 9th International Conference on the Reduction of Drug Related Harm. These meetings represented an important moment of articulation of harm reduction professionals, culminating in the creation of two harm reduction associations: the São Paulo Harm Reduction Association (APRENDIA), and the other association of national scope, the Brazilian Harm Reduction Association (ABORDA). In March of that same year, the first state harm reduction law was passed in São Paulo (*State Statute no. 9,758/97*). Subsequently, other states and districts approved similar laws (Fonseca et al. 2006).

(Lindner 2005:25). The heterogeneity of the AIDS movement became obvious at the event in Santos, as did the fact that different organizations had unrelated and disparate social and political aims. The hybrid identity of ENONG was recognized and declared. Part of the discussion on identity resulted in the foundation in 1990 of a PLWHA organization *Grupo de Incentiva à Vida* (GIV) in São Paulo with the main goal of fighting for their lives – *lutasse pela vida*. The approach of the new organization is closely linked to questions of solidarity, human rights, and support for AIDS-positive people and their families.

The first years of the 1990s were a period of conflict concerning the federal politics of AIDS and NAP. It was a time of political confusion under president Collor's frustrating government, which ended with his impeachment and resignation. No significant steps to prevent or stop the epidemic were taken by the health authorities and PLWHA were still rather invisible in society. At the 4th ENONG in 1991, representatives from NAP participated for the first time at an ENONG meeting, and the criticism from civil society was strong, with massive protests against passive governmental policies. Some leaders, such as Paulo Bonfim and Herbert Daniel, were both fragile and bore traces of AIDS,¹¹ and were living examples of the political failure.

International conferences continued to assemble academics, policy-makers, and AIDS activists around the world. At a conference in Florence, Italy in 1991 several Brazilian AIDS NGOs were represented. Information, knowledge, and networking influenced the agenda on the upcoming ENONG meeting in 1992. One important event that can be seen as a turning point in the Brazilian AIDS governance was the government's negotiations with the WB on loans for prevention, treatment, and institutional building to handle the AIDS epidemic. Brazil was granted a loan of more than 160

¹¹ Daniel died in March 1992 and Bonfim in October the same year.

million USD from the WB in 1992 to develop and implement a comprehensive National AIDS Program (Galvão 1997). As part of this WB project, over the period 1993–1998 more than 9 million USD were distributed to nearly 200 community-based organizations working with AIDS-related issues – not only AIDS NGOs, but also gay, transvestites’, sex workers’, and women’s organizations that previously had been largely left outside of AIDS-related funding circles. Two smaller loans from the WB, AIDS II and AIDS III, resulted in even more support for NGOs and community-based organizations over the coming years (1999–2002; 2003–2006) (Nunn 2009:176). This expansion of the types of organizations receiving federal AIDS funding was complemented by the creation of projects and subcommittees within the National AIDS Program that focused on specific “higher risk” populations. Some of the categories identified were: men who have sex with men, sex professionals, injecting drug users, and people in prison. The availability of these funds and the opportunities for a constructive dialogue provided by the National AIDS Program helped reduce competition between AIDS NGOs and gay groups. This development stimulated a significant growth in the 1990s of HIV prevention projects directed toward men who have sex with men.

The WB loans became a central political debate at the 5th ENONG in 1992 and various programs played important roles in the emergence of more visible gay communities in Brazil (Kulick and Klein 2010). At the end of 1991 the well-established NGOs in Rio de Janeiro and São Paulo were cooperating and the AIDS network was strengthened through new strategies of partnership. Some strong and well-established NGOs – GPV/Rio de Janeiro, GPV/São Paulo, and ABIA – cooperated in projects with researchers and medical doctors committed to the development of a vaccine and vaccine trials (Oliveira et al. 2001). This emerging subject, related to tests for an anti-HIV vaccine, became controversial among the AIDS NGOs. A divide of opinions was articulated and many PLWHA activists were in

favor of vaccine trials in their fight for life.¹²

The director of the NAP during this period was Lair Guerra de Macedo. She became a committed leader with a strong connection to the previously mentioned Sanitary Movement and she re-organized the AIDS program with a special unit responsible for cooperation with civil society.¹³ During this period the NAP had a dedicated leader, open to partnerships with civil society, there were committed and knowledgeable activists, and economic resources from the WB loan made it possible to implement new projects.¹⁴ The 5th ENONG meeting was funded by NAP, OXFAM, and other institutions, which meant a better economic situation for the arrangements and for the costs of the participants, which altered the character of the movement. It gained new momentum – as was described by the participants (Terto Jr. cited in Lindner 2005:37).

The economic dependence on and closer links to the government and international donors resulted in discussions on the autonomy of the AIDS NGOs. This new momentum, with the movement, through projects and campaigns, acting in partnership with the “powers they once criticized” was called into question. This is the time when new political discussions on the function and identity of civil society organizations came up (Castro 2001:17). At the 5th ENONG there were debates

¹² A central person from this period until today is the professor of mathematics and AIDS activist Jorge Beloqui from São Paulo, active in GIV/SP, whom I interviewed in November 2003 and met during ENONG 2009.

¹³ Lair Guerra appointed the medical doctor Paulo Roberto Teixeira to be responsible for this unit. He has been another central leader over the years for the development of the Brazilian AIDS governance and was present at the 1992 ENONG meeting.

¹⁴ “The AIDS movement’s, and particularly Betinho’s (Herbert de Souza), historical connections to inside policymakers like Lair Guerra had direct tangible impacts on historical development of Brazil’s AIDS policies; three of the twelve people NAP Director Lair Guerra hired to write the World Bank loan proposal were activists from the NGO sector” (Nunn 2009:63).

related to the organizational culture and how to build institutions. Another pertinent question was how to design new projects with support from international donors and the possibilities and ethics of cooperating with corporations, such as e.g. the pharmaceutical industry (Lindner 2005:38). During the “era of projects” the process of NGO-ization became even more apparent. A more formal organizational structure was needed to succeed in the process of formulating and implementing projects, and a predominant feature of the movement was professionalization, which appears to have been a prerequisite for managing the new project administration.

The hybrid identity of the movement was frequently highlighted during the conferences; some participants mentioned the importance of supporting marginalized groups to be reached by public health policy and to undertake social actions among them – the advocates of service provision. But, this is a divided storyline and has no strong voice. Some asserted that civil society is taking over parts of the health authorities’ responsibilities – *terceirização* – with the outsourcing of health care provision; while some opinions comes closer to promoting the idea of charity.

This also reveals something about the role of the state: “As the government increasingly outsourced assistance to nongovernmental and philanthropic organizations, it reconceptualized itself as an activist state” (Biehl 2007:393). The other storyline articulated is the human rights standpoint with a more political view. Its proponents wanted to have more impact on the government AIDS policy and there were also demands for more profound political changes in society. One question raised was related to sexual politics. Gay activists dominated the discussions on sexuality and demands for sexual politics. They stressed the political aspects and illustrated how these are related to human and sexual rights as well as questions of visibility, prejudice, solidarity, and empowerment (Lindner 2005:38–39). Some participants indicated the

importance of diversity for a prolific movement articulated through the hybrid identity of ENONG and as a sign of openness. Other saw the debates as fruitless and fraught with conflicts.

The meeting planned for 1994 with about 100 representatives from all over the country had economic support from NAP (through the WB) and from several other institutions and corporations. The meeting was, according to some sources, characterized by “frictions and disputes” and a power struggle between “King NGOs and small groups” (Lindner 2005:42). Other participants (among them the sociologist Cristina Câmara) describe it as a dynamic event (44). One friction was related to an external donation received, and the formation and development of some of the NGOs. ABIA had received extensive funding and expanded its administration and activities with professional staff and initiated the development of a documentation center on literature related to AIDS. They also started projects in close cooperation with the NAP. One dispute during the conference was related to the election of 5 NGOs to represent civil society in the National AIDS Commission, *Comissão Nacional de Aids* (CNAIDS). The debate was filled with tension and friction and resulted in the exclusion of ABIA from CNAIDS in 1992–1993.¹⁵ The controversies resulted in a changed representation of CNAIDS and more community-based organizations entering such as *Associação Nacional de Moradores* and *Conselho Nacional de Igrejas Cristãs* (CONIC) as well as *Sociedade Brasileira para o Progresso da Ciência* (SBPC), the Brazilian equivalent of the American Association for the Advancement of Science.

The 1994 meeting also highlighted the tension regarding transvestites and the support that was expressed for *casas de apoio* (houses of support). Biehl discusses these places as a consequence of state outsourcing, but he also emphasizes that

¹⁵ The Commission was created in 1986. See footnote 19, Lindner p. 43.

they are important for the survival of poor AIDS patients. They promote treatment adherence and provide an opportunity for survival and dignity for those who are excluded from society (Biehl 2007:394). But he also sees a risk that civil society will vanish, and raises the questions of who represents the people in this civil society–state interface and what fuels NGO activities today.

Between this conference and the following one, the planning commission responsible for organizing the upcoming event consisted of “small” NGOs. This was a reaction or resistance against the power of the “King NGOs.” The 1995 meeting started with a demonstration against the local health authorities to protest the censoring of certain materials produced to use in a media campaign. The practical issues related to the conference were criticized: the distribution of airline tickets, accommodations, and the conference panels. Alongside the practical complaints, the clash of identities and ideologies among the participants become visible. One fraction wanted ENONG to be more politically oriented with demands for power and social changes, and disapproved of the depoliticization and amateurishness of the organization. The other side, simply put, can be seen as advocating service provision, with demands for active support for PLWHA and their relatives.

One controversy during this period was related to the idea of civil society as being co-opted and serving as the prolonged arm of the state, through partnerships in joint projects. There was also concern about the mobility of individuals moving from working for NGOs to becoming government officials, e.g. at the NAP. This question was connected to the fact that more money was available through the WB funds, and there were new opportunities to apply for economic support for projects. Once again the identity of the network and its included organizations was in focus. “What does it mean to be an AIDS NGO?” The heterogeneity of the organizations was becoming

broader with prostitute organizations, syndicates, feminist movements, self-help groups, gay activists, transvestites, and transsexuals participating (Lindner 2005:50). With new organizations entering, new questions were put on the table, and particularly the transvestite and transsexual groups articulated the issues of gender politics and human rights. The demands from these groups were formulated differently from the demands of prostitutes and feminists regarding the same topics (Kulick 1998).

In parallel to the ENONG meetings, new organizations were growing locally, regionally, and nationally. The previously mentioned *Associação Brasileira de Gays, Lésbicas, Bissexuais, Travestis e Transsexuais* was created, giving new visibility to the group of citizens the organization represents. Two views are articulated in a novel way: *assistencialismo* – service provision; and *política assistencial* – political service. The latter emphasized the necessity of strengthening the public politics of human rights, the importance of becoming visible and constructing a political agenda (Lindner 2005:51).

The dynamic growth of the social AIDS movement during this period was remarkable. The network *Rede Nacional de Pessoas Vivendo com HIV/AIDS* (RNP+) is just one example of an organization created to strengthen the situation for PLWHA. They demanded the right to increase their presence in AIDS NGOs and also on governmental committees where decisions related to AIDS are taken. The meeting in 1995 closed with a manifestation against the Catholic Church and its declaration to condemn the use of condoms. This was a strong political statement in a society where the Church has a powerful position.

The weak arrangements of the former meeting resulted in the more professionalized and experienced NGOs taking over the preparations for the upcoming meeting in São Paulo in 1996. The Health Minister (Adib Jatene) participated, and a new

phase in the alliance between civil society and government can be discerned. This time the activist José Stalin Pedrosa from Rio de Janeiro used his extensive network and good personal contacts with government health authorities to arrange useful connections. The panel discussion with the minister was tense and many issues were related to the situation for PLWHA and health plans which the government had not fulfilled. One growing question concerned PLWHA's demand to directly participate in the implementation of projects and the politics of AIDS. The RNP+ had a broad activist basis and gained a certain political significance as PLWHA became more visible within ENONG. This meeting has been described as being more politically mature. One breakthrough, and new feature of the dialogue with the government, was the AIDS organizations' demand for direct influence on the politics of AIDS (Lindner 2005:56). The WB also put pressure on the government by demanding that the health authorities integrate civil society organizations into the AIDS agenda to obtain the second loan (AIDS II).

The professionalization of the AIDS NGOs was becoming explicit in the structure of the ENONG conferences, which were organized with pre-meetings, invited speakers, panels, and certificates for participants. The next step suggested was a strategic policy. By planning to hold the upcoming meeting in Brasilia – the federal capital – the organizers wanted the event to be closer to the center of power, which might facilitate more involvement in the national AIDS politics (Lindner 2005:57). The conferences had by this time grown considerably in number of participants, as had the articulation of the two familiar dominant storylines: the service provision group, who wanted to distribute condoms and give economic and health care support; and the more politically oriented group, who had human rights on the agenda, wished to change the political culture of the society, and demanded the right to take part in

governmental commissions and councils. José Stalin Pedrosa¹⁶ was a strong voice at this meeting with a forceful political mandate and the goal of linking health and human rights, and he stressed the importance of treatment for PLWHA to promote good quality of life.

The meeting in Brasilia in 1997 took place the same year as the WB AIDS I loan came to an end.¹⁷ The title of the conference was Public Politics and AIDS: Health and Citizenship. The participation of *Movimento dos Trabalhadores Rurais Sem Terra* (MST) and several Latin American AIDS activists represented a new step forward and an opening up of ENONG thematically, regionally, and globally. The political and identity discussions continued with frequent questions along the lines of “what is a true AIDS NGO?” Once more, controversies could be seen between more activist and political groups and PLWHA. The latter wanted more power and visibility. ENONG was now a truly professionalized institution, engaged in frequent dialogue with the government, discussing partnerships, and articulating the political influences of civil society. *Controle social* – the right of civil society to control the government’s health politics, the watchdog function – is by some perceived as a re-active political stance on the part of the AIDS NGOs (Lindner 2005:65, Terto Jr. and García 2008).

At the 10th conference in 1999 a state-of-the-art document was produced, *A necessidade da rearticulação do movimento social de AIDS*,¹⁸ written by the activist Nelson Solano (Lindner 2005:67). It contains three admonitions: a) the importance that the commission plan the event well; b) that the meetings be given a more political character – broader than the concept of

¹⁶ José Stalin Pedrosa died in October 2000.

¹⁷ Between 1993 and 1997 more than 18 million USD for hundreds of projects were distributed to 175 organizations by the government.

¹⁸ ENONG: The necessity of rearticulating the social AIDS movement.

“militancy”; and c) to decide and select which are the most important themes for the collective AIDS NGOs to discuss (Lindner 2005:67). With these objectives guiding the conference, the process of excluding some organizations from ENONG was initiated. In the CN DST/AIDS database it is recorded that some organizations were excluded because they were counted twice and some because they did not fulfill the definition of an NGO, one condition of which is to be a non-profit organization – *sem fins lucrativos*. The outcome was turned into a database with 587 NGOs, many which had never responded to any invitation from ENONG and had no communication with the Ministry of Health. After an evaluation, 215 NGOs were registered for the upcoming meeting in Belo Horizonte. In the new format the participants were assigned to *Grupos de Trabalhos* GT (Working Groups) with pre-decided themes, and relevant preparatory documents were sent to the participants in advance. The themes were related to questions of identity, ethics, and political principles, and they were not negotiable (Lindner 2005:69).

An ongoing divide in opinions between the AIDS NGOs and PLWHA could be perceived, which was related to the creation of a *Movimento Nacional de Luta Contra a AIDS*. Another new profile or characteristic of the activities is the direct involvement of a UNAIDS thematic group. Another controversial suggestion, which was approved, was to integrate the Brazilian Catholic Church into the civic AIDS work – *Pastoral da AIDS*.

The conference in 2001, with the title *Repensando o Movimento* (Re-thinking the Initiatives), began with a manifestation outside the US consulate to protest the US patents on AIDS drugs and demand that the patents be annulled. The conference was held in Recife – in northeastern Brazil, the poorest part of the country – which reflected the theme of the event. AIDS was discussed from the perspective of poverty, exclusion, social injustice, large-scale unemployment, malnutrition, feudalism,

“machismo,” and development in general. (For a more detailed discussion about patents, see Lindner 2005:73–77).

The Minister of Health attended the subsequent conference in São Paulo, 2003. He stated that civil society organizations interface with different segments of society, and that cooperation and partnership with the government are essential. The government representative stressed the need for cooperation, and the outcome was a strengthening of the *controle social* – the watchdog role of civil society with regard to government health care policy.

In 2005 the location of the event was Curitiba, and the participation from Latin American countries and different segments of Brazilian society was more extensive than ever. A Political Commission was elected and the five themes discussed during the conference were: a) Analysis of the international and national situation; b) Public policies on HIV/AIDS; c) Financing and projects; d) Activism; e) Representation and relations with the government and other instances of participation. The program was ambitious with 19 special sessions, several panel discussions, and five working groups going on in parallel (Lindner 2005:90–100). In 2007, ENONG was cancelled due to organizational and economic problems.

ENONG 2009 – *Políticas Públicas e Ativismo* – was held in Rio de Janeiro. I participated and attended lectures and roundtable discussions organized by different subgroups. Around 350 delegates participated, coming from all parts of the country. The political commission consisted mainly of delegates from the “King NGOs.” The keynote speakers talked about prevention from the perspectives of financing, regulation, knowledge, and values. Another speech was on activism and social movements, and the working groups had different themes. The energy, enthusiasm, and commitment were evident. I found the meeting politically oriented with social demands for more impact in society being directed at the

government. But many questions concerned down-to-earth issues related to better prevention, the treatment roll-out, drugs, and patents.

12 representatives were asked to respond to my questionnaire, and I will summarize the responses. The respondents had worked between 2 and 30 years with civil society questions related to AIDS, with an average of 13 years. Most of them had the following target groups: men having sex with men, bisexuals, transvestites, PLWHA, and/or the general public. The majority mentioned that they worked with several of these groups. One worked with youth and education, and two added that they also worked with people suffering from Hepatitis C. To the question "What is the most important task for the NGOs," the following answers were given: to get new information and knowledge about treatment; to work with prevention; and to support PLWHA, especially those abandoned by their families. Exposure to stigma and being abandoned were more obvious in small cities where AIDS-positive people are more visible and vulnerable. Other activities mentioned were the support and buddy function, including helping PLWHA back onto the job market. Other issues mentioned were to prioritize defending human rights and improving public policies, and to be aware of the autonomy of the NGOs and not work too closely with the Federal government. One response was: "The most important task for the NGOs today is to take action related to social control, since the NGOs only exist because of the absence of the Government when it actually does not offer policies to the public as it should according to the constitution and the rules of SUS" (Sistema Único de Saúde/The National Health Care System). The importance of recognizing the connection between HIV/AIDS and co-infections such as tuberculosis and viral hepatitis was also mentioned.

Regarding the importance of the ENONG conferences, the responses were as follows. Yes it is important to exchange

ideas, lift up new leaders, and meet old friends. It is important for our small NGO to meet others with different experiences and it is an indicator of active participation by citizens and the fight for public politics. The view was also expressed that ENONG has a certain amount of power to improve the situation for PLWHA. Everybody interviewed assumed that ENONG's role of working for better AIDS politics is of crucial significance. On the question of whether the tasks of the NGOs are different today than 10–20 years ago, all the answers were positive. ENONG was considered important, but there were doubts regarding its professionalization and distance from the poor. There was a recognition of the accumulated experience and knowledge that existed in the network, but a worry that pure activism is not enough, that politics must be put into practice. One answer illustrated the frustration caused by the situation "At earlier meetings the expectations were high regarding the necessity to manifest the political role of ENONG and how this was accomplished. Today, any gathering of the AIDS movement in the country to exercise its role more intensively is lacking, including the role of monitoring its own actions. After 15 ENONG conferences, what is the result of all the work? Who has monitored the effectiveness and recommendations of ENONG? What happened at the ENONG/Goias where the organizers disappeared with the resources they were given? At this ENONG/2009 in Rio de Janeiro three states have issued a note of repudiation; it is time to re-articulate ENONG."

The next question was: "What tendency can be seen on the AIDS NGOs agendas today, is it prevention or treatment?" The answers stressed the importance of prevention, but most of them also highlighted that prevention and treatment have to go hand in hand. Prevention is about much more than just using condoms, and there must be a prevention component in the treatment regime too. One respondent stressed that the LGBTT groups are better organized today and are better reached by information on prevention and treatment, but that there is less

money in the system for civil society prevention programs and no new “houses of support” have been inaugurated. In answer to the question “What are the greatest shortcomings of the National AIDS Program?” it was evident that there was a rather positive view of the governmental AIDS program, and the complaints concerned issues such as a lack of cooperation with the NGOs, that the decree 1,824¹⁹ did not include children and adolescents with AIDS, and a lack of knowledge and of effective treatment at the hospitals. Most respondents mentioned the Plans of Actions and Goals as things that are not functioning well.

Discussion

I have found three articulated storylines in my investigation of the ENONG activities from 1989 to 2009.

- The first storyline is the most politically oriented one, with human rights/solidarity as its motto. This part of the movement gives expression to a wish for social change and a will to influence the political situation in a broader sense, not just the health sector and the situation for PLWHA. This storyline was largely initiated by Herbert Daniel and the early leaders and founders of the AIDS movement. According to my examination of the AIDS social movement, this is the most expressly articulated storyline. The historical context of the democratization of society after the dictatorship played a part in the radicalization of the AIDS movement as did its strong connections to the early health reform movement *Movimento para Reforma Sanitaria*. This strong political tradition from the late 1960s has influenced today’s new social movements.

¹⁹ Decree n° 1,824 of September 2, 2004 created support homes for adults living with HIV/AIDS (Oliveira 2006).

The concepts of human rights and solidarity have through the years been a part of the ENONG activities and the AIDS movement. This storyline also includes the principles of universality and equality, and strong demands for sexual politics and sexual rights.

- The second main storyline represents the public health oriented part of the movement, and includes the service provision storyline. This storyline also uses the concept of solidarity, but in a sense that comes closer to charity, philanthropy, and service- or assistance-oriented views – and there are also traces of greater emphasis on victimization. This part of the AIDS movement stresses prevention programs and the function of social control – the watchdog function. It stresses the importance of support to AIDS-positive individuals as well as their partners and families, and includes the construction of houses of support – *casas de apoio*.
- The NGOs initiated by PLWHA function in a sense as a bridge between the first two storylines. They want more influence within ENONG, and they demand to be part of governmental committees and decision groups concerning the politics of AIDS – to be active participants in decision making. But they also see the need for more health care support to people with AIDS, including their relatives, children, and surviving wives or husbands. They are also active in groups together with the pharmaceutical industry to find a preventive or treatment vaccine.
- A third storyline is on a more general and structural level. It deals with the role and autonomy of civil society and civil society organizations. This storyline is an overarching discussion of the role of the network, the institutional building of civil society, NGO-ization, and professionalization. These issues were discussed at

the conferences in terms of the question “What is an AIDS NGO?” and the issue of inclusion and exclusion of organizations and themes in the social AIDS movement.

Conclusions

The process of social change concerning AIDS governance in Brazil has shown strong sub-political characteristics. The ENONG case, with its negotiations with government authorities, the pharmaceutical industry, and other social movements, illustrates how it is “trickling up, down and sideways” and creating a sub-political realm. The authoritarian political culture in Brazil with its historically hierarchic, centralized, and patriarchic structural traits was gradually weakened through democratization and the demands for citizenship and participation in the public sphere. The changes in the country’s democratic political culture were expressed in the 1988 Constitution which, among other things, promotes new civil rights. The transformation included changes in the relationship between the state and civil society from being one of direct opposition, *statism*, to technical-political cooperation, partnership with the state, and networking with other civic organizations and corporations – a *polycentric condition*. With the demand for participation and more transparency in governmental politics, a new political culture is emerging.

The most prominent storyline to emerge from my case study is the one based on human rights/solidarity, with the goal of using politics to accomplish social change. Social solidarity is a concept that can be traced over the years in the Brazilian AIDS civil society. However it is not a static or homogenous concept, but has changed over the years. During these first years one voice frequently recurs, that of Herbert Daniel, a person with charisma, authority, and a political background as activist. He radicalized the solidarity storyline by connecting solidarity and

participation with a strong repudiation of charity. “*A palavra solidariedade muito utilizada, naquele período, pretendia ter, naquele momento, uma conotação e método de intervenção nas políticas de Aids*” (Lindner 2005:16).²⁰

Civil society and the government have the same rhetoric, and are thereby included in the same storyline. A strong synergy can be found between civil society – AIDS NGOs – and the government’s politics of HIV/AIDS. João Biehl refers to the government as an “activist state” in relation to AIDS questions, and cites the very close cooperation between civil society and government through partnerships, alliances, committees, and activists moving between AIDS NGOs and governmental organizations (Biehl 2007:68ff). Whether civil society organizations, as quoted earlier in this article, can be seen as “... co-opted by the powers they once criticized (such as the state and transnational capital and their agents)” (Castro 2001:17) or whether they should be seen as having achieved a win-win relationship, a form of persuasive relationship that will produce mutual positive impacts for both the government and civil society (Mendonca 2004) remains to be determined. In any case, the Brazilian AIDS governance is today a polycentric governance, and through globalization it has spurred several important shifts in the international AIDS governance as well.

ENONG’s ability to gather hundreds of NGOs at its conferences over the years is one indication that the organization has been and still is a vital part of the civil society AIDS movement in Brazil.²¹ ENONG as a network or an umbrella organization for

²⁰ The word solidarity, widely used during that period, was intended at every moment to have a connotation and method of intervention in the politics of AIDS (translated by the author).

²¹ Another important social movement in Brazil is the *Movimento dos Trabalhadores Rurais Sem Terra* (MST). This is one of Latin America’s most successful social movements active in the rural areas, thereby differing from the AIDS movement, which has its epicenter in the urban settings.

AIDS NGOs can be identified as a social mechanism, and an arena of participation. The conferences constitute a distinct sphere, which creates social integration through debates, discussions, and negotiations, and where power aspects and ideological divides between the different NGOs and the opinions of the activists have resulted in a sub-politics which has influenced the political culture in Brazil and, together with other CSOs and social movements, created a new political culture.

With regard to tendencies of exclusion and inclusion, ENONG can be characterized as a network of participants mainly from urban NGOs, who for the most part are well educated and belong to the Brazilian middle class. Even if there were discussions about AIDS affecting the poor population, drug users, and prisoners, these groups are generally not the focus of ENONG, and these categories are not represented among the activists and can be seen as excluded. ABORDA, the organization for injection drug users, lives a parallel life to ENONG, a statement that can be understood as an identity divide between the more gay-oriented ENONG, with strong advocates, and ABORDA, which defends the IDUs – a group often excluded from society, and without strong advocates. The urban professionalized NGOs have their strongest mandate in the cities and often work closer to the centers of power: local and federal authorities. The rural-community-based organizations work directly with the poor, but are mostly not part of ENONG.²²

On the other hand, looking at the themes discussed over time it is also possible to see inclusive features and an ambition to broaden the organization. There have over the years been

²² I interviewed the CSO Mother Teresa in Porto Velho in 2004. They support families with one or more family members with AIDS and work directly with the poor and marginalized population, but do not participate at ENONG meetings.

discussions on infected blood, sexual politics, children and AIDS, mental health, risk behavior, drugs, women, and poverty. These themes have been raised, but have not created storylines, nor are they in any explicit way included in the storylines that exist.

The urban gay population has strengthened its visibility through ENONG and has succeeded in influencing the government's sexual politics to some extent. Discrimination and stigmatization still exist, but with ARV and the universal access to treatment and information, a slow change of people's perceptions can be anticipated.

Concerning lesbians, transvestites, and transsexuals, certain changes can be anticipated even if they are uncertain (Kulick and Klein 2010). The groups are today visible in some television programs and tabloid papers²³ and certain constitutional rights have emerged, which might be an effect of cross border inspiration between ENONG and ALGBT. Biehl speaks of a disappearance of civil society when professional NGOs come to dominate, and he sees an exclusion of the poor and marginalized, e.g. drug users (2007:393).

The universal access to treatment stipulated by federal law in 1996, is ensuring the right to free ARV treatment for PLWHA. This is often described as a success of the partnership between the government and civil society. The synergy between a strong and determined civil society and a number of committed presidents and health policy, resulted in this law, which has meant the difference between life and death for PLWHA, being passed. The decision in Brazil was taken before it was accepted within UNAIDS or in any other country of the world. The law also entailed national negotiations with the pharmaceutical industry about patents, pricing, and compulsory licensing, and the same issues were on the international agenda at the WTO

²³ See Kulick and Klein, this volume, on the visibility of transvestites in media.

and TRIPS discussions (Sell 2004, Chaves et al. 2008).

The autonomy of civil society and the interfaces with the State and the pharmaceutical industry are often highlighted as a hallmark. This is part of the frequent discussions related to identity of AIDS NGOs during the ENONG conferences. My impression is that the AIDS NGOs are more integrative in their approach than exclusive, and that they prefer partnership over confrontation. It is also possible to see in this approach a strategy of “infiltration” of the State by the social movements (Nunn 2009:45). Also, with regard to vaccine and drug trials, there is more of an attempt to “intervene” and take over the drug trials on the part of the NGOs than a confrontative strategy (Oliveira et al. 2001). This is controversial in various ways, for instance because it is the main interest for the gay movement, but not always for the transvestites, and even less so for IDUs and other identity NGOs. Even among the gay actors there are controversies concerning which strategies to put forward regarding sexual politics. The future of the social AIDS movement depends on how the epidemic unfolds, the politics of the upcoming government, and what follows after the NGO-ization and professionalization of civil society. External and internal forces are influencing this pace and it is difficult to predict which actors, discourses, practices, and institutions that will govern.

References

- Altman, D.** (1999) Globalization, Political Economy, and HIV/AIDS. *Theory and Society* 28:559–84.
- Altman, D.** (2008) State Fragility, Human Security and HIV. *The Politics of AIDS. Globalization, the State and Civil Society*. Basingstoke: Palgrave/Macmillan.
- Alvarez, S.** (2009) Beyond NGO-ization? Reflections from Latin America. *Development* 52:2, pp. 175–184.

- Alvarez, S., E. Dagnino and A. Escobar** (1998) *Cultures of Politics, Politics of Cultures: Re-visioning Latin American Social Movements*. Boulder, Colorado: Westview.
- Avritzer, L.** (2002) *Democracy and the Public Space in Latin America*. Princeton: Princeton University Press.
- Barnett, T. and A. W. Whiteside** (2002) *AIDS in the Twenty-first Century: Disease and Globalization*. New York: Palgrave/Macmillan.
- Bastos, C.** (1999) *Global Responses to AIDS. Science in Emergency*. Bloomington: Indiana University Press.
- Beck, U.** (1992) *Risk Society. Towards a New Modernity*. London: Sage Publications.
- Biehl, J.** (2007) *Will to Live. AIDS Therapies and the Politics of Survival*. Princeton: Princeton University Press.
- Câmara da Silva, C. L.** (1998) ONGs/Aids, intervenções, sociais e novos laços de solidariedade social. *Cad. Saúde Pública*. 14 (Sup. 2):129–139.
- Camargo Jr. K. R.**(1994) *As ciências da AIDS & AIDS das ciências: O discurso médico na construção da AIDS*. Rio de Janeiro: ABIA/IMS/Relume-Dumará.
- Castells, M.** (1996) *The Rise of the Network Society: The Information Age – Economy, Society and Culture*. Vol. 1. Cambridge, MA: Blackwell.
- Castro, M. G.** (2001) Engendering Powers in Neoliberal Times: Reflections from the Left on Feminisms and Feminisms'. *Latin American Perspectives* 28:6, pp. 17–37.
- Chaves, G., C. M. F. Viera and R. Reis** (2008) Access to Medicines and Intellectual Property in Brazil: Reflections and Strategies of Civil Society. *SUR. International Journal on Human Rights*. vol. 5, no 8, pp. 163–189.
- Dagnino, E.** (2002) Civil Society and Public Sphere in Brazil. Limits and Possibilities. Paper prepared at the ISTR Fifth International Conference, Cape Town, South Africa, July 7–10.
- England, R.** (2008) The Writing is on the Wall for UNAIDS. *British Medical Journal*. 336, p. 1072.
- Epstein, S.** (1996) *Impure Science: AIDS, Activism and the Politics of Knowledge*. Berkeley: University of California Press.
- Epstein, S.** (2005) AIDS Activism and State Policies in the United States. *No Name Fever. AIDS in the Age of Globalization*. Lund: Studentlitteratur, pp. 167–191.
- Follér, M-L** (2005) Civil Society and HIV/AIDS in Brazil. The emergence of an AIDS policy. *No Name Fever. AIDS in the Age of Globalization*. Studentlitteratur: Lund, pp. 193–226.

Follér, M-L and H. Thörn (2005) AIDS in the Age of Globalization – an introduction. *No Name Fever. AIDS in the Age of Globalization*. Lund: Studentlitteratur.

Follér, M-L and H. Thörn (2008) Introduction: The Politics of AIDS. *The Politics of AIDS. Globalization, the State and Civil Society*. Basingstoke: Palgrave/Macmillan.

Fonseca M. da, E., J. Ribeiro M., N. Bertoni and F. I. Bastos (2006) Syringe Exchange Program in Brazil: Preliminary Assessment of 45 Programs. *Cadernos de Saúde Pública* vol. 22, no 4, pp. 761–770.

Fourie, P. (2006) *The Political Management of HIV and AIDS in South Africa. One Burden too Many?* Basingstoke: Palgrave/Macmillan.

Fourie, P. (2007) The Relationship between the AIDS Pandemic and State Fragility. *Global Change, Peace & Security*, Volume 19 (3):281–300.

Galvão, J. (1997) As respostas das organizações não-governamentais brasileiras frente à epidemia de HIV/AIDS. *Políticas, Instituições e AIDS. Enfrentando a Epidemia no Brasil*.

Galvão, J. (2000) *AIDS no Brasil. A agenda de construção de uma epidemia*. Rio de Janeiro: ABIA editora 34.

Galvão, J. (2002) A política brasileira de distribuição e produção de medicamentos anti-retrovirais: privilégio ou um direito? *Cad. Saúde Pública*. 18 (1):213–219.

Grangeiro, A., L. Laurindo da Silva and P. R. Teixeira (2009) Resposta à aids no Brasil: contribuições dos movimentos sociais e da reforma sanitária. *Rev Panam Salud Publica*. 26(1):87–94.

Haraway, D. (1988) Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies*. Vol 14, no. 3, pp. 575–599.

Hein, W., S. Bartsch, and L. Kohlmorgen (2007) Introduction: Globalization, HIV/AIDS and the Rise of Global Health Governance. *Global Health Governance and the Fight Against HIV/AIDS*. W. Hein, S. Bartsch and L. Kohlmorgen (eds.). Hampshire: Palgrave/Macmillan, pp. 1–17.

Kulick, D. (1998) *Travesti: Sex, Gender and Culture among Brazilian Transgendered Prostitutes*. Chicago: University of Chicago Press.

Kulick, D. and C. Klein (2010) Escândalo: A política da vergonha em meio às travestis brasileiras. *Anales* no. 13. (this volume).

Landim, L. (ed.) (1988) Sem fins lucrativos: as organizações não-governamentais no Brasil. *Cadernos do ISER*, Rio de Janeiro, no. 20.

- Lieberman**, E. S. (2009) *Boundaries of Contagion. How Ethnic Politics Have Shaped Government Responses to AIDS*. Princeton: Princeton University Press.
- Lindner**, L. (2005) ENONG. Encontro Nacional de ONG/Aids. Construção de sonhos e lutas. www.enong.org.br.
- Mann**, J., D. **Tarantola** and T. **Netter** (1992) *AIDS in the World*. Cambridge, MA: Harvard University Press.
- Marques**, M. C. da Costa (2003) *A história de uma epidemia moderna. A emergência política da AIDS/HIV no Brasil*. São Carlos: RiMa/Eduem.
- Mello e Souza**, A. (2007) "Defying Globalization: Effective Self-Reliance in Brazil." *The Global Politics of AIDS*. Paul G. Harris and Patricia D. Siplon (eds.). Boulder: Lynne Rienner Publisher.
- Mendonca**, P. (2004) Decentralization of Social Policies, State and Civil Society Relationships in Brazil: Towards Synergy? Conference paper presented at Toronto, Canada.
<http://www.istr.org/conferences/toronto/workingpapers/mendonca.patricia.pdf>
- Mistry**, N. (2008) HIV Exclusion does not Mitigate Risk. *Lancet Infectious Diseases*. Vol. 8, no. 3, pp. 147–148.
- Nattrass**, N. (2007) *Mortal Combat. AIDS Denialism and the Fight for Antiretrovirals in South Africa*. Pietermaritzburg: KwaZulu-Natal Press.
- Nunn**, A. (2009) *The Politics and History of AIDS Treatment in Brazil*. New York: Springer.
- Oliveira**, M. A., E. M. **dos Santos** and J. M. C. **Mello** (2001) AIDS, ativismo e regulação de ensaios clínicos no Brasil: o Protocolo 028. *Cadernos de Saúde Pública* vol. 17:4, pp. 863–875.
- Oliveira**, R. M. R. (2006) Gender, Human Rights and Socioeconomic Impact of AIDS in Brazil. *Revista de Saúde Pública*. Vol. 40, supplement.
- Parker**, R. G. (1991) *Bodies, Pleasure and Passions. Sexual Culture in Contemporary Brazil*. Boston: Beacon Press.
- Parker**, R. G. (1994) *A construção da solidariedade: AIDS, sexualidade e política no Brasil*. Rio de Janeiro: ABIA/IMS_UERJ/Relume-Dumará.
- Parker**, R. G. (1997) Introdução. *Políticas, Instituições e AIDS. Enfrentando a epidemia no Brasil*. Rio de Janeiro: Jorge Zahar Editor/ABIA, pp. 7–16.
- Parker**, R. G. and P. **Aggleton** (2003) HIV and AIDS-Related Stigma and Discrimination: a Conceptual Framework and Implications for Action. *Social Science and Medicine* 57:13–24.
- Scholte**, J. A. (2004) Globalization and Governance: From Statism to Polycentrism. In *CSGR Working Paper* No. 130/04.

Sell, S. K. (2004) The Quest for Global Governance in Intellectual Property and Public Health: Structural, Discursive, and Institutional Dimensions. *Temple Law Review* vol. 77, pp. 363–400.

Terto, V. Jr. (1999) Seropositivity, Homosexuality and Identity Politics in Brazil. *Culture, Health & Sexuality*. Vol. 1, no. 4, pp. 329–346.

Terto, V. Jr. and **J. García** (2008) Mechanisms of Representation and Coordination of the Brazilian AIDS Responses: A Perspective from Civil Society. *The Politics of AIDS. Globalization, the State and Civil Society*. Basingstoke: Palgrave/Macmillan.

UNAIDS (2008) *Report on the Global AIDS Epidemics*. Geneva: UNAIDS/WHO.

Valle, C. G. O. (2000) *The Making of People Living with HIV and AIDS: Identities, Illness and Social Organization in Rio de Janeiro, Brazil*. Doctoral Dissertation. Department of Anthropology. University College London.

Whiteside, A. (2009) "Is AIDS Exceptional?" *Heard. Aids 2031 Working Paper No. 25*. www.aids2031.org/pdfs/aids%20exceptionalism_paper25.pdf

Wogart, J. P. (2007) From Conflict over Compromise to Cooperation? Big Pharma, the HIV/AIDS Crisis and the Rise of Countervailing Power in the South. *Global Health Governance and the Fight Against HIV/AIDS*. W. Hein, S. Bartsch and L. Kohlmorgen (eds.). Hampshire: Palgrave/Macmillan, pp. 67–91.

Annex 1

ENONG I	Belo Horizonte	14–16 July 1989	14 organizations
* The creation of a solidarity network with influences from Montreal			
ENONG II	Porto Alegre	13–15 October 1989	38 organizations
* Solidarity as a slogan and guiding the actions			
ENONG III	Santos	20–22 April 1990	43 organizations
* Confrontations between different visions of the social movement – the idea of creating a network is buried			
ENONG IV	São Paulo	1–5 November 1991	43 organizations
* The health situation in the country is the impulse for new meetings of AIDS NGOs			
ENONG V	Fortaleza	8–13 November 1992	87 organizations
* ENONG wins conference format, is professionalized, and discusses the possibility to seek international loans from the World Bank			
ENONG VI	Vitória	21–24 April 1994	103 organizations
* Representation and financing are the running theme of the discussions			
ENONG VII	Salvador	13–16 April 1995	120 organizations
* Projects, projects, projects			
ENONG VIII	São Paulo	3–7 July 1996	103 organizations
* For the first time a minister participates at an ENONG meeting			
ENONG IX	Brasília	19–23 April 1997	
* The president of the Republic receives activists from AIDS II			
ENONG X	Belo Horizonte	1999	
* The last ENONG conference during the century			
ENONG XI	Recife	2001	
* Protests in front of the American embassy mark the meeting			
ENONG XII	São Paulo	15–18 June 2003	273 organizations
* Activism, social control, and discussions with the government			
ENONG XIII	Curitiba	3–7 September 2005	
* Challenges for activism for the future			
ENONG XIV	Goías		Cancelled
ENONG XV	Rio de Janeiro	November 2009	350 organizations
* Activism and public politics on HIV/AIDS			