



# HIV/AIDS AND THE EXPERIENCE OF A CANADIAN NGO AND ANOTHER BRAZILIAN

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## **ABSTRACT**

People living with HIV/AIDS (PHA) have been facing many difficulties in their lives because they are discriminated in various contexts, such as family, community, and work. Currently, AIDS Non-Governmental Organizations (AIDS/NGOs) have become increasingly important because, beyond providing traditional social support, they also offer an environment where PHA may openly express and share not only their experiences with HIV/AIDS, but they can change their personal and professional projects. We analyzed historical documents, in-depth interviews, and questionnaires answered by community members within two AIDS/NGOs, one in London, Ontario, Canada (NGO-Ca) and another in Greater Sao Paulo, Brazil (NGO-Br). In this article, some pathways of political participation, which are relevant to both communities, are discussed. Surely, this may contribute to the decreasing of stigma and discrimination related to HIV/AIDS: compassion and altruism as a bridge to political participation, effects on activism, and fostering based on solidarity and co-responsibility are also important discussed issues.

## **Keywords**

Acquired immunodeficiency syndrome, Stigma, Non-governmental Organization, Political participation, People Living with HIV/AIDS.

## **RESUMO**

As pessoas que vivem com HIV/AIDS (PHA) têm enfrentado muitas dificuldades em suas vidas porque são discriminados em vários contextos sociais. As organizações não governamentais (AIDS/NGOs) que atuam no campo do HIV/AIDS se tornaram um lugar muito importante porque, além de fornecerem suporte material, ofereceram um ambiente onde PHA pudessem expressar e compartilhar suas experiências com o HIV/AIDS. Nós analisamos documentos oficiais, entrevistas em profundidade e semi-dirigidas, e questionários respondidos por participantes de duas AIDS/NGOs, uma em London, Ontário, Canadá (NGO-Ca) e outra na grande São Paulo, Brasil (NGO-Br). Caminhos de construção da participação política são discutidos, destacando o impacto subjetivo do HIV/Aids e a qualidade das interações institucionais como aspectos associados ao processo de enfrentamento do estigma e da discriminação relativos ao HIV/AIDS: compaixão e o altruísmo como elementos de transição para a participação política, fortalecimento do ativismo, e a solidariedade e a co-responsabilidade.

## **Palavras-chave**

HIV/AIDS, Estigma, Organização não Governamental, Participação Política, Pessoas que Vivem com HIV/AIDS (PHA).

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After 20 years, the HIV/AIDS epidemic continues to be a serious problem that affects different segments of the population in both developed and developing countries. Over this time, much progress has been achieved in terms of treatment and prevention. As a result, people who living with HIV/AIDS (PHA) have achieved a much better quality of life. In the developing world context, Brazil, in particular, has shown itself as a model, through both the development of innovative prevention programs and in lowering the cost of HIV/AIDS medications through the production of generic drugs (often in full violation of international patent laws). This has allowed many affected people in Brazil to receive their medications at little or no cost (Galvão, 2005 ; Berkman, et. al, 2005)

At the same time, in many parts of the world, PHA have been suffered greatly because of discrimination and stigma which predominantly affects vulnerable groups within society, and particularly women, who are increasingly affected by the disease. In Canada, for example, the number of women—especially those in the 15-29 age group—acquiring HIV/AIDS is growing disproportionately (Ontario Advisory Committee on HIV/AIDS-OACHA, 2002). In Brazil, between 1980 and 2003, 277.154 HIV/AIDS cases were reported. Were notified in 2003, 5,762 new cases of AIDS and of these, 3,693 in men and 2,069 in women, indicating that the epidemic grows among women

Stigma related to HIV/AIDS is a complex social problem because it associated with other kinds of marginalization. At the same time such marginalization frequently contributes to infection of HIV/AIDS. In Canada, for example, a survey conducted by the Canadian AIDS Society found that most PHA are living in poverty, and 60% report annual income under \$20,000 (Ontario Advisory Committee on HIV/AIDS-OACHA). Furthermore, people are far more vulnerable to discrimination when they live in a country where oppressive forces are at play, resulting in enhanced stigmatization. To resolve this stigmatization, the collective participation of PHA in AIDS- Non-Governmental Organization (AIDS/NGOs), may be a strong contributing factor.

This study focuses on the experience of two AIDS/NGOs which operate in the developed and developing world, respectively. The first NGO is located in the city of London, Ontario, in Canada (NGO-Ca). The second NGO-Br is situated within the Greater Sao Paulo area, in Brazil. Background provided in Table 1 reveals significant differences in the membership in the two groups, concerning condition of life. There are considerable differences as well in the political contexts in which these communities operate. Whereas, Canada is a stable democracy with a long tradition of adherence to civil rights; Brazil only recently emerged from a 20-year-period of military rule; and while democratic consolidation continues, large segments of the population remain disenfranchised (Ribeiro, 1998; Gohn, 1997; Sawaia, 1997; Sader, 1995; Dagnino, 1994).

Through this study, we discuss AIDS/NGO as a place for combating the effects of social discrimination and stigma suffered by PHA. Specifically, we describe the psychosocial aspects operating within these groups (PHA who are engaged with AIDS/NGO) which contribute to the reduction of the stigma and social discrimination experienced by PHA.

Nevertheless, there are distinct differences in how such groups are organized and function.

These differences are not well understood, but could provide clues as to how the activities of



AIDS-NGOs might be strengthened and made more effective. In order to shed more light on the global experiences of AIDS-NGOs, this comparative case study focuses on two groups which operate in the developed and developing world, respectively. The Table 1 provides a comparative socioeconomic profile of the communities involved, revealing significant differences in living standards between them. There are significant differences as well in the political contexts in which these communities operate.

Table 1  
*Socio Economic Profile of communities Involved in the study*

	Canadian Municipality	Brazilian Municipality
Population	325,646	323,116
Persons per residence	2.52	3.85
Infant Mortality/1000 inhabitants	6.1	21.3
Hospital beds	1969	447
Persons with high school or more education (%)**	74	9
Average monthly earnings***	\$2,223.75	\$542.00
Unemployment rate (%)	9.60	15
Municipal budget (Can\$)	435,000,000	111,014,150

Source: Statistics Canada; SEADE; IBGE; EMPLASA

\* All figures are for 1996

\*\*Persons aged 20-64 with high school or more education

\*\*\*Can\$; median for 15 years and over (income includes earnings, gov transfers, and other sources of income)

The research results are limited to the cases under study, by comparing NGO experiences in the two settings. Nevertheless, we hope to shed at least some light on the process by which such groups not only fight for the rights of their participants, but actively work to promote an enhanced sense of citizenship for vulnerable groups living in quite distinct sociocultural and political contexts.

We expect as well that this research will provide valuable lessons to AIDS-NGOs in developing areas which are struggling to meet the needs of their constituencies. In addition, we expect the study will promote new research on this phenomenon, perhaps involving larger numbers of groups in different national contexts.

### ***HIV/AIDS- related stigma-reduction approaches***

In the very beginning of the HIV/AIDS epidemic, discrimination and stigma have been associated with PHA (United Nations Programme on HIV/Aids, 2005; UNAIDS, 1999). Based on Goffman's Stigma (Goffman, 1988), the stigmatization to be an underestimate of social and

cultural relations. Moreover, it suggests that we must understand stigmatization and social discrimination within the context of power relations and domination.

Thus, the more obvious manifestation of stigma associated with HIV/AIDS may reveal masked social and cultural relationships. In addition, overcoming the stigma associated with HIV/AIDS often marks the beginning of much deeper social transformations. Therefore, it represents just the top of the iceberg revealing a small fraction of the visible elements of a culture deeply rooted in conservative moral values, expressed through a lack of solidarity and a progressive increase in individualism.

Indeed, the stigma and discrimination associated with HIV/AIDS, and its resulting social exclusion, have a long history. It is connected with other social exclusion mechanisms that affect PHA, such as poverty, gender discrimination, sexuality, race, and ethnicity (Parker & Aggleton, 2002).

This social discrimination and stigmatization leads to several consequences for PHA, including: unemployment, the disintegration of social relationships, and negative public labeling. From this exclusionary framework, it becomes clear that social vulnerability is one factor that may expose far too many people to HIV. At the same time, it may also suggest some viable pathways to confront it (Ayres et al. 2003; Gostin & Mann, 1999). To strengthen human and civil rights, for example, becomes an important strategy in the reduction of the stigma and discrimination connected with HIV/AIDS. The fight to achieve and retain human rights contributes to PHA realization of their citizenship; that is, they strive to exist with dignity, autonomy and better quality of life.

### **The paths to build social identities and the process of political participation in the AIDS-NGOs**

Since the beginning of HIV/AIDS epidemic, AIDS-NGOs have been playing an important role in giving material and social-emotional support to PHA. As such, along with providing concrete assistance to HIV/AIDS patients and their families, these groups have focused on building and strengthening the rights of patients; including their rights of citizenship (Parker, 1994; Altman, 1995; Camara & Lima, 2000).

In Brazil, the HIV/AIDS movement originates from the broader social movements context. In the 1980s, social movements used to work as a setting where people could fight for improvements in their lives, such as urban infrastructure, and sharing situations of social oppression, mainly gender, race and sexuality. In this way, the NGO setting promoted personal development and enhanced citizenship.

Furthermore, Castells (2001) observed that we live in an increasingly high-tech society, which expresses the new capitalism as bringing about both hope and fear. Besides, this author perceived the efforts from different “social actors” as having an increased willingness to transform their society on a grassroots level. Moreover, their struggle to drive their own lives and their social environments may in fact lead to a conflict where new social identities are necessarily constructed.

In fact, Castells (2001) proposed three ways for building these new social identities: 1- *Legitimate Identity*: some institutions reinforce the established social standard and traditional moral values. 2- *Resistant Identity*: some “social actors”, who are suffering with social exclusion, develop strategies in opposition to socially dominant institutions. 3- *Project's Identity*: these “social actors” propose effective alternatives to transform social structure, that is, this



“social actor” acts beyond the criticism of dominant institutions. For instance, the feminism movement envisioned and, in fact, created alternative methods of social and economic production and reproduction; that is, this movement arose as a criticism to traditional patriarchal structures.

In this way, the AIDS-NGOs may create new meanings for the suffering shared by PHA, as well as emphasize the psychosocial dimensions related to the stigmatization and discrimination process. These institutions cater to people who are identified with social oppression; and through their political participation, the construction of a common identity becomes far stronger. Therefore, the comprehension of political participation, as related to group identity, may help us to develop and consolidate changes that started from grassroots movements, NGOs and related social actions.

Montero (2003), in reference to Zimerman & Rapaport (1988), discusses psychological strengthening as a connecting point between personal development and the willingness to act in the public space. This, in turn, demonstrates the importance of political participation because effectiveness of public policies is connected with a subjective dimension; as such people engage in political participation based on whether it will be effective in transforming the quotidian expectation of themselves in terms of personal development (Sawaia, 2002; Castr-Silva & Hewitt, 2004). Other studies have focused on strengthening in singular contexts. Silva (2002), for example, has researched AIDS-NGO in Rio de Janeiro (“Grupo Pela Vidda”). Employing Habermasian theory, she interprets this setting as improving group participants’ communication capacity and, as a result, their active involvement with both their community and other PHA.

### **Research Methods**

Data for this case analysis were collected using a variety of methods. During the initial phase of the project, background information on the two AIDS-NGOs was obtained from unpublished and published materials produced by each group. This information was supplemented by data obtained from the leadership of these groups using semi-structured interviews. Data on the background, attitudes, and behaviours of group members were requested using a closed self-administered questionnaire distributed to all active participants. The numbers of respondents were  $n=23$  for NGO-Br, and  $n=34$  for NGO-Ca. Once the questionnaires were returned, these quantitative data were supplemented with information obtained from a smaller sample of group members ( $n=8$  for NGO-Br and  $n=5$  for NGO-Ca) using semi-structured interviews. Respondents were questioned about their experience of living with HIV/AIDS, levels and quality of social interaction within their groups and the impact these groups had on their lives. Ethics approval for the Canadian and Brazilian sites was obtained by the research ethics offices at the University of Western Ontario and the Cruzeiro do Sul University, respectively.

### **Descriptions of the Canadian and Brazilian NGOs**

#### *The NGO-Ca*

The NGO-Ca, located in London region, has its origin in 1984 by a small group of predominantly middle-class activists associated with the gay rights movement in Ontario. The first action was to combat the fear, ignorance and the lack of medical support which characterized the initial onset of the HIV/AIDS epidemic in Canada.

This has been supported by a number of umbrella organizations, including the AIDS Network and the Canadian AIDS Society. Furthermore, it has also received funding from government, other local NGOs, and the private sector. This funding has contributed to develop and maintain programs which directly support AIDS patients and their families. Moreover, the NGO-Ca activities are addressed to education and advocacy, as well. Its activities are guided from strategies developed by the Ontario Advisory Committee on HIV/AIDS (Ontario Advisory Committee on HIV/Aids, 2002). One of the Committee's goals is working to enhance awareness of negative social factors; such as discrimination, poverty, sexual discrimination, social isolation, and sexual violence – all of which can affect access to care and potentially render individuals more vulnerable to the disease itself.

#### *The NGO-Br*

The NGO-Br is situated within the Greater Sao Paulo region. Its origins may be traced to 1997 when, as public service, they assisted groups of HIV/AIDS patients from a range of social backgrounds registered at the local ambulatory clinic. It was formally established in 1999. Its intention was to create a space to share experiences, fears, doubts, concerns and perspectives associated with their HIV/AIDS status. Its strategies include: group's inception, the delivery of condoms, (HIV/AIDS) and lectures about HIV/AIDS prevention, including Sexually Transmitted Disease (STD).

Since its origins, this group has been broadly concerned with citizenship and human rights advocacy, as expressed in NGO-Br's mission statement: "The mission of the NGO-Br is to promote quality of life, citizenship, human rights and cultural and socioeconomic inclusion for the benefit of HIV/AIDS carriers in the municipality." This has been possible through the publication of educational materials and workshops informing HIV/AIDS patients of their rights.

#### *The Background of the NGO-Ca and NGO-Br Members: Worlds Apart?*

Given the disparate sociocultural and political environments in which they operate, one might expect significant differences in the background characteristics of the members of the two groups (Table 2). On the contrary, in many cases, remarkable similarities exist. For example, while homosexuals form the core membership of NGO-Ca (for historical reasons, as mentioned earlier), in NGO-Br most members are heterosexual. In both groups roughly half the members are married. Also, while members of NGO-Br are typically younger than their Canadian counterparts, their levels of education are not altogether dissimilar. Both age and education levels in the two groups may contribute to explain differences in employment status. While a large number of NGO-Br members are currently working (compared to the larger percentage of retired persons in NGO-Ca), a greater segment is also unemployed.



Table 2  
*Membership Background (in percentages)*

	ONG-Ca	ONG-Br
Members under 40 years old	41.2	91.3
Respondents who identified as homosexual males	38.2	8.7
Member has lived in the local area for more than 5 years	79.4	56.5
Male respondents	50	39.1
No religious affiliation	55.9	56.5
Married or have a partner	44.1	47.8
Completed high school	45.5	17.4
University - incomplete	33.4	26.1
University - completed or higher	15.2	13
Working	48.5	65.2
Unemployed	3	13

### **Comparing the process of political participation in Brazil and Canada**

The process of political participation in the AIDS/NGOs appears to be related to two factors: 1 – The intensity of the psychological impact resulting from HIV/AIDS stigma and social discrimination; 2 – The quality of the dynamic relationships between participants and social institutions. We employ three different empirical indicators to illustrate the various avenues leading towards political participation: - The relationship between participants and the institution; - Perceptions about human rights; - The relationship with the community and public services.

#### **1- Compassion and altruism as a bridge to political participation.**

The first association many participants had with HIV/AIDS was negative in nature, often tied to illness and death. This association was reinforced out of the fear that the disease could result in leave very clear physical symptoms, such as dramatic weight loss, including side effects from medications. These indications act as a negative mark (Goffman, 1988) which may encourage shame and embarrassment.

The increased suffering and felt stigma, as defined by Maluwa, Aggleton and Parker, (2002), among participants create greater distance and deficiencies in communication and understanding between themselves and those around them; this can damage the social bonds as shared frameworks break down (Parker & Aggleton, 2002). One NGO-Br participant relates:

*Difficult, it is difficult. The information is there, but nobody believes in it if it doesn't happen with them. So, I think the worst thing is not the disease itself, but people's prejudice. How can you change people's minds if not even the community agents can do it?... (Vanessa, HIV positive).*

Mary from NGO-Ca similarly relates:

*My church is against HIV and homosexuality so I don't tell that I volunteer. But my husband always makes sure I have a ride wherever I need to go volunteer my time and makes sure our car is clean in case I need to give anyone else a ride. The words HIV AIDS scare people. If they next to someone they think they will catch it, we need to let people know they wont, and don't need to be afraid (Mary, HIV negative).*

This kind of report reinforces the idea that HIV/AIDS is within the exclusive domain of the “other,” clearly defined and distanced through the use of artificial social boundaries. PHA are prematurely marked for death, thus encountering even greater degrees of marginalization. Moreover, Mary understands discrimination as a reaction from people who do not appreciate her situation and associate it with uncomfortable, mysterious and fearful elements. She compared the treatment of PHA in her own community to that of foreign people. That is, they condemn that which they are unfamiliar with:

*People in Canada don't like people talking other native tongues, because we always think they're talking about us. [HIV/AIDS] similar to analogy of foreign people. We don't understand them so we condemn them (Mary, HIV negative).*

The suffering caused by discrimination marked the beginning of PHA participation in both Canadian and Brazilian NGOs because, among other needs, they wanted to establish an atmosphere where HIV/AIDS life experiences might be shared (Castro-Silva & Hewitt, 2004). The desire to exchange personal experiences is significant in both organizations, clearly indicating the NGO as a special place where HIV/AIDS experiences are shared, helping to alleviate some of their suffering (Table 3). Furthermore, most of them also desired to be more informed regarding their social rights and new medical advances, including potential side effects (Table 3). (This finding is confirmed by Câmara, (2000); Galvão, (2000); and Silva, (2002).

Furthermore, PHA looked for NGO's support with the desire to help other PHA demonstrating that altruism is a powerful motivation for them (table 3). This kind of result is found by Ferreira, (1999); Stewart & Weisntein, (1997), Ramirez-Valles & Brown, (2003). As a result, Selma claims:

*It can take a long time for you to get sick if you know how to take the medication; if you know how to be happy with what you have. From the moment that you are helping a person, this also brings a very positive return. So, I think that it is a thing that encompasses a lot, how could I put it..If you give what made you suffer, you pass on to others, then you strengthen yourself through it. (Selma, HIV positive) .*





Table 3  
*Motivations for Participation (in percentages)\**

	NGO-Ca	NGO-Br
Respondent was involved in community action groups prior to becoming involved in NGO	23.5	65.2
As a member, respondent participates in group activities/functions at least once a month	38.2	60.9
Respondent has been a volunteer in organization for 2 years of less	38.2	43.5
Respondent joined the organization because of their desire to help others	100	78.3
Respondent joined group because of their desire to have greater contact with people who live with HIV/AIDS	79.4	82.6
Respondent joined group because of their desire to become (much) more politically active	23.5	56.5

\*Respondents indicating “agree” or “strongly agree”

In general, participants expressed a profound disappointment related to human rights because they understand that, while human rights are valuable to all, they are mainly accessible to a small and often non-afflicted population. For example, most of NGO-Br interviewees felt that human rights improve the experience of incarcerated people. This example offers evidence supporting the notion that the exercise and application of human rights are fundamentally impregnated with prejudices which may only increase stigma. As Eloisa states:

*Human Rights, is so complicated. Generally, human rights are talked about, you remember of the prisoner who is in jail and has to be defended for a lot of things. But what made this guy to commit an assault, to rob, to commit a crime, to murder? What does human rights mean to children who are now in 5<sup>th</sup> grade, if there is no employment even for the ones that already have an university degree? (Eloisa, HIV positive).*

The intensification of social exclusion damages the exercise of human rights and reinforces the perception that the political participation is illegitimate. Besides, the perception of the PHA about their relationship with public space becomes undefined expressed in terms of disconnection. As a result the PHA feel involved in a non-productive patient-client role (Paiva, 2002), establishing a relationship with NGOs based on consumerism; that is, PHA see NGOs as a place where they obtain practical, yet ultimately, temporary solutions without promoting any significant changes in the strengthening of their citizenship. We may conclude that the kind of

identity built, based on Castell's types, is a combination of both legitimate identity and resistance identity.

## 2- Effects on PHA activism

Participants appear, based on our examination of two AIDS/NGOs, more willing to exchange dialogue and share personal experiences with other participants, as well as with the larger community (Table 4). As a result, they demonstrate more self-confidence, as well as a greater sense of belonging. In spite of this positive development, however, it is possible that they could develop strong feelings of attachment and dependency towards the institution. Furthermore, participants perceive their participation at NGOs as strengthening their new life project, both in a personal and professional capacity; including the possibility of developing other skills through their volunteering experiences. As Antunes from Brazil states:

*Inside of the movement is where it is learned how to better deal with AIDS, how to better deal with myself. I learned the importance of taking the medication at the proper time. [...] Today I do things within the AIDS world, directed to certain people, and this gives me satisfaction. I do it without any financial gain, but, on the other hand, I have other gains, maybe greater than money. I make a great circle of friends; I have a great circle of friends, I know I am useful for many people (Antunes, HIV positive).*

Statements from Brian from NGO-Ca:

*My citizenship status has changed very dramatically... A couple of years ago my life was going in a very different direction. Before, I was an alcoholic-addict. Since becoming involved with NGO-Ca, I have now earned the right to carry the label of education-outreach worker. I have gained respect of the community...(Brian, Hepatitis, C)*

From the institutional dynamic, the process of psychosocial strengthening occurs differently between the two countries. In the NGO-Br, political participation is part of a collective process marked by the emphasis given to the exchange of experiences among the PHA and the efforts of the collective construction of the organization. As Vanessa relates:

*It is like a situation of gossipers, you know (laughs). Wanting to know about someone else's life. I like to know how people live, the one who is a carrier is dealing with this situation and the one that doesn't know is interested in knowing the subject. It is good to interact with people that are HIV positive and people that don't know as well, because you put the stuff together and see what can be useful (Vanessa, HIV positive).*

While in NGO-Ca, political participation tends toward an individual empowerment, leading subsequent involvement with others, their families and communities. As Brian states:

*When I started, I was still living in a recovery home. Through the staff, I began working at the reception and learning office skills... The staff at the NGO-Ca was supporting me when I needed it.... Therefore NGO-Ca is there for the transition. No just for client support but also for services all around the client, ya know, the client's family and stuff (Brian, Hepatitis C).*

For participants of NGO-Br, the association between HIV/AIDS and human rights, however, revealed a possibility for changing this scenario of helplessness and indignation (Table 4). They talked with more propriety and a greater sense of citizenship. This feeling was reinforced, for example, by the achievements related to the free access to treatment and medication (Galvão, 2005; Berkman et al., 2005). Furthermore, participants perceived that such achievement came as a result of various social movements. As Antunes relates:

*In this sense I reconsider a little bit my opinion, because today through human rights [...] I have free medication, I treat my HIV virus; I treat it with medication, with professionals, with doctors,*



*all for free. We fought a lot for this; we had a lot of militancy to get to this. We had a war with the police, a war with the government, in order to have these benefits, these gains, here today, for free. When I say, us, I refer to us NGOs, but without the human rights we would not have achieved this. In this part, we have to give them their due, yes!(Antunes, HIV positive).*

In the NGO-Ca, the reference to human rights occurs from the perspective of maintaining a status quo that is already established, for example, the guarantee of life conditions and appropriate treatment for all that live with HIV/AIDS. Their empowerment as individuals is more evident. For example, the NGO is a setting where people receive information about their rights and, as a result, feel stronger. Brian states:

*... when I decided to make changes in my life, and I went into a rehabilitation home for a year, knowing that I had the right to ask social services for help. I had the right to receive funding, the right for housing, and the right to receive support out there...(Brian, Hepatitis C)*

And,

*A lot of things. Specifically, the right to privacy, the right to an opinion, the right to be informed (Son, HIV negative).*

These participants are quite engaged with public policies. Furthermore, they are more likely to criticize the policies. However, they also demonstrated great resistance and distrust towards the government, expressed through feelings of antagonism and resentment, especially the attitude of NGO-Br towards the assistance offered by the region's public service. As a result, we see that there has been built an identity of resistance, as suggested by Castells (2001).

### **3- Fostering based on solidarity and co-responsibility.**

The interviewees noticed that there is a strong connection between PHA and other social minorities related to stigma and discrimination because both groups suffer the consequences from social exclusion, among them the vulnerability to the HIV/AIDS. AIDS/NGOs participants expressed a solidarity based on their profound identification with people positively infected with HIV because they perceived themselves as vulnerable to infection. In this way, the identification seems to be an important aspect in understanding the motivation for the involvement with social movements (Ramirez-Valles, 2003). As Sonia states:

*...a life experience, like this, is cool! I think that for coming from a working class, with all the difficulties, it is a journey that I look back and feel much fulfilled. I started to work here in this municipality, in the health area....assisting career. There is a thing that always hit me very hard...it is that I am able to easily do a retrospective of my life and see that I experienced many situations where I could have gotten in contact with the HIV virus..I had boyfriends, situations when I didn't use condoms, so...(Sonia, HIV negative).\*\*\**

There is an understanding that to cope with the epidemic goes beyond individual initiative, that is, it is a fight that is collectively built. In this sense, the politicization of HIV/AIDS impact has the meaning of building strategies that promote better life conditions for all, for example, improving the public service assistance or creating affirmative actions regarding people living with HIV/AIDS, and perceiving them as co-responsible for the effectiveness of public policies that depend on their participation in different public places.

In this way, the feelings of guilt and isolation of the participants may be transformed into a positive perspective through the sharing of life experiences, for example, by activities that can give information to different community groups about HIV/AIDS prevention. Furthermore, AIDS-NGOs became a space much more legitimately connected and respected within the

community (Table 4). In addition, political actions have increased because this PHA perceived that the process of overcoming discrimination and stigma resulted from this collective experience with NGOs. States Mary:

*Their programs here at the NGO-Ca are very important. They educate people about what AIDS really is, and how you can get it. The most important thing is that these programs help people, in general, to break down barriers (Mary, HIV negative).*

They feel that it is in the collective fight that they will achieve better life conditions for all, that is, the social interaction in the NGO is a space where they can outline and develop their hopes for a more fraternal and healthy community in full enjoyment of its civil and political rights (Table 4). Furthermore, Sousa Santos (2000) affirms that human rights are built from cultural politics, with a respect for different people and cultures. Therefore, the Human Rights Declaration should be accessed by all and adapted to conform to specific social and cultural contexts. This is clearly revealed in the statement made by Sonia:

*...(long pause) human rights... I think that they are life's essential and basic conditions...This, unfortunately, is not respected. We know that there are people living in precarious conditions without access to the minimal conditions. I, as a citizen, I find myself thinking about this a lot. I say that each one of us is a bit responsible for every child that is born and for everyone who is not studying... It is the duty of each one of us, to collaborate, to do... And to hold this part of this responsibility..(Sonia, HIV negative).*

This point of view exemplifies the building process of the identity of project, as suggested by Castells (2001), because they tend to criticize the quality of the public service. However, it is a constructive criticism - improving a dialogue between PHA, the public service and the larger community as well.



Table 4  
*Changes As a Result of Group Membership (in percentages)\**

	<b>NGO- Ca</b>	<b>NGO-Br</b>
Respondent felt more empowered to act in defense of their political/ civil rights as a result of their involvement with NGO	<b>52.9</b>	<b>73.9</b>
Respondent felt more motivated to work with others in the community as a result of their NGO involvement	<b>61.8</b>	<b>87</b>
Respondent felt more motivated to become involved in other political activist causes as a result of their NGO involvement	<b>32.4</b>	<b>56.5</b>
Since becoming involved with the NGO, the respondent's involvement with other community action groups has increased	<b>35.3</b>	<b>39.1</b>
In the respondent's opinion, since they have become involved with the NGO, respect for the NGO within the community has been enhanced	<b>29.4</b>	<b>78.3</b>
In the respondent's opinion, since they have become involved with the NGO, community participation in the NGO has been enhanced	<b>20.6</b>	<b>69.6</b>

\*Respondents indicating “agree” or “strongly agree”

### **Conclusion**

The results of this study show that the political participation of PHA in both NGOs contributes to make them stronger when coping with discrimination and stigmatization. This is possible through a process of politicization made by various forms of participation which are associated with the capacity of questioning their personal values triggered by the experiences of discrimination and stigmatization related to AIDS/HIV.

To participants of NGO-Br the HIV/AIDS impact is strong because they feel themselves abandoned and feel no respect as individuals and citizens. In this way, the NGO-Br setting represents an important place to access their rights. Furthermore, in there they are able to collectively build these rights. Somewhat, differently, participants of NGO-Ca see the institution as a place where they can access their citizenship status. Therefore, in both NGOs human rights are important tools to overcome HIV/AIDS related stigma.

In addition, we have observed that the process of institutional democratization is a relevant aspect to strengthening personal development and citizenship. In NGO-Br the relationship of power between the participants must be reviewed. In NGO-Ca, incentives for political activism must be reviewed.

The study suggests that the NGOs should develop institutional practices that promote the individuals to the status of citizens. These practices can start right now from the first reception of these PHA by the NGO through projects designated to strengthen his/her self-esteem.

Understanding and welcoming different ways of political participation mean that we must value the psychosocial perspective that allows the strengthening of the process of building up their citizenship because that perspective highlights the social-historical and cultural aspects of the subjective experiences.

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