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The Invisible Citizens' Revolution

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# THE INVISIBLE CITIZENS' REVOLUTION

HIV/AIDS AND CITIZENSHIP IN THE LGBTI COMMUNITY OF QUITO, ECUADOR

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“Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.”

- Susan Sontag, *Illness as Metaphor* (1978)

## ***1. Introduction***

The moment we stepped outside it started to pour. I had been in Quito almost two months and had not seen anything like it up until that day. Rain was an afternoon staple, but now hail stones the size of tennis balls were falling down like small cannonballs. We decided to take a taxi, but before we found one we were already soaking wet. John and I were on our way to meet Alberto, the last informant I would be interviewing during my fieldwork. He was waiting for us in a community center for sex workers and people living with HIV (PLWHA). While the taxi snailed through flooded streets, John joked: “I wish it would rain condoms this hard! We would never have to beg the Ministry again!” John was the receptionist of Equidad, the NGO I had been visiting. A young gay man, warm and outgoing and with a great sense of humor. His joke referred to the shortage of condoms Equidad had been struggling with since the Ministry of Public Health, their supplier, had run out of condoms. He laughed loudly, then continued, twisting his face into a quasi worried expression. “Maybe this is it, the great deluge. We’ll be punished for our sinful behavior.” That joke referred to one of the characterizations of homosexuality as immoral by Ecuador’s religious and conservative groups. In their discourse, however, the divine punishment for immoral behavior is usually HIV/AIDS.

That afternoon was full of bits of evidence that HIV/AIDS and sexuality form a crucial site for the struggle over power, morality and rights. Shortly after, Alberto and I were sitting at a table in the community center. Everyone had gone home, and it was just the two of us drinking tea, trying to warm up by placing our hands on our mugs. Alberto was one of the few people that I met in Quito who was very open about his HIV status, and he had been an outspoken advocate for the expansion and improved protection of rights of PLWHA. He was convinced he thanked his success to being candid about his HIV status, not think twice about being shunned, and having had previous experience in activism as a young man. “Yes, people might cut you out of their lives. They may, no, they definitely will say mean things. That hurts, but you have to continue fighting and get to the decision makers.” When I heard Alberto sound so resolute, it sounded so easy: eyes on the prize and ignore all the rest. But as I had learned in the weeks before, it was not that easy for the majority of the people that I interviewed. They feared their families and friends would cut off ties with them, their employers would fire them, and others in the community would avoid them, leaving them alone in social isolation. They preferred to keep their HIV status a secret.

This is a study about the interplay of stigmatization and exclusion of lesbian, gay, bisexual, transgender and/or intersexual (LGBTI) people living with HIV/AIDS, and it considers ways in

which the LGBTI community in Ecuador challenges discrimination and barriers to care and full social and political inclusion. It is built upon observations of individuals as well as a non-governmental organization (NGO) trying to create a space with more rights and a better position for themselves. Interested in the strategies LGBTI employ to face their adversity, I set out to document how these populations challenge the way they are treated and perceived by health care professionals, politicians, and larger society. Is their resistance effectively diminishing their stigmatization and marginalization? Does it transform them into more fully included citizens? In answering these questions, I consider dimensions of the nature of this resistance, the space where this resistance took place, and a united as well as a more individual form of resistance, the role of organizations like Equidad in this.

My aim is twofold. First of all, I want to expand insights regarding sociopolitical and medical experiences of LGBTI, to contribute to minimizing their vulnerability to discrimination, exclusion and HIV infection. As argued by Padilla and colleagues, the health and wellbeing of LGBTI people can only be guaranteed if their unique needs are acknowledged in the healthcare system (Padilla et al. 2007). Secondly, I seek to deepen our understanding of the functions of citizenship and how its empowering abilities and its limitations directly impact the lives of LGBTI people living with HIV/AIDS in Quito. The notion of citizenship is central to contemporary Ecuadorian politics or plain everyday life. Seven years after Correa brought the concept into sway, citizenship remains a focal point of contention, with key concerns such as participatory democracy, political engagement and the guarantee of human rights as inherent to all citizens. But although every citizen is equally deserving of that citizenship according to state rhetoric, in practice this equality principle seems less strictly adhered to. I examine two interrelated issues: the degree in which members of the LGBTI population and PLWHA enjoy full-fledged, unconditional citizenship, and the possibilities for LGBTI PLWHA to claim rights and effectuate social change for the benefit of their well-being. Citizenship can be understood as a form of membership, of belonging, with only one requirement to be issued a membership card: to be a citizen. However, if there are different tiers of membership, the idea of equal and universal rights is lost.

Accounts of both individual attempts as well as the organizational work to cope with HIV/AIDS and the related social and medical concerns are relevant. My research formed part of operational research for the Aids Fonds led alliance called Bridging the Gaps. Funded by the Dutch Ministry of Foreign Affairs, this program aims to contribute to new insights and more effective health interventions in the HIV/AIDS context in particular local settings as well as on a global

level.<sup>1</sup> The Bridging the Gaps program is especially working on vulnerable populations such as sex workers, injecting drug users and the LGBTI community. Equidad is a local Bridging the Gaps partner in Ecuador, working on LGBTI rights. My relation to this program determined part of my research interest in the workings of civil society organizations and how they influence the lives of those they work for. Because my interest also lies with individual experiences, I have combined an ethnography of an organization with more personal accounts, sketching a layered overview of what happens when individual actions and motives and organizational ones meet.

Equidad was founded fifteen years ago to offer services for LGBTI, particularly focusing on HIV/AIDS related services. Their work consists of research, offering community and health services to everyone across the LGBTI spectrum — among which also HIV/AIDS related services such as prevention activities, testing and counseling — and political participation to ensure that inclusive policies will be implemented and enforced. They have generated spaces of discussion and collaboration with government agencies, and have important alliances with other NGOs working on HIV/AIDS, even though their strategies, politics and public are quite diverging. Among the highlights of their work are a decree against discrimination in the work environment, and the inclusion of an article in the 2008 constitution that criminalizes discrimination based on gender, sexual orientation, or HIV status, among others.

When Equidad started its activities, HIV/AIDS, sexuality, and gender were all but impossible to discuss. Homosexuality had been decriminalized only two years earlier, in 1997, and although LGBTI people no longer risked confinement, their risk at being brutally attacked — physically as well as in the media — or being ostracized from their communities, work places, and even families remained. Discussing sexual or health rights of a group of people who up until recently had been deemed delinquents by the law, and were still deemed delinquents by a large part of society, asked for a careful, strategic approach. Slowly but surely, there is a progressive trend in how sexuality and gender issues are perceived by the majority of Ecuadorians. It is difficult to determine how positive this trend has been in terms of health and overall wellbeing of PLWHA among the LGBTI population. HIV/AIDS, just like sexual orientation and gender identity, remains in many cases a contested, controversial topic related to shame and stigma. Although local partners of the Bridging the Gaps program in Ecuador's urban centers, such as Equidad and fellow NGO Kimirina, have been working very closely with PLWHA and LGBTI populations, there is a hiatus in available data regarding PLWHA's (experiences of) barriers to health care (Corporación Kimirina 2011; UNAIDS 2012b). I set out to gather information to contribute to minimizing this gap. Data

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<sup>1</sup> <http://www.hivgaps.org/>

regarding the specific experiences of LGBTI people living with HIV/AIDS are scarce, and Ecuadorian NGOs working with LGBTI populations and/or people living with HIV/AIDS were gladly anticipating any new data. In agreement with the needs of Equidad and the larger Bridging the Gaps program, the following research question came to guide my research:

- How do people living with HIV/AIDS in the LGBTI community employ their biosocial circumstances to put forward resistant forms of citizenship and subsequently challenge barriers to treatment?

This question encompasses both the experiences of PLWHA in the LGBTI community and their resistance to possible discriminatory behavior, leading to two subquestions:

- What are the Ecuadorian LGBTI community's experiences with stigma and exclusion, and do these affect their access to health and function as barriers to treatment?
- Do LGBTI living with HIV/AIDS organize themselves to put up resistance and claim better lives?

To give meaningful answers to these questions, I will first introduce the reader to Ecuador's current sociopolitical landscape and to the theoretical themes that guided my research. After setting the stage for my ethnographic research with a contextual setting and theoretical outline, I will discuss my methodology with special attention for my research population and ethical considerations. With a topic fraught with so much moral judgment and potentially negative social implications, ethical integrity is highly important, which is why I have included some remarks on how this influenced my research.

In the second chapter I show my findings regarding HIV/AIDS' impact among LGBTI in Ecuador. This chapter deals with the many ways in which LGBTI PLWHA are confronted with stigma and discriminatory attitudes both in and outside the healthcare setting and how that affects their well-being and health. LGBTI people at elevated risk for HIV/AIDS, reflected in comparatively high prevalence rates when contrasted with the general population. I show how these relatively high rates are related to barriers to access to HIV/AIDS treatment and care as experienced in Quito.

The third chapter shows that PLWHA's position in the HIV/AIDS field does not just render them powerless, but that the biosocial features they share with others creates opportunities for them to stand up to challenge their second-degree rank in the citizenship arena. I will show if and how LGBTI living with HIV/AIDS resist dominant power structures in both the political and medical context, and how this helps them — or fails to do so — to claim a better position in which their

sexual, identity and health rights are respected as the Citizens' Revolution with its promise of social transformation unfolds.

In the conclusion, I will summarize how exactly groups of LGBTI living with HIV/AIDS as well as organizations that concern themselves with their faith have utilized the recent political openings in Ecuador to claim and promote inclusion, both in- and outside the medical setting. Did new doors open that PLWHA used to their benefit, or were all doors actually slammed shut?

## **Sexual diversity, HIV/AIDS, stigma and citizenship in Ecuador**

### *Introduction to theoretical themes*

Vulnerable or key populations within the HIV epidemic are LGBTI people, injecting drug users and sex workers. They are considered key populations because the number of PLWHA among these groups is extremely high in comparison to the general population, while only a small percentage of these groups has access to prevention, care, treatment and support services (Bridging the Gaps 2014). In Ecuador, the LGBTI community is hit the hardest. According to UNAIDS, 0.6% of the total Ecuadorian population is infected with HIV, but among MSM, this is 19% (2012). There are no official data of HIV/AIDS infection rates among transgender people due to the high invisibility of this population, but estimates hover around 30% (Equidad, Pan American Health Organization, and Ministry of Public Health 2012). There are no data on women who have sex with women. Populations with elevated risk of acquiring HIV are often already suffering from socially marginalized positions that negatively affect their health, access to health, and health seeking behavior (e.g. Parker & Aggleton 2003; Farmer 2004; Altman et al. 2012; Sullivan et al. 2012). In the traditionally hierarchical context of medical services, health professionals and users are guided by assumptions about social position which direct their conduct during the clinical encounter or prevent a medical encounter from even taking place (Lorentzen 2008). Often, socially disadvantaged groups are barred from health care, not adequately treated or do not seek health care services because they (feel they) are stigmatized, discriminated against or excluded (Cáceres et al. 2008; Smit et al. 2012).

For a thorough understanding of the relationship between HIV/AIDS, sexual orientation, exclusion, and citizenship it is essential to look into health-related stigma. In his classic work on stigma and identity, Erving Goffman (1968) stated that stigma is a powerful tool for social control that can function as a marginalizing force for those who do not fit the societally determined mold of morally agreeable behavior. Stigma's essence is founded on the question of deviance; to be labelled

as diverging from the norm, as “not normal”, compels stigmatized individuals to view themselves and others as discredited or undesirable. Goffman noted that when people are marked as different, it means they are “reduced in our minds from a whole and usual person to a tainted, discounted one” (1968: 3). The stigmatized person is seen as “not quite human”, as substandard, and becomes an easy target of discrimination, resulting in reduced inclusion in society and life possibilities (1968: 5). Arthur Kleinman explains that stigmatization can be related to moral and religious beliefs in which a person is considered sinful or immoral -- displaying “deviant behavior”, in Goffman’s words. Such labels help define the values of the social group by projecting its negative values on the other who is labeled defective (Kleinman 1988). This explains why groups linked to high HIV prevalence, such as LGBTI people, sex workers, and injecting drug users, are stigmatized even if they are not infected; they are associated with immoral activities and/or contemptible identities. Kleinman noted that the stigmatization process usually begins with the community’s response to the person, but eventually the person “comes to expect such reactions, to anticipate them before they occur and even when they don’t occur”. He continues to explain that many people “feel shame, not because of the cultural meaning of illness, but rather in response to the reactions of family and especially health professionals” (1988: 160). This correlates with Goffman’s division of stigma into “felt stigma”, the shame that the supposed deviant feels, and “enacted stigma”, the treatment community members give to the person that deviates from the norm (Goffman 1968; Buseh & Stevens 2006). Throughout my thesis, this enacted stigma or self-stigma will be a recurring theme. Stigmatization based on deviant attributes depends on changing ideas about what is considered “normal” and is guided by dynamic social, political, cultural and economic processes that simultaneously produce and intensify stigma and discrimination. Parker and Aggleton (2003) maintain that it is especially important to think of stigma as a social and cultural phenomenon linked to relations between groups of people. Theorizing stigma — both felt and enacted stigma — in this way highlights its connection to power; stigmatization affects how relations of power and control are (re)produced and is therefore intertwined with social inequality and exclusion. Stigma functions as a gatekeeper of the prevailing social order, at “the intersection of culture, power and difference” (Mahajan et al. 2008: S77). It can be understood as founded upon a complex of common ideas or related attitudes intersubjectively shared by a specific group of persons, which are internalized through socialization or discursive strategies to construct sameness (Bourdieu 1990). This leads to the maintenance of a specific “in-group” on the one hand and respective “out-groups” on the other hand. Sharing certain attitudes or identities results in solidarity with one’s own group as well as the readiness to exclude the others from this constructed collective and to debase

them. Individuals in the “out-group” are set aside, outside the mainstream of society. For those that fall on the wrong side of the boundary, the political and social boundaries separating ‘us’ from ‘them’ based upon a perceived or constructed consequential difference become very real. LGBTI community members have had attacks and forms of institutional violence directed at them. There are high levels of intra-familial violence. Over a third of gay men have been subjected to (physical or mental) violence based on their sexual orientation. Almost one in ten has had to move because of this reason. There have been reports of violence committed in educational institutions, in the workplace, the health setting, by the police, and in terms of access to legal assistance (Equidad, PAHO & Ministry of Public Health 2012).

Numerous sources emphasize that structural factors, such as social stigma, lack of access to health care services, and insufficient sexual health education increase HIV vulnerability among sexual minorities (e.g. Díaz et al. 2000; Parker & Aggleton 2003; Beyrer et al. 2012). Mahajan et al. (2008) and Smit et al. (2012) claim that the stigma LGBTI face may not only result in low turn-out for testing, treatment and care, but also in a downward spiral of identity crises and isolation because of a retraction from social life. This is especially the case in the context of HIV/AIDS, which do not only disproportionately affect traditionally stigmatized or excluded social groups such as LGBTI people, sex workers, and drug users, but carry an extra symbolic value with them, being linked to morally deviant (sexual) behavior (Parker & Aggleton 2003; Díaz et al. 2010). In a society like that of Ecuador where the Catholic church and prevailing machismo ideals are only slowly losing their grip on sexuality and gender issues, such exclusion is especially powerful (López-Vicuña 2004; Salgado 2008) and can hinder health seeking behavior. PLWHA, even more so when they are already branded as socially deviant, are excluded from fully participating in society and denied the health care that they are entitled to as an essential human right.

The link between stigma, exclusion and HIV is also acknowledged in the approach of Bridging the Gaps, whose project in Ecuador focuses on “changing attitudes towards LGBTI people and improving the quality of services they can access” as this “will reduce the HIV risks they face, reduce HIV prevalence, and improve these communities’ overall health” (Bridging the Gaps 2014). With Equidad, this happens, for example, by organizing workshops for parents with LGBTI children or for family members of PLWHA. These workshops have the objective to “break structures within the paradigms we have as a society” and to familiarize family members with sexual and gender diversity or to educate them about HIV, so that they approach both the subject matter and their children (and hopefully other LGBTI or PLWHA they are not related to) more positively.

### *The Potential of Citizenship*

The suffering LGBTI people living with HIV/AIDS experience as a consequence of their stigmatization manifests itself on an individual level, but as Kleinman and Kleinman indicate, relationships and interactions can be very influential to the experience of suffering (1997). Stigma and suffering determine individuals' perception of themselves, but also lead them to unite with similarly suffering individuals and address their source of suffering. Uniting on the basis of shared biological identities is what Rabinow (1996) has named "biosociality". In this instance, even though the group of PLWHA people is extremely diverse, its members share their source of suffering. The marginal position and the stigmatizing experience because of their sexual orientation and/or gender identity and their HIV-status are what makes PLWHA within the LGBTI community seek each other out. Petryna takes this concept a bit further by tying it to the notion of citizenship. According to the idea of "biological citizenship", individuals come together on the basis of a shared biology, but then use the clout of the group to demand, for example, that their rights are respected or their access to care or treatment is improved (Petryna 2002; see also Rose and Novas 2001). Biological citizenship is an individual and collective survival strategy in the face of illness and stigma, in which "the damaged biology of a population has become the grounds for membership and the basis for staking citizenship." (Petryna 2002: 5) Uniting on the grounds of a common biology and reclaiming citizen's rights plays an important role in the contentious politics that take as its starting point "citizens' relationship to their biological bodies" (Ibid. 2002: 5). In the case of Ecuador, PLWHA's claims relate to shared goals such as increasing their social capital, rupturing taboos and discriminatory values, extinguishing exclusion, and to have their rights to health care, work, education and a life free of discrimination guaranteed. It shows the potential for PLWHA, particularly those within the LGBTI community as a powerful force to influence their own social and political position; they may be more vulnerable, they are also in a unique position to challenge current figurations of citizenship. This citizen empowerment can be tied in with the greater involvement of people living with AIDS (GIPA) philosophy, which focuses on empowering PLWHA and involving them in citizen-led interventions to hold state institutions accountable for the minimization of discrimination and exclusion and the availability of health services they can utilize without fear.

Most of these claims are directed towards the state, and therefore the existence of a stable state with functional institutions is a requirement for success. And not just for the groups of PLWHA themselves, but for all actors working to promote their well-being, such as NGOs. In the process of reshaping their citizenship and gradually unmaking marginalization, LGBTI living with

HIV/AIDS concerning themselves with advancing health, sexual and gender rights need help from the government in order to change social perceptions and inscribe social advances in a more static manner; the law. HIV/AIDS activists in Brazil have demanded antiretroviral treatment (ART) under the premise of the right to universal health care for all citizens, and have been successful in ensuring that PLWHA, regardless of sexual identity or gender orientation, receive free ART (Biehl 2007; Biehl & Petryna 2013). Could actions like those in Brazil be viable in neighboring Ecuador? The wave of the new Latin American left swept up Ecuador, too, and as the government opened up to more progressive ideas, more democratic practices and transparency created opportunities for a more powerful civil society and the fight for more rights. During the last decades, the notion of citizenship has become increasingly influential in Ecuador. The idea of the duty of the state to guarantee rights to all its constituents on a universal basis initially mainly functioned as a common reference among a variety of social movements, such as indigenous groups, women, LGBTI, the urban working class, patient organizations, and environmentalists. Although these movements were organized around different demands, the concept of citizenship served not only as a useful tool for their specific struggles, but also functioned like a powerful link between the different groups. This redefinition of citizenship goes far beyond obtaining (equal) legal rights; much importance is ascribed to the sociocultural aspect of being a full-fledged citizen, with all the recognition, inclusion and participation opportunities implied with it. Concerns with subjectivities, identities, and the right to difference take up a central place, observes Dagnino (2007). The Ecuadorian constitutional guarantee for equal rights for all citizens, regardless of ethnicity, gender, age, sexual orientation and health status, is thus not enough, even though it is an important and essential element on the road towards inclusive, comprehensive citizenship. Rather, the aim is a transformation of cultural practices and ideas that reproduce inequality and exclusion throughout society to asks for input from civil society, for involvement of citizens who define what they consider to be their rights and struggle for their recognition. In 1997, the criminalization of homosexuality was deemed unconstitutional as it violated the principle of equality, marking the first time sexual rights were institutionally affirmed as human rights (Salgado 2008). Since 2008, same-sex couples can have civil unions, and since 2009 transgender people can legally change their sex (Camacho Zambrano 2009; Páez Vacas 2010). But President Correa refuses to go any further than that, and, as will be discussed in Chapter 3, government discourse on LGBTI rights oscillates between comprehensive protection of rights and unapologetic discrimination. Also, “reparative therapy” clinics promising to “cure” homosexuality under the guise of offering psychological treatment are still scattered throughout the country (Torres & Ortiz 2008). After a global media outrage over the torturous

methods employed in these clinics, the government promised to pursue the shutdown of all of the clinics in 2012, but up to this day many of them continue to function, although a precise estimate is unattainable since they operate and recruit clandestinely (Duque 2012). Government involvement supported by legal action aimed at expanding rights is important in fighting stigmatization for its ability to influence discourse and have mitigating effects on discrimination and exclusion. In combination with public campaigns to increase awareness and to bust myths about HIV/AIDS, legally extending rights reduces the branding of PLWHA and LGBTI as deviants that inhabit some space outside of society, which should lead to less stigmatization lowering barriers to prevention, treatment and care, as Mahajan et al. claim (2008).

After a dramatic rise in new infections, due to lack of sexual protection and information in the early 2000s, a funding agreement was formalized between the Global Fund to Fight AIDS, Tuberculosis and Malaria and Ecuador's Ministry of Public Health in October 2004, which indicated a more targeted and serious national attempt to address HIV/AIDS (Salgado 2008). A National HIV/AIDS program was part of this coordinated response, as was funding from other countries and international organizations. But the Global Fund turned out to be of major importance, because of the mechanism through which it works and affects the ways in which the funded NGOs function. It is strict in what its recipients can spend their money on, and about the implementation of at times irrelevant and time-consuming monitoring and evaluation activities, for example. Even though it has decreased its funding over the past rounds due to Ecuador's growing economy, the Global Fund remains by far the largest international donor (UNAIDS 2013; Equidad 2014b).

As national and international efforts to fight HIV/AIDS grew stronger and more robust, in 2010, Ecuador's Ministry of Public Health and the Global Fund declared victory as the number of new HIV infections had decreased to below 1% (Equidad 2013b; INEC 2013). In 2012, the number was established at 0.6% in the general population in 2012 (UNAIDS 2012a, 2013). ART became available without cost in 2001 and, in theory, freely available to all Ecuadorians and longterm residents as national expenditures on HIV/AIDS efforts were scaled up. However, the dwindling numbers of HIV/AIDS incidence in the general population are not reflected in the incidence and prevalence rates of specific populations at high risk for HIV, among which sex workers and LGBTI people. The HIV/AIDS budget, for which the Ecuadorian government has been lauded by UNAIDS and the Global Fund, among others, is not well balanced: 80% of it goes to medication, 20% to prevention efforts (Ministry of Public Health 2011). For the state really to change their course and deal with the issue more structurally and profoundly, an ideological shift has to take place first. The

LGBTI population and others most vulnerable to HIV-infection can only be reached comprehensively and thoroughly if the state decides to steer away from the path of promoting traditional family values. But with a president who maintains the “basis of society”, consists of man, woman, and child, that seemed far away at times, even in Equidad’s living room buzzing with activist spirit during a Monday morning team meeting.

## **Methodology**

I spent ten weeks in Quito, carrying out research with people from and working with the LGBTI community. One of my main interests was to learn about the impact of NGO activities on the lives of PLWHA in the LGBTI community. As an intern within the Bridging the Gaps program, focus lay with the activities of the NGO Equidad, and this meant a significant part of my fieldwork consisted of witnessing daily happenings in and around the Equidad office. Equidad’s main offices are in Quito, Ecuador’s capital, and in Guayaquil, Ecuador’s largest city, which boasts a significant LGBTI population. They also work in smaller towns and more rural areas, such as Santo Domingo, Otavalo, and Portoviejo, but these chapters have no permanent offices and are mostly managed from the head office in the capital. The Quito office is located in the heart of the entertainment district, where most venues frequented by LGBTIs are also concentrated. The modest office houses a tiny laboratory where rapid tests are carried out; several offices that double as counseling rooms; a small medical office; a room for the psychologist; a minuscule media room with a TV and a book and media library; and a “living room” where all workshops, meetings and other social activities are held. The walls are covered in posters announcing the upcoming Gay Pride, campaigns for HIV prevention, and slogans against homophobia. For ten weeks, this was my research home base. I spent days here observing daily activities: Equidad staff discussing new campaigns, preparing for meetings with other NGOs or potential funders, carrying out tests for HIV, syphilis, and other sexually transmitted infections; visitors coming in to use the media room to watch a movie about transgender life in Russia, and visitors and staff spicing up the living room on Thursday’s karaoke — a popular pastime in Ecuador — nights. I complemented my observations by attending weekly team meetings and accompanying staff members to conferences and meetings with other important actors such as fellow NGOs and government representatives. I also went on a weekend field trip with Equidad’s staff and visitors to foster intensive contact beyond the office.

As I was also interested in experiences from the perspective of individuals, I furthermore collected data by combining participant observation, five in-depth interviews, fifteen life history interviews with LGBTI living with HIV/AIDS, and collecting relevant materials and documents

such as Equidad's briefs and education material. Two of my informants invited me to come along on medical appointments and one informant showed me around one of the two public hospitals with specialized HIV/AIDS care located in Quito. I sat in on workshops with groups of predominantly young LGBTIs organized by Equidad, which were organized twice a week. On two occasions I was present at a meeting group with PLWHA, and I took part in two workshops with parents of LGBTI. As time passed and my informants and Equidad's staff came to see me more and more as one of their coworkers, as part of the team, my position as an observer shifted to that of an active participant. Nonetheless, with a topic still clouded in so much secrecy, I concluded that my informants would feel more comfortable and inclined to talk in a familiar setting and format, which is why I decided to observe during these meetings rather than actively guide a discussion. Three times I came along on nightly promotional activities in nightclubs, bars and other venues where LGBTI people would gather, when the Equidad team would hand out prevention packages including condoms, lubricant and information on how to practice safe sex. During interviews, I used a recorder, but all my observations and the data I gathered outside interviews were noted down in a fieldwork journal.

Most of my interviews were with PLWHA in the LGBTI community, in the form of life histories. Life histories — personal narratives of one's life — are very useful to get insight into the experiences of others as perceived by them. Informants get the freedom to tell what they deem meaningful and transmit their feelings and interpretations, making these interviews rich and layered. Besides unveiling the informant's personal story they expose how power structures or hierarchies are experienced. Life histories enable an expression of the self while simultaneously offering a view on sociocultural and political mechanisms, and as such are valued as an important vehicle for learning about both the individual's perception and its relation to the social fabric. The encompassing character of life histories furthermore prevents interviews from being solely based on the illness narrative, which can be too reductionist.

Although I had a list of questions that I aimed to get answered in all my interviews, usually, I started out by asking my informants to tell me about their lives as it was impacted by HIV. This was always enough to have them launch into detailed narratives. Most of them would start with their diagnosis and the events around it, others with an HIV/AIDS-related event that had made a great impact on their lives, and others would begin to relate what spot HIV/AIDS had in their daily life. Some of the life histories were collected over the course of multiple sessions. In these cases, we revisited salient issues, anecdotes or stories from the first session for further discussion in the next

session. A positive side effect of this was the intimacy that resulted from listening to and telling stories on various lengthy occasions.

All my informants were residing in Quito, in varying parts of the city. They were all living with HIV/AIDS; some had been diagnosed with HIV a few months before, others over a decade ago. Their age ranged from 20 to 55. With the exception of two, all of them were on antiretroviral treatment (ART). They were all lesbian, gay, bisexual, transgender and/or intersexual, and thus a part of a population deemed particularly vulnerable for HIV infection. Who exactly belongs to the LGBTI community is not always a case of unambiguous clarity, however. Furthermore, identities are dynamic, and not as clearly set as labeling groups of people suggests. As a very recent Rutgers WPF rapport on the sexual health of the LGBTI population once more confirmed (de Graaf, Bakker & Wijzen 2014), this group is highly heterogeneous and at times divisions between different letters of the acronym can be greater than their unity. Nonetheless, I have chosen to use the collective term LGBTI throughout my research, for two reasons. Firstly, I am relating about this group not only in a social and public health aspect, but also about their involvement in political and societal interactions. "LGBTI" is a universally used and understood acronym used in health interventions such as the Bridging the Gaps program, and in social and political activism. Despite their differences, all those falling under the LGBTI acronym face stigmatization, social and cultural subjugation, discrimination and marginalization based on their sexual and/or gender identity, and they are all at heightened risk of HIV/AIDS, partially because of how their identities are perceived by society. Secondly, LGBTI often fight for similar or identical causes, mostly linked to acquiring or protecting equal rights and the struggle to improve their social capital and health by fighting stigmatization based on deviant bodies and/or sexualities. For the sake of clarity and insights into both the common experiences LGBTI have as individuals who deviate from the sexual or gender norm, but also to make it possible to compare between the groups within the LGBTI population. In my time with Equidad I witnessed some of the dynamics at play underneath the technicolor LGBTI blanket, but in the end it was still a blanket rather than individual, diversely colored strips. I do, however, want to emphasize that I consider this population far from uniform. The same argument about diversity can be made for PLWHA, who are a mixed group of people from across the social, political, economic and gender spectrum. I have attempted to include participants with diverging backgrounds in my research, and this thesis takes into account their diversity and the variety of their experiences.

## Ethical Considerations

HIV/AIDS, sexual orientation and gender identity are sensitive and polemic topics in Ecuador that are, as showcased in this thesis, tied to stigma and marginalization. Fearing the negative consequences if those around them would learn about their HIV status, some of my informants wanted to meet outside of the Equidad office, as they assumed coming into the office to have a long talk behind closed doors with me would give away information they wanted to keep secret. Protecting the identity of my informants therefore meant conducting interviews in a cacophonous coffee bar, a sunny square in an upscale residential area, a seafood restaurant mostly visited by families in a popular neighborhood near the city's northern edge, a community center for sex workers and PLWHA, and a car as we drove up the *Panecillo*, a small mountain topped with a virgin statue overlooking Quito. I enjoyed these alternative interview locations, as they gave me a peek into the lives of my informants and confirmed once more how heterogeneous the group of PLWHA is.

Most of my informants had told only a handful of relatives or friends about their sexual orientation or HIV status, and the rest of their social circle, including parents, siblings, friends, and employers, were uninformed. Aware of the need to treat my data with care and discretion, I have used fictitious names for all the informants living with HIV/AIDS to protect their identity and respect their privacy. As opposed to my interviewees living with HIV/AIDS, I have not used fictitious names for Equidad staff, as they asked me not to. The data I gathered in interviews were not discussed with other informants.

In accordance with the AAA Code of Ethics (2012), I have provided my participants with full disclosure about my research before the start of any interviews. All informants were asked for their explicit informed consent before participating, and were given a copy of the informed consent form signed by them, which also gave information about the research and information on how to contact me with any questions or doubts regarding the research project. Participants were reminded they could discontinue their participation at any time.

The research proposal upon which my fieldwork and thesis are based was reviewed and approved by the University of Amsterdam. As the study was partially carried out as operational research within the Bridging the Gaps program, Bridging the Gaps, too, reviewed and gave approval for the study.

## **2. Being LGBTI, in- and outside of the hospital**

### **Sexuality, HIV/AIDS, and stigma**

*“Because of stigma, many people are afraid to see a doctor to get tested or treated. It is the principal reason still so many people die from AIDS, because they prefer to die as part of the community, than to live and be alone.”*

— Alberto

It was a warm, humid night in Tonsupa, the small beach town where Equidad’s staff and visitors<sup>2</sup> had landed for a weekend trip that was to strengthen ties of solidarity, friendship and camaraderie. Lula was getting dressed. She was the night’s main act. Seemingly not bothered by the heat, she put on nylon tights, taped in torso and loins for a more feminine shape, put on her leotard, an enormous wig, layers of make-up — which was a little complicated by the humidity, regardless of her expertise and her abundant collection of products — and platform stilettos. Lula was to perform for us only, but when the speakers failed to let out anything more than white noise, she proposed to go out and find a beach bar to perform in. While she strutted her way through the dimly lit, sandy streets, locals and visitors alike stopped her and asked for a photo opportunity. Looks of admiration and amusement seemed to be her prerogative. She looked strong and fearless, reveling in the freedom to express herself the way she most enjoyed. Nonetheless, how carefree and relaxed this may seem, I could not stop thinking how brave it was to be(come) Lula in a place where attacks against those with a sexual orientation or gender identity that dissents from the heteronormative standard take place on a regular basis. “Tonsupa... even Quito or Guayaquil; it’s not Amsterdam,” someone in our group said. I could see the energy that oozed out of her when she transformed into Lula. She seemed strong, invincible, untouchable. But she was also vulnerable. This celebration of Lula’s sexuality is part of a paradox where she and other LGBTIs can openly celebrate their identity and possibly challenge embedded repressive gender structures, while they are still largely ridiculed and marginalized.

Sexual orientations and gender identities that diverge from the heterosexual, male-dominated norm are still often frowned upon and condemned in Ecuador. Negative attitudes towards people with a deviating sexual orientation are found across all layers of the Ecuadorian

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<sup>2</sup> I use the term “visitors” to refer to the people that visited Equidad’s offices, participated in their activities, and/or used their medical or counseling services. This term was adopted from the way Equidad staff referred to those visiting their offices.

population, although they seem less prevalent in younger and urban communities. In smaller towns and rural settings, communities are more tight-knit with a strong sense of social control through community vigilance, and values of what is right and wrong are mostly based on what is preached by Catholic rhetoric. One Monday morning, Equidad's team meeting started off with Jimmy saying: "They contacted us from the Otavalo chapter. A boy has been beaten up by his family after coming out to his parents, and after that he was banned from the community." Otavalo is modestly sized town of about 90,000 inhabitants two hours away from Quito, with a relatively young population, and a large weekly influx of tourists on Saturdays, when travelers come in search of the perfect alpaca sweater in the famous Otavalo artisan market. But Equidad's Otavalo chapter serves not just those within the city limits. Located in a fertile volcano valley, Otavalo is surrounded by numerous villages where potatoes, maize and chickens are the main source of income and town gossip is the principal manner to manage social relations and determine hierarchy. The Otavalo chapter has LGBTI coming in from many of those communities, and none of them have shared their feelings about their sexual orientation or gender identity with people in their villages. The boy who had been banned by his community was from one of those villages, and had not want to tell his parents about his homosexuality until leaving home to attend university. But when his parents caught him on the sofa kissing a boy, he decided that would be the moment to tell them. Their reaction was exactly what he had been fearing.

Although negative attitudes towards LGBTI seem to be stronger in rural communities, discrimination also remains a reality for most sexual minorities in large cities. My field journal is gushing with accounts of smaller and bigger acts of discrimination on the basis of gender or sexual orientation, mostly observed while I was in Quito. Contemptuous looks, supposedly playful remarks about "hysterical faggots" (*maricas histéricas*), a lesbian girl receiving derogatory remarks from fellow students, a violent attack on a young man after leaving a bar famous for its drag performances, and within the health setting, the insinuation of a perverse sort of causality between being gay and HIV positive: "You have HIV because you are gay and promiscuous". The persistence of such discriminatory acts explains why despite an overall greater acceptance of diverging sexual orientation or gender identity many LGBTI people in Quito are not keen to discuss their orientation or gender identity with their families. In the joint interview I had with Fernando and Alejandro, they said they told their mothers and siblings about being gay, but not their fathers. Fernando and Alejandro had been partners for a year when I spoke to them. They felt they could only talk freely and comfortably about their sexuality or their sexual health with each other and shied away from discussing being gay with their families and colleagues. They proposed to meet

outside of the Equidad office to avoid running into familiar faces. We met in a coffee bar with a mix of vintage and modern furniture, where young *Quiteños* and tourists came for flavored coffees, freshly squeezed juices and freshly baked chocolate cake. My informants fit right in with the handsome, fashionable clientele. As we sank into a couple of oversized cushy chairs, Fernando started telling how his family had dealt with his “coming out”. His siblings thought it was “cool”, his mother had accepted it but was struggling to reconcile it with her religious beliefs. Fernando thought that his dad knew that he was gay, or at least that his mother had discussed it with his father. “I have not talked about it with him directly. I think he accepts it but prefers not to mention it,” said Fernando. “Or maybe he thinks it will go away on its own again, like mine?” Alejandro suggested. He laughed as he said this, but the expression on his face was sour. While stirring his caramel latte, Alejandro continued, turning the conversation a few tones heavier. “Imagine how he’d react if I’d tell him I have HIV. He knows that won’t go away on its own again.” “Then he knows more about it than my dad!” exclaimed Fernando. “He has no clue about it, just that you get it from doing ‘bad things’.” Fernando and Alejandro had been visiting Equidad for years, and felt coming together with others from the LGBTI community made them feel better about themselves and gave them a sense of belonging and safety they did not find in their daily lives, in the classroom or at their workplace. However, although they got a boost from sharing experiences related to their sexual orientation, they never discussed their HIV status with any of the other Equidad visitors, out of fear that others would judge or even avoid them. This is an example of various of the instances of self-stigmatization that I found amongst my informants. Out of fear for the reaction of their surroundings, PLWHA decide not to be open about their HIV status, which can hinder them in their search for the right treatment both in and out of the medical setting. Secrecy is also an impediment when challenging exclusionary and discriminatory practices; it is hard to claim rights without giving full disclosure about the grounds the claims are founded on.

I found many cases of marginalization amongst the marginalized during my fieldwork. For example, transsexuals and transvestites may suffer from discrimination not only from society at large, but from other transsexuals, gay men, bisexuals, or lesbians who likely have experienced discrimination themselves. Lula, for example, told me she bonded with only a small group of people within Equidad, because of the negative comments she had received about her drag performances, especially in her early days on the drag stage. Stigmatization and marginalization is strongest towards LGBTI who are living with HIV/AIDS. This marginalization within an already marginalized community leads to an increasing fragmentation of LGBTI communities along the lines of HIV-status. Smit et al. (2012), who provide an extensive overview of how stigma is

experienced by communities of gay men in general as well as on a more individual basis, make the reader aware that such double marginalization can have a negative impact on prevention and testing behavior, general health, and emotional well-being. Ronald described this sense of double marginalization rather poignantly in his interview: “Before, I felt marginalized. Now, I feel like a pariah among the marginalized.” Angel told me how he would see plenty of familiar faces at the clinic, but never talked with any of them: “Sometimes I would like to talk to them, just to see... to know what it’s like for them, to share the experience. But I’m afraid they will start telling other people I have HIV.” For many PLWHA, knowing someone else is infected does not provide enough confidence there will be a reaction of sympathy and solidarity when coming out about their HIV status.

Informants who had disclosed their HIV diagnosis to their families preferred to start with their siblings. Because they are younger, they are more knowledgeable about and open to discussing sex, sexuality and HIV/AIDS. The Internet means that access to information about these topics has greatly increased. Most of the informants told their partner first. Rafael explained why. “After telling my family I was gay, I didn’t want to tell them I had HIV.” But Rafael’s partner was “in the same boat. We had many talks about it, how to face this challenge, how to deal with certain things. We understood each other perfectly.”

Equidad tries to combat negative family attitudes by organizing workshops for parents with LGBTI children or for family members of PLWHA. These workshops have the objective to “break structures within the paradigms we have as a society” and to familiarize family members with sexual and gender diversity or to educate them about HIV, so that they approach both the subject matter and their children (and hopefully other LGBTI or PLWHA they are not related to) more positively. In a very non-confrontational way, they succeed in getting the mothers to look at their children with pride, an emotion that was previously hindered by worries over socially constructed conventions that determined how their children should behave. One of the mothers, Sonya, a homemaker who has spent her life taking care of her family, has transformed from a subdued woman with rather conservative ideas to a true warrior, not only insisting on the rights of her son, but that of all LGBTI people. She is at the forefront of organizing activities for parents and family members, and organized for the parents to walk with their own flags and banners during the 2013 Gay Pride, which started with “I’m proud of my...” and parents could complete them with phrases of their choice that described their children. It was inspiring to see how an elderly woman who had all her life been convinced of certain values, could be moved to change her ideas and accept her son and his sexuality. For some of my informants, this redemption had not arrived yet.

In my second month in Quito, I met Rogelio. He was a young man with a successful career in the petroleum industry. He would be deep in Ecuador's rainforest areas for months on end. Teams exist almost exclusively of men, and there is a strong macho vibe at the drill sites. Being openly gay, he had been the target of discrimination that almost made his job impossible to carry out.

"I reported my supervisor to human resources. It was hard. They wouldn't immediately act upon it, I had to work with that man for a while longer, while he was throwing all sorts of insults at me, excluded me from team meetings, and even got me into some dangerous situations at the drill site. Finally, when I threatened I would take legal steps, the company did something. But I no longer wanted to work there. As soon as I got an offer from another company, I switched. At first I thought I had made a mistake; one of my new colleagues also started insulting me. But he was fired right away. Still, I don't think it's a good idea to be open about my HIV status. Not at the workplace, and definitely not my workplace."

Rogelio had recently moved into a new house where his new partner would join him soon. His partner was HIV positive, and they spoke about it with each other, but no one else within their social circle. Rogelio visited a patient meeting group of PLWHA on a frequent basis, as will be discussed in Chapter 3, but he was not sure if his partner would join him there. As he showed me around, I could not help but feeling all his material boasting, as well as the emphasis on his prestigious position at the petroleum company, was to compensate for what he could never be to his mother: the perfect son.

"I used to be my mom's favorite when I was little. I was the youngest child and all my siblings were a lot older. I was sweet, bright, handsome. But when I told my mom I was gay... something inside her broke, and it can't be fixed."

Rogelio's family was unaware he was diagnosed with HIV a year before, but he was planning to tell them soon. He was worried about their possible reaction. As we sat on the terrace of his beautiful new home, his face was crinkled by worries. It was gripping to see how this arranged life in the gated community had been uprooted. How in the midst of Rogelio's arduous attempt to construct a steady life full of material and professional accomplishments, HIV came bouldering in and imposed itself upon his life like an uninvited guest who ruins the party.

## Barriers to HIV/AIDS prevention, care and treatment

Pamela remembers her first image of AIDS well. In an early 1990s campaign, there was an image of a pale, emaciated young man covered in distinctive dark patches of Kaposi's Sarcoma, looking as if he could collapse any moment. She was reminded of that image in the months right after being diagnosed with HIV, as she was treated in a clinic where HIV patients waiting for their doctor's appointments or their ART sat down in the space were cots were filled with bed-ridden by AIDS and close to dying. "I was scared that would be me soon. My doctor didn't tell me that taking my medication and taking good care of my body — eating well, no drinking, no smoking — could give me a long life outside of the hospital. The clinic seemed to have been deliberately set up like that, so that we would see the sick people and be scared."

She had always been told AIDS was a "disease of prostitutes and gay men"<sup>3</sup>. When she started feeling sick, she was told not to worry. People living or associated with HIV/AIDS were construed as dangerous and indecent. A good girl like her? It was surely nothing too worry about.

"At first, they didn't know I'm bisexual. Once they found out, their attitudes changed. I was accused of sleeping around, of bringing it upon on myself. It is the task of the doctor to make you feel as good as possible, and not just by giving you medication. But it seems they think it's more important to preach their values and to chide you when you don't stick to their rules. Then you deserve to be scared. And you shouldn't even think about having a happy life. Some girl... she asked the doctor about the possibilities to have a baby. The doctor told her she shouldn't have children, because she would infect them. Everyone knows that's not true, that you can take medication and your baby will be born healthy."

Through a combination of circulating stories about HIV/AIDS and the attitude of health care professionals, Pamela, like many others, came to think about and experience HIV/AIDS in ways that were tied up with moral judgments and fear. But she changed to another clinic and reached out to others with HIV/AIDS and got organized in a patient group for young PLWHA. Together with her fellow group members, she is becoming more open about being HIV positive outside of the safe environment of the group. They have plans to give talks in universities and other places where young people are concentrated to address this topic. I ran into her again during a conference about

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<sup>3</sup> In Spanish, prostitutes are pejoratively referred to with the word *putas*, while for gay men, the male equivalent *putos* is used. There is a strong moral judgement attached to the construction of HIV/AIDS as the illness of *putos/as*.

sexual education in educational institutions, where she was exchanging business cards with a speaker who had just finished an engrossing plea for starting with sexual education in the early years primary school. Exuberantly, Pamela shared the good news with her peers: “She’s going to help us with the sex ed talks in the universities!” She looked determined to extinguish the moral judgments she had to endure. The belief that viruses make moral judgments and choose their victims accordingly, alive and well, even amongst doctors, is harmful. Discrimination, whether real or perceived, has a negative effect on wellbeing. It also dissuades those who are discriminated against from seeking the care and treatment they need. Some of the informants told me they were reluctant to seek any medical care because of the way they had been treated in the past.

“I have felt from firsthand experience that discrimination can do much more damage than HIV itself. When I got sick... the company doctor wouldn't let me get back to work. She refused to sign the form that said I could resume working, using all sorts of inconsistent pretexts and discriminatory arguments.”

Rogelio gets angry just thinking about it. “I don’t go anymore, unless I can’t get by with seeing the doctor at Equidad.” Because he has not started ART yet he does not rely on the hospital for now. “Until I get really sick and I have to, I won’t go back.” Narratives like these highlight ways in which stigma can heighten barriers to treatment on an individual level and foster mistrust between patient and health care provider. In conversations with Equidad staff, Efraín has hinted at this mistrust, offering the lack of training on HIV/AIDS and “gender and sexuality sensitization” among health care professionals as the main reason PLWHA and LGBTI are discriminated against when they seek medical attention. At Equidad, too, they are thinking about sexual education in schools and universities, and plans for sensitization activities amongst health care professionals are years in the making. But so far they have not reached an agreement with government representatives. By way of compromise, they have published a manual for health care professionals working with LGBTI populations and PLWHA. In late April, Equidad started talks about a new sensitization project in the military that they would run together with the Ombudsman.

In other studies carried out amongst people living with HIV, participants expressed a strong sense of alienation from health institutions that mistreated them, which erected a barrier to treatment not only because it made them wary of seeking medical treatment at that particular health care site but had created general feelings of mistrust towards medical staff (Cáceres et al. 2008; Formby 2011; Kako 2013). Accounts from my informants show how such barriers might be

experienced. Most said they preferred using Equidad's HIV testing service over any traditional health care setting, as they talked about negative experiences with doctors and nurses and a lack of privacy. Also, it was such a "hassle" to go to a hospital, and not always free. But behavior of health care professionals weighted in the most heavily. Rafael said the doctor, an older, religious man with a large family, just could not understand him. Ronald mentioned feeling uncomfortable disclosing his sexual orientation to the doctor, but that in the end, he did so because he felt the need to stand up for himself. "The doctor hinted I must have gotten HIV because I was one of those 'typical promiscuous gay men'." He furthermore described the doctor as a despot and says the attention he received was less than humane. He switched to another hospital, the only other public hospital in Quito with a specialized HIV/AIDS ward, where he has been contently meeting with his psychologist, but is not happy with the doctor. About this same doctor, Carlos related:

"And besides that, the medical attention was horrible. The doctor who treated me at the time... she's not a person. She doesn't have vocation for what she does. Because she should know she is treating human beings and not animals, to say it like that. Anyway, this doctor, she treated me really bad from the moment I arrived. I had a lot of problems in the hospital... but really, the doctor she was the most terrible. She never told me what to do, she was careless with giving me the right information, while with a person with HIV, you have to be careful giving the right information. She wasn't treating someone with an innocent flu."

Three months after the doctor told Carlos he had to start ART, he was in his doctor's office to receive his medication. Carlos asked his doctor some questions about the medication; what it would do to his body, possible adverse effects, how strict he had to be with the time schedule. Then, knowing that Carlos had already waited three months and that he should start his ART as soon as possible, the doctor refused to give Carlos the medication. She argued he was too anxious and she was not certain he would adhere to the medication regimen. She instructed him to come accompanied by a family member the following appointment, and made it a requirement: if Carlos would come alone again the next time, he would still not receive his medication. "She violated a process of confidentiality, forcing me to discuss my HIV status with others." Carlos is a calm, soft-spoken young man, a little shy. But as he recalled his experiences with the doctor, he got agitated.

“[My doctor] focused on the clinical part and not on the human part. She thought that with giving a diagnosis and writing a prescription she was finished. But for me, part of her work is to understand what her patients are going through, which she didn't.”

Every appointment was more hostile than the previous one. Eventually, no longer able to bear the doctor's inconsiderate attitude, Carlos decided to ask the other doctor in the ward if he was willing to treat him. “All these issues affected me even more. I was emotionally wrecked.” Changing to another doctor or hospital or demanding the doctor improve his behavior, as Carlos and Ronald — and more of my informants — did, is a way of putting up resistance against discriminatory attitudes. I will elaborate further on such acts of resistance in Chapter 3.

Even though the majority of my informants received their HIV diagnosis in Equidad's office — three of them got initially diagnosed elsewhere — and informants indicate they prefer getting tested in Equidad's tiny laboratory over a traditional hospital setting, testing rates are not nearly as high as Equidad staff would like them to be. They find this especially worrying in the light of a recent peak in incidence, which they believe can be partially explained by a failure to reach as much of the vulnerable LGBTI population with prevention efforts. If their target population does not receive condoms and messages about safe sex practices, that could mean testing and treatment messages do not reach them, either.

The HIV/AIDS burden is high among gay, bisexual, and other MSM (UNAIDS 2012b, 2013; INEC 2013). According to data collected by Equidad, HIV prevalence continued to expand over the past years and rates of new diagnoses have been increasingly higher: 11% of the people that got tested by Equidad was diagnosed with HIV in 2011, in 2012, this was 13,5%. Definitive data on 2013 are not published yet, but from the data they have processed, Equidad staff estimates incidence has gone up again (Equidad, PAHO & Ministry of Public Health 2012). High prevalence, lack of awareness of HIV status, increased viral loads among those not on ART, sex role versatility, and social determinants such as the ones discussed above play central roles in this disproportionate burden. The increasing accessibility of ART has reached a growing number of Ecuadorian PLWHA in the past years, but this potential is limited by discrimination and other barriers to healthcare such as limited treatment facilities: in Quito, the country's capital and main medical hub, there are only two public hospitals with departments that specialize in HIV/AIDS care. The doctors working here attend to the majority of PLWHA in Quito and surroundings. There was a clinic specifically attending to the transgender community, but it was on the veer of being closed as I was wrapping up my fieldwork in May 2014. Persons aware of their infection are less likely to transmit the virus, and

HIV testing is an essential first step towards care and treatment. Increased uptake of HIV testing and more frequent testing might reduce the number of people unaware of their HIV status and reduce HIV transmission. Now, many men come to Equidad when they already have symptoms. They are afraid to discuss HIV testing with their doctors, do not know they can get tested at Equidad's office, or are hesitant to go there because they are afraid that once they walk through the laboratory's door, everyone will assume they are HIV positive. During my relatively short stay, there were two cases of young men who had been told the symptoms they were suffering from were manifestations of advanced stage AIDS. In the most affecting case AIDS had progressed so far that the man died within a few weeks of his diagnosis. This young man, in his early twenties, was a good friend of John, Equidad's receptionist. He had been feeling unwell for some weeks, and finally decided to visit a doctor, after which he was hospitalized and diagnosed with AIDS. In the weeks after, John and his friends had been dreading the worst outcome, and one Thursday morning he came into the office I shared with Efraín — who was in Washington for a meeting with the Inter-American Court of Human Rights to report on the status of LGBTI rights in Ecuador. Seemingly upset, John told me that his friend had passed away. At the other side of the office, the phone started ringing. Teary-eyed, he mumbled something about answering the phone and walked to the reception. Five minutes later he stepped back into my office and started crying, relating the events of the previous night in the hospital. Even though I personally never met John's friend, his death still sternly struck me. Seeing the sadness of John and his friends after losing a close friend was heartbreaking, but there was something else that stung me. Someone had died from AIDS. Not because of lack of diagnostic means or unavailability of medication. Because he was too scared for social repercussions tied to an HIV/AIDS diagnosis. Even though I was aware that still many people fail to be reached by HIV prevention interventions and care and treatment, while I was talking to my informants who were all at least receiving care or counseling and were aware they were living with HIV/AIDS, I had seemed to forget that rather than a chronic illness with numerous social shunning factors, AIDS is deadly if it is allowed to freely roam your body. Self-stigma inhibiting people from getting tested and becoming aware they are infected with HIV/AIDS can be fatal. It is a loud wake-up call when someone dies from AIDS because of not receiving a timely diagnosis and medication, and it shows that there is still a long way to go before everyone can use prevention, testing and treatment services without fear of judgment.

A little less than 10% of MSM had tested for HIV in the past 12 months (Equidad, PAHO & Ministry of Public Health 2012). Equidad and its partner organizations are scrambling for ways to promote testing uptake and condom use. In the months I was in Quito, one recurring problem

contributing strongly to the inability to effectively reach a large number of LGBTI, was the lack of condoms and prevention packages. Prevention packages consisted of three condoms, lubricant, and a booklet on how to practice safe sex. A significant portion of the condoms Equidad received were provided by the Ministry of Public Health free of cost; 10.000 condoms each month, theoretically, although in practice this turned out to be less. Instead of automatically being provided with their standard supply each month, Equidad had to file a request for their supply that would take weeks to be processed. In April, the condom well dried up almost completely because of a packaging error and distribution problems within the Ministry program. The Ministry promised to make emergency purchases, but these were delayed so much that Equidad had to ask their partners within the Bridging the Gaps program for an emergency loan to buy condoms themselves. For seven consecutive weeks, the scarcity of the condoms and the strenuous collaboration with Kimirina on this issue came up. For the prevention activities that Equidad was carrying out together with Kimirina, Equidad received the condoms from the Ministry of Public Health. However, when the supplies continued to shrink and Kimirina refused to use some of its own supplies for the joint prevention activities, tensions rose. Equidad staff frustrated with the restraints of the Global Fund and the clashing work methods of Kimirina exclaimed:

“They don’t know what LGBTI want! They only focus on the biomedical logic behind HIV transmission. ‘You can prevent transmission by using a condom, so let’s just give as many people as we can condoms, and when we register it all and at the end of the month we have distributed 10.000 condoms, the problem must be solved. And when we hand out 11.000 we do even better.’ That’s honestly their approach! And the Global Fund supports it. That’s a useless strategy.”

In 2013, the Global Fund remained Equidad’s biggest funder by far: the next funders on the list, Bridging the Gaps-partners COC and MSM Global Forum, each donated a fifth of what the Global Fund’s invested. However, Efraín pointed out these smaller sources of funding were extremely important, because they came with less requirements, more spending and programming freedom, and without the required collaboration that was at times less than ideal for both Equidad and Kimirina. International funding has been shrinking with the rise of Ecuador’s GNP and the ascent to middle-income country status. This was both a curse and a blessing. Seemingly, when international organizations such as the Global Fund who exert too much control over local organizations’ work manners retreat themselves from the Ecuador, that leaves the governing, designing and

implementation of programs to the local government and non-governmental institutions. However, when funding dries up, that renders organizations just as powerless, with only the government to depend upon. Various staff members voiced their concern that the government is not fighting HIV effectively, mostly focusing on treatment and not so much on prevention and education. They were disheartened by the ineffective, simplistic “chemical solution to a social problem,” as Efraín stated. For the state really to change their approach and deal with the issue more structurally and profoundly, an ideological shift is essential. The LGBTI population and others vulnerable to HIV-infection can only be reached comprehensively if the state decides to steer away from the path of promoting traditional family values, and opts for a non-discriminatory approach. But with a president who maintains the “basis of society”, and a Ministry of Health investing the bulk of its HIV/AIDS program spending on ART rather than condoms, a change of course seemed far off.

Condoms can reduce the risk for HIV transmission, but often are not used consistently. During my interviews, informants would state they always used condoms, except for that one time, when they must have gotten infected. After probing them somewhat about their condom use, some of the interviewees would change their answer. It seemed that part of their narrative had been constructed — and repeated to the health care workers who were mostly the only ones my informants discussed their HIV status with — as to avoid disapproval of their behavior and being blamed for getting infected. This was their tactic of warding off moral judgment and further discriminatory statements from health care workers. After being ‘caught’ lying about their condom use, informants would call out others, too. “I know I should use condoms,” said Alan. “But sometimes, in the heat of the moment... well, you know. And everyone who says they always use condoms? Not always, my dear, otherwise they wouldn’t be talking to you.”

Angel, who works in an adult movie theater, is sure his costumers not always use condoms.

“I see them at the hospital and I see them where I work, and I know they have unprotected sex. I can’t warn their partners and I can’t warn them. Why? I will get fired if I get involved with the costumers like that. I feel bad about it, yes, of course. But what can I do? I want to help people from preventing they get infected, I don’t want them to have a life like me. But I don’t want to lose my job, and I don't want people to ask why I am so persistent about the condom use. They might suspect something.”

Some of my informants attempted to decrease their risk for HIV by engaging in unprotected sex only with partners perceived to have the same HIV status as their own. A risky practice for those

who are HIV negative, since others with HIV might not know or disclose that they are infected and assumptions about the HIV status of their partners can be wrong, as Carlos found out. “I had no idea my partner had HIV. From what I knew about it, I always thought you’d look very sick, like a skeleton and very pale.” He did not remember where that idea came from, but he associated HIV with “horrible looking people”. Later, someone at Equidad told him that it was not always possible to tell whether a person was HIV positive. But the association of a ghastly appearance people stuck with him. “Now I look at myself and I think: ‘You look great!’ I look great but yet I’m sick, I guess that’s proof.” Trusting their sexual partner is HIV negative is also a risky practice for those who are HIV positive, because of the possibility of reinfection, tell my informants. Many of them feared reinfection. “Once you get reinfected, there’s no medication that can help you,” said Alejandro. Alberto said something similar. His doctor had warned him to use condoms not only to protect his partner from getting infected, but also to avoid reinfection. This was also brought up by Angel, who considered it an important reason for not engaging in any sexual activity. Angel had given up an active sex life because he preferred saving himself from any possible negative reactions over intimacy, no matter how much he missed it.

“But then there’s the other part, the human part, to say so... It’s going to be two years that I’ve separated from my boyfriend... And where I work, I met this person who is always around, talking with me, laughing... but I’ve put up a wall. [...] I would have to tell him: ‘Look, I have this disease, and well... you decide, OK? Whether you want to be with me or not.’ Anyway, I prefer not to be with anyone, not sexually, not emotionally. It holds me back, you know? The idea to make someone else sick, or get sick myself... My conscience wouldn’t be able to deal with that.”

Besides giving up intimacy and cutting off any possibilities to be in a relationship, Angel is no longer seeing many of his friends.

“It’s hard. You already are not telling your friends the truth, about having HIV... Then you also stop hanging out with them, because they want to go out and party, drink a lot... I just can’t do that, but I can’t tell them why. I know they feel I abandoned them. But that’s not true. Or maybe it is. But my health is more important. And I don’t want to tell them why.”

Others have pointed to having made similar concessions. Alejandro and Fernando see their friends sporadically, as they no longer want to stay out late every week, and stopped smoking and drinking alcohol for health reasons. “No cigarettes, no alcohol, no late nights out,” summarized Fernando. He nodded at his partner. “He sometimes does. Have a drink or a smoke.” “But then I immediately notice it. I feel bad the next day,” Alejandro confirmed. He relates how at one outing with his friends, he felt pressured to drink beer and join his friends in their seemingly careless fun, to belong again, to be careless like them. One of Alejandro’s friends repeatedly asked him why he refused to drink beer. Feeling that it was suspicious not to drink anything, as he always had been a beer fanatic, Alejandro drank some beer. He did not enjoy it. Now he tells colleagues and friends he is on a diet and wants to live more healthily.

This retraction from social life is a harsh consequence of the stigma related to HIV/AIDS. The negative associations made with it are so strong that people prefer to not tell their friends or family about it, but prefer to have their social lives heavily curtailed. And fear for negative reactions was not limited to the social circle, but also applied to professional relationships. As Manu related the trajectory of the past twenty years of his life with me, it became clear his life had been greatly influenced by HIV. HIV was the “third person” in his early relationships and the driving factor behind the major life choices he made as a young man, such as choosing a career path and deciding to move to another country. “But not anymore,” he said. Now it was just a question of taking a pill and that was it. Manu could afford private healthcare in one of Quito’s most expensive hospitals, where he was attended by a doctor who had been trained abroad and was more open to dialogue. He could also afford plastic surgery to combat the appearance of his lipodystrophy. He had managed to survive, and not just that: he was thriving. Nonetheless, he was burdened by the weight of his HIV status, that he did not share with anyone but his former partner — who had infected him, and who had died 8 years earlier — and his mother. Not even his close friends with a “progressive” mind-set, who seemed to discuss anything including their own experiences with a (chronic) sexually related infection — albeit one that carries less stigma than HIV — knew that Manu was HIV positive. His reasoning for not telling anyone was the fear of losing customers in the high-end branch where he runs his own business. “I’m scared they would stop coming and that it would mean the end of my career.”

Another reason for the extent of invisibility of PLWHA in Ecuador may be precisely that there already is free access to ART, and people feel advocacy is less urgent. In the West African setting of the late 1990s Nguyen (2010) describes, talking about HIV/AIDS became a survival tool in order to procure life-saving ART. In West Africa, especially when ART was not yet widely

available and prohibitively expensive for most PLWHA, talking about (living with) HIV/AIDS, often encouraged by researchers and employees from international organizations and health agencies, was a way to obtain lifesaving medication and thus a survival strategy. In Quito, this strategy is not (deemed) necessary, since medication is available. This means the sense of urgency is not as high.

Even though great strides have been made in the fight against HIV/AIDS in biomedical terms and access to treatment has greatly increased, the stigma surrounding HIV endures, the experiences and behavior of my informants show. The people I interviewed continue to hide their diagnoses from families, friends, employers, educational institutes and broader society out of fear they will be ostracized. Equidad received several requests for legal counseling from LGBTI who had either been obliged by their (potential) employers to test for HIV/AIDS, or had been tested during regular medical check-ups without their knowledge, which are both determined illegal by law. Several of my informants spoke of health care professionals refusing to treat patients with HIV/AIDS. With the exception of the medical personnel working at Equidad and other NGOs working on rights of PLWHA and/or LGBTI populations, doctors and nurses are not actively informing people that HIV/AIDS does not spread unless there is exchange of blood or (intimate) bodily fluids. The very way in which health care professionals — expected to use their knowledge to treat their patients with care and compassion and to inform the public — treat PLWHA contributes to the fear surrounding HIV/AIDS.

### 3. “We're Ecuadorians, too.”

#### *Medical and political resistance*

#### **No priorities**

*“I oppose same sex marriage. Civil unions, the criminalization of homophobia, more equal opportunities, the fight against discrimination... But if there’s no same sex marriage, I’m a traitor! It’s all or nothing! [...] They should recognize there has been progress. [...] Of course, it’s a reaction, right? Of groups that have been held back, mistreated, etcetera. I understand that for them, it’s a priority. But the majority of these topics, same sex marriage, gender identity... they're not priorities. And we have to focus on what are the majority’s priorities. They say we don’t respect their rights, but we do, within the constitution. The constitution says marriage is between a man and a woman. I’m not a traditionalist, but I believe it’s the basis of society: a family consisting of man, woman, and child.”*

— President Correa, May 2013

This quote suggests that Ecuador’s president Rafael Correa thinks equal social, cultural or sexual rights are a luxury. Ironic, considering that an essential part of his rhetoric is based upon the idea of equal rights to guarantee complete equality and citizenship for everyone. Equality, but more for some than for others, and on his terms only, he seems to indicate, reminiscent of an Orwellian maxim. The imagined dialogue between state institutions and civil society at the heart of his citizenship discourse is also on his terms, both in terms of content and in who is supposed to be in control. Through this, the state upholds not only the traditional political hierarchy with its institutions at the top, it simultaneously maintains the sexual hierarchy with the heteronormative family — as the cornerstone of society — at the top. This chapter features examples of ways in which the state aims to exert its dominance, and, mainly, routes NGOs and individuals take to challenge this dominance, both in collective and individual manners. And what are the consequence of this in terms of treatment, care and prevention of HIV/AIDS? This chapter is tied up with my research question of how people living with HIV/AIDS in the LGBTI community employ their biosocial circumstances to put forward resistant forms of citizenship and subsequently challenge barriers to treatment.

Correa’s speech shows the extent to which the state intervenes in sexual behavior at a very intimate level of social life and how that results in LGBTI people being denied the rights that

correspond with full citizenship. But more actors than just the president and his administration have stakes to claim; various conservative, politically involved groups, most of them linked economically and ideologically to the Catholic church, promote exclusion of LGBTI and impede them from fully enjoying their rights. And although the involvement of state actors in themes of sex and sexuality is staggering, most everyday social control is extra-legal (Rubin 1999: 157-158). Less formal, but very effective social “sanctions” — such as exemplified by the stories of Angel, Rogelio, and Washington in the previous chapter — are imposed on members that do not comply with the set standard of behavior or identity, and these are often experienced as much more severe than legal punishment. Correa’s quote illuminates manners in which the Ecuadorian state maintains “proper” constructions of sexuality, embedded structures of power, codes of behavior, and forms of prejudice. His discourse both shapes and is shaped by the prevailing attitudes in society and a reflection of the sexuality, gender, identity and health hierarchy amongst Ecuadorians. Both state and society define the parameters of acceptable behavior, identity and health status.

### **The Citizens’ Revolution and Citizenship in Ecuador**

In Ecuador, the rise of the citizenship discourse has been linked to the experiences of social movements and reinforced by efforts toward democratization, especially with the political turn to the left and the political rise of Rafael Correa, who’s been leaning heavily on the idea of the Citizens’ Revolution (*Revolución Ciudadana*). The Citizens’ Revolution is a political, economic and social project in which democratic citizenship and citizen participation take up central roles. Besides the conventional judicial, executive and legislative state functions, the Ecuadorian state furthermore has a Transparency and Social Control branch. This branch has the task not only to control the functioning of public entities and organisms so that they carry out their tasks with responsibility and transparency, but also to promote equality and stimulate citizen participation (*participación ciudadana*), ensuring the implementation and safeguarding of rights (Constitution of the Republic of Ecuador, 2008). This institution is responsible for promoting collaboration between the state and civil society, and is the regulatory mechanism of accountability in the country. The most important institutions within the Transparency and Social Control branch are the Council of Citizen Participation and Social Control (*Consejo de Participación Ciudadana y Control Social*) and the National Ombudsman — the *Defensoría del Pueblo*, of great importance in the fight for equal treatment, particularly for LGBTI. At the time of my fieldwork, the office of the Ombudsman was working on various cases linked to unequal treatment at the workplace, forced HIV testing, and

other cases of discrimination on grounds of sexual orientation, gender identity, or HIV status. As it involves a judicial route to demand rights, the Ombudsman is a useful instrument in the legal side of the citizenship struggle — it makes sure that rights defined by the constitution are implemented and respected. For influencing exclusionary cultural practices/stances, the influence of this office is less rapidly noticeable, even though fights fought in the legal arena that do have their influence on sociocultural constructs, albeit slowly the Ombudsman himself at a showcase event of a documentary about the legal limbo of a lesbian couple who wanted both to be lawfully recognized as a mother to their daughter. In their refusal to have one of the mothers assigned as an adoptive mother, the couple had been defended by the office of the Ombudsman in their court battles. Although the baby's nominal faith still had not been settled at the time of the documentary<sup>4</sup> and the legal struggle over the definition of "family" continued, the possibility that such a struggle can exist is a testament to how much things have changed, as also the Ombudsman opined. He went as far as to call the case a "precursor": "In ten years from now, we will be seeing this documentary as a piece of history. In some years, we won't be dealing with these problems anymore." The documentary was shown at the modern cinema room in FLACSO's<sup>5</sup> brand new library building, and the cushy seats and high attendance rate did not give the impression this was an event addressing a marginal issue. It was at least an issue the government was willing to invest time and money in. Equidad staff also present at the showcase event later told me most of the public consisted of government employees attending as part of a sensitization initiative amongst public officials incentivized by the Ombudsman's office and the Ministry of Justice and Human Rights.

Although this judiciary approach is an important supportive pillar in claiming and defending universal citizen rights, there are some limitations. Many of the cases tied to gender, sexuality and sexual health that reach the courts, especially when they are pioneer or — to quote the Ombudsman — precursor cases dealing with issues that have no precedents in the Ecuadorian legal context, receive much publicity and the attention of conservative Catholic groups. This might be deterring, particularly for many PLWHA, who have not told most people around them they live with HIV/AIDS. Only two of my informants said they would go for such an approach if they ran into discriminatory practices: Alberto, who was very open about living with HIV to everyone around

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<sup>4</sup> *The importance of being called Satya Bicknell Rethon*, original title *La importancia de llamarse Satya Bicknell Rethon*.

<sup>5</sup> Latin American School of Social Sciences, an intergovernmental institute dedicated to education and research on Latin America and the Caribbean, with campuses across the region.

him, and Rogelio, but only after telling his family that he was HIV positive (which he “was planning to do soon”). The others said they preferred to deal with it in more low profile ways.

This means bad news for Equidad’s advocacy efforts. If PLWHA prefer to remain invisible rather than come out and be open in order to improve their situation, this not only causes them to be socially isolated, as discussed in the previous chapter; it also impedes the defense of their rights. After all, how do you fight for the rights of a population that “does not exist”? And, as some of Equidad’s visitors who came to the center only for LGBTI services asked, why would you invest the already scarce resources in that invisible population, rather than advocate for those who are visible? As I concluded, the invisibility of many PLWHA makes it hard to justify efforts made to improve their overall position and to reach out to them.

Groups where PLWHA gather to share experiences with each other and discuss possible political ways of challenging exclusionary practices and social attitudes have highly fluctuating numbers. Several of my interviewees said they felt uncomfortable to go the group meetings because it was well-known they were held at certain days, times and places. If you would walk into a particular building at, for example, Thursday night or Saturday morning, everyone would know you were HIV positive, was their reasoning. This is particularly relevant in the case of the group meetings held at the Equidad office, as this office is always buzzing, and most of the visitors are not PLWHA. But even participants of other groups, such as *La Coalición*, are afraid the set time and location of the meeting might lead to undesired disclosure. Rogelio said he parked his car two blocks away from the building where the meetings were held and then, while he walked those two blocks, constantly looked over his shoulder to see if no one followed him. The first time he went to the meeting, he was so nervous that he came early and drove around the block until he saw some people gathered in front of the door. He then parked his car some blocks away and walked towards the building, but then waited on the corner until everyone had gone in. For ten minutes, he was wavering to ring the doorbell. When someone opened the door for him, Rogelio stormed passed him, and when he entered the room where the group was gathered, he sat in a corner and remained there the whole meeting there, without saying a word, as he told me in one of our interviews. The next time, once participating in the meeting, however, he felt safe and comfortable. Other informants also said they enjoyed sharing experiences and thoughts. Fernando and Alejandro called it “refreshing” to be able to talk freely without fear of the judgment of others. Pamela told me about the solidarity she experienced amongst the group of PLWHA she gathered with: “There is a lot of support. We talk, we cry, we laugh together. We see each other get sick and die; it’s less difficult when you are together.” Washington said meeting with other PLWHA could lift up his week. “We

talk about everything. The virus, the medication and how it makes us gain weight, being scared... but also about our Friday night out or a promotion at work. It helps to remind us that we are complete human beings.” This form of social support based on shared social and biological circumstances is an important coping strategy especially for those living with an illness with a highly stigmatizing character, and according to Moskowitz et al. (2009) it has a diminishing effect on stress and suffering. The suffering PLWHA experience as a consequence of their stigmatization manifests itself on an individual level, but as Kleinman and Kleinman indicate (1997), relationships and interactions can moderate suffering. These group meetings’ collective way of coping in which various individuals living with HIV/AIDS get together, help each other to accept to live with HIV/AIDS, and discuss their experiences with peers has in some cases led to activism and resistance. Alberto, whose story already was discussed in the second chapter, found that the most fulfilling part of getting together with other PLWHA was to work on changes to make living with HIV/AIDS easier and to prevent others from getting infected. His meeting group, at the *Hospital del Sur*, has been instrumental in improvements to treatment circumstances in the hospital. HIV/AIDS patients formerly were treated in a ward that was part of the department of infectious diseases, where they had no privacy at all. Some of the health care professionals had discriminatory attitudes, and equipment was old and defective. Although it took years, through much dialogue between the hospital director, the treating doctors, and Alberto as the spokesperson for the meeting group, the ward got its own, discrete location in a building behind the main building, personnel received sensitivity training, and the most important old instruments and machines were replaced with more sophisticated, functioning equipment. Although it is but one example, it is an encouraging illustration of what PLWHA can accomplish if they weren’t inhibited so much by self-stigmatization.

In Ecuador, the most well-known group of PLWHA coming together is La Coalición. Because of the low participation rates at the Equidad group meetings, Equidad staff also often refer people to La Coalición meetings, which are for all PLWHA, not just those from the LGBTI community. Although the population living with HIV/AIDS is extremely diverse, its members share some goals: to extinguish discrimination and exclusion, increase their social capital, and to have access to the (HIV) care they need. As Rogelio relates, its group members seek each other out, talk about common issues, experiences, problems; they do so to feel empathy and understanding. This is more than just sharing the same feelings for “that head nurse in the hospital's HIV/AIDS department” who always injects the needles too briskly or calls out the patient’s full names through the hospital’s echoing hallways, not caring about their right to privacy. It goes beyond collectively

abhorring one of the two specialist doctors at the Eugenio Espejo hospital, who seems to treat her patients with such contempt. There is discussion of problems, but there are also attempts at problem solving. Suffering determines individuals' perception of themselves, but also leads them to unite with similarly suffering individuals and address their source of suffering; the biosociality of Rabinow at work. PLWHA make up a collective identity based on their shared experiences and/or biology, and in the groups where they meet and discuss and devise ways to resist exclusionary practices, they use their vulnerable position to articulate a social critique with claims about rights and exclusion and notions of citizenship (Brown et al. 2004).

PLWHA, particularly those within the LGBTI community, have a strategic position to redefine what it means to be a fully included, participating member of society. In the process of reshaping their citizenship and gradually unmaking marginalization, PLWHA concerning themselves with claiming and advancing rights need to enter into dialogue with state institutions in order to change social perceptions and chisel out social advances in legal documents. This is where the Ombudsman comes in as an instrument for accountability. But it's not just the meeting groups of PLWHA who are struggling on their own; NGOs working on HIV/AIDS issues, among which Equidad (and its Bridging the Gaps partner Kimirina), are meaningful actors, too.

Equidad has generated spaces for discussion and forged collaboration with government agencies, such as the office of the Ombudsman, with which they will start a campaign on the defense of rights of sexual minorities this year, for example. As already mentioned, Equidad has important alliances with other NGOs working on HIV/AIDS, even though their strategies, politics and public are quite diverging. Among the highlights of their work are a decree against discrimination in the work environment, and the inclusion of an article in the 2008 constitution that criminalizes discrimination based on gender, sexual orientation, or HIV status, among others. In terms of HIV prevention and treatment, "there have been ups and downs, but in comparison to when we started, things have gotten much better," according to Efraín. He explained that in Ecuador, the government has been opening up to more progressive ideas and a wave of more democratic practices and transparency opened the door for a more powerful civil society, although smaller than Correa lets believe. When asked about the meaning of this for Equidad and its work for the LGBTI community, Efraín plunged into an explanation of how, with a new political discourse exerting its influence on every screw and bolt of the political machine, the interaction between state and civil society in Ecuador has been reconfigured. There was a time when most advocacy was about trying to gain access to or change closed decision making spaces. Over the last decade, many of these spaces have been opened to participation, but, according to Efraín, "they have opened up on their

terms, and only let the NGOs go as far as they want.” The Ministry of Public Health, for example, organized round table discussions with representatives of HIV/AIDS (patient) groups, but did nothing with the proposed suggestions. “The discussion points of the day remained just that, discussion points,” Efraín complained. A cautionary tale to all civil society organizations in Ecuador has been that of Pachamama, an indigenous rights movement. This movement became too boisterous in the eyes of the Correa administration, its voice too powerful and too defiant. In December 2013, the government shut down the offices of Pachamama, on the pretext it did not comply with legal requirements all NGOs had to fulfill, such as having legal statutes that were written by a legally trained employee. In his weekly address to his constituents, Correa chided Pachamama for instigating violence and dissent. The fear to “end up like Pachamama if we get too loud”, as Efraín stated during one of the team meetings, is one of the reasons Equidad’s advocacy efforts are subtle and take up much time.

One of Equidad’s strategies to appeal to its target population and the general Ecuadorian population in a non-confrontational way has been to employ the inclusionary rhetoric that forms the basis of the Citizens’ Revolution. Their campaign for the 2013 Gay Pride was very telling and an obvious reference to the idea that LGBTI people are Ecuadorians (citizens) just as much as anyone else. Figures 1 and 2 on page 41 show images from the campaign, courtesy of Equidad. They show LGBTI people in daily life settings, participating in everyday activities such as working, studying, meeting with friends, buying fruit, driving a car. The Gay Pride’s rainbow logo make clear that the depictions are of members from the LGBTI community while bold white letters stating “I am Ecuador” (*Yo soy Ecuador*) appeal to the idea that these populations, too, are part of Ecuadorian society.

As evident from what happened to Pachamama, NGOs need to be cautious and selective in choosing where and when to engage with different institutions and spaces. As related above, all too often, rather than a commitment to change, state institutions have opened spaces for participation as a way to silence their critics, offering little, if any opportunity for real influence on policies and decision making processes. Alberto, the informant open about being HIV positive who has been a visible HIV/AIDS (rights) advocate for over a decade, described the phenomenon of the “policy mirage” where the rhetoric around opportunities for policy changes attracts many people to engage, but at the end of the day much energy has been spent and the policy is still eternally postponed [or implemented but not acted upon]. This was also related to me by Efraín, who added to this that as a consequence of their limited time and resources, advocates are developing criteria to help them



Figure 1. One of the posters used in the 2013 Gay Pride campaign



Figure 2. One of the posters used in the 2013 Gay Pride campaign

determine when a space offers real opportunities for change and when it is simply a tool for public relations. “Although,” he added, “public relations are essential, too.”

Correa's Citizens' Revolution discourse is thus paradoxical: ostentatiously, it extends to the Ecuadorian people an expansion of their rights and possibilities to enjoy a more complete citizenship with higher physical, mental and social wellbeing, and to exert influence over decision making and policies. The alleged purpose of the Citizens' Revolution is to empower his citizens. At the same time, because the state has tightened its grip on civil society organizations and only allows for meddling in political affairs on its own terms, meaning less social mobility and wiggle room for NGOs and individuals than before, citizens continue to feel powerless and like incomplete or secondhand citizens because real empowerment remains an unfulfilled, empty potential.

Besides this incongruent strategy of state institutions, the work of NGOs such as Equidad is complicated by funding parties and other collaboration partners. Equidad is partially depending on funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria for the prevention and promotion activities they carry out in collaboration with fellow Quiteño NGO Kimirina. Besides difference about strategies and philosophy with Kimirina — and the lack of condoms and prevention packages throughout the trial stages of their new joint project, for which the Ministry of Public Health was to blame — the biggest issue Equidad had with this collaboration was that the Global Fund, and Kimirina as the main funding recipient, imposed their own set of working and monitoring and evaluation approaches upon Equidad as a requirement to receive funding. Some of these requirements, such as collecting detailed personal information about the people they reached during prevention and condom promotion activities that took place in nightclubs, bars, erotic video clubs, and saunas were not feasible. Equidad staff, having years of experience with such prevention activities, tried to explain why collecting personal information in these places was not going to work, but ran into a headstrong Kimirina team. While I was in the office, during one tense, seemingly never-ending Friday afternoon, the NGOs butted heads for several hours. When it had already been dark for at least two hours, Efraín asked us to leave; he would stay with Juan Carlos, one of the program coordinators, and two of Kimirina's program coordinators. They never exactly came to an agreement, and in the weeks thereafter, every time the project was discussed, a sour or disappointed remark would point to how much smoother the project would run had it not been tainted by the “perverse conditions” set by the Global Fund. Within the Dutch Bridging the Gaps program, the funding Equidad receives appeared less tied to strict conditions about ways to spend the money and monitoring and evaluation data to be presented; an annual report of activities and

financial are sent to Equidad's (funding) partner organizations within the Bridging the Gaps network.

Even though the Citizens' Revolution has not been a straightforward success in terms of more chances to influence policy making and bring about a true social transformation, it has given Equidad more opportunities to engage in a struggle over respectful and equal treatment and to fight stigma; through collaborations with the Ombudsman and the Ministry of Justice and Human Rights, for example, they support legal actions necessary to fight discrimination, and prevent PLWHA from being [fired] from their jobs, barred from the university or sent away in a doctor's office. But there is still another factor that hinders their work on HIV/AIDS; the already noted self-stigmatization surrounding HIV/AIDS that makes that many of the PLWHA remain silent about being HIV positive, rendering them invisible.

### **Political Resistance vs. Resistance in the Medical Encounter**

Being deprived of participating fully in society, which can be understood as political and social exclusion, and discriminatory medical treatment are different sides of the second-degree citizenship coin. The exclusion LGBTI living with HIV/AIDS suffer is fought on two different fronts: on the political/social front, which is inherently a more collective struggle, and the one fought mostly in doctor's offices, which can be perceived as a predominantly individual, one-on-one struggle, even though many political and social strings are attached to and shape the encounters between health professional and patient.

On a more personal level, the citizenship debate pushed forward by organizations like Equidad helps LGBTI living with HIV/AIDS in the sense that it provides them with a rhetoric to fall back on, the knowledge that they have certain rights and now also the institutional and legislative back-up to claim their rights provided by the Ombudsman. The NGOs have not only been important fighters in the struggle for citizenship, they also have made sure messages about expanded rights and possibilities are spread to create awareness amongst both their target as the general population. For example, Equidad has been instrumental in providing individuals with knowledge about what constitutes fair and good treatment through its workshops. Counseling at Equidad includes advice on legal and political issues. Visitors can also receive legal assistance or mediation between them and family, friends, employers, school heads, etc. Alan took me with him to the Eugenio Espejo Hospital, where most of my informants received treatment. Before Alan met his doctor we had to pick up the results from the blood analysis taken the week before. After

standing in line for half an hour in the overcrowded diagnostic area of the hospital, we were told the results were already at the HIV/AIDS ward. When we walked into the waiting room, a door at the other side of the room was wide open. Alan whispered to follow him, and he walked through the door. There was a passage that led to the ward, and at the beginning of the passage, immediately after passing through the door, it was impossible to not bump into an enormous open cabinet, almost resembling a scaffolding, with piles of papers. He grabbed a pile of the papers, browsed through it, and took one paper out. “Look,” said Alan. It showed his full name, birth date, CD4 count, and viral load.

“They just lie there in the open, up for grabs for anyone who is interested. It has been like that for years. Now, finally, after repeatedly complaining to the nurses, the doctors, even the director, threatening with legal steps at the advice of Equidad, finally, it will be gone soon.”

This cabinet was notorious amongst my informants; many brought it up as an example of the disregard of their privacy. Alberto narrated how there'd been a cabinet like that at the Hospital del Sur, too, but how the patients advocacy matters made it disappear. This illustrates how Equidad's work can also function, without being overly political or aiming for grand social transformations.

However in the end, even though they are in contact with organizations like Equidad or La Coalición, my informants still preferred to confront doctors on their own, because of the secrecy surrounding HIV/AIDS discussed earlier. Real “militants” were scarce. Those that were defending their shared social circumstances in the LGBTI sector in a sustainable way, seemed to be mostly employed in NGOs working on the topic. With the exception of Alberto, none of the PLWHA that I interviewed had organized themselves in collective acts of resistance outside of their meeting groups. The few PLWHA that were open about their HIV status were three heterosexual men working for La Coalición whom I met during a meeting of different state and civil society representatives regarding the creation of a manual to guarantee and claim the rights of PLWHA.

As soon became evident, my informants performed their acts of resistance in the hospital rather than in the assembly building. Carlos' account of the unpleasant experiences with his doctor do not only show us how the doctor upholds her value system and her authoritative role in the encounter with him, it also shows us how Carlos interacts with her attitude.

“She refused to give me the medication. She argued I was too anxious. I recognize that maybe I was a little anxious. Because everything was completely new to me. I was about to start life-long medication. I don't think it is easy for anyone. So I think it is normal to ask questions about the treatment, about the illness... And she exploded, said I asked her too many questions and that she wasn't sure I would take the treatment. I went to the psychologist and he didn't agree with the doctor, said it was understandable I was a little tense because I had to face this heavy situation, that it's not easy. Living with HIV... And even with his instructions to start me on the medication she still wouldn't do it. And then I filed a complaint.”

Both Manu and Ronald invited me along on medical appointments. Alan brought me with him to the hospital, but I stayed in the waiting room as he was meeting with his doctor. Manu was being treated in one of Quito's most prestigious private hospitals, and his doctor, who was relatively young, had studied and lived many years in the United States. The relation between Manu and the doctor seemed amicable, as if they were old friends catching up. They seemed like equals in the interaction. When discussing Manu's upcoming plastic surgery targeting the lipodystrophy that was a side effect of his medication, hilarity ensued when the doctor let his Edding marker indicate how much of fat tissue he thought should be removed. We left the office in high spirits, as if there was no such a thing as HIV that Manu was already living with for fifteen years, and passed by the pharmacy as if it were a cinema concession stand. “This was very different when I was young and poor,” said Manu.

“I had to go to the public hospital, and ART was not free and universally available then. Every check-up, I had to fight with the doctor to make sure he told me everything I needed to hear, and to make sure he respected me. To get my medication, I used to travel back to my home country every few months, because in Ecuador it was impossible to get it. I complained with the hospital, I complained with the doctor, told him to treat me better, filed lawsuits for non-compliance against the state because they failed to provide people with a life threatening illness, like me, with medicines that keep them alive... But nothing helped, until I started to make money and could find myself better care instead of demanding it.”

Based upon stories he heard from other PLWHA, Manu assumed things had gotten better in terms of possibilities to claim better treatment and care, that doctors saw their patients more as equals and less as “ignorants” who did not know how to take care after themselves, but he could not base that on any of his personal experiences as he no longer received treatment in a public hospital. Ronald invited me to come to the encounter with his doctor in the public Eugenio Espejo Hospital. He had warned me in advance he and his doctor were not on very good terms. But he had received some counseling in Equidad when he fell “in an abyss” after receiving his diagnosis, where he had been told of his rights and was warned about the intimidating behavior of some of the doctors at the treatment facilities. He had slowly grown more assertive with his doctor. Once in the office, after the doctor told Ronald dryly his CD4 count and viral load were fine, Ronald related he had been inquiring about possibilities for alternative healing practices, and that he was traveling to a city in the South for a first meeting with the healer that coming weekend. As I noted, the doctor let him hardly finish his story, and without even asking about the details, she was quick to dismiss alternative medicine as ineffective and possibly dangerous. Ronald replied he was going to travel there anyway, even if just to get acquainted with the healer and his approach. To this, the doctor responded that it was his health and she could not keep him from doing stupid things, but that “she certainly felt it was a waste of time she was investing in treating him while he just impulsively did whatever he felt like, without thinking of the consequences for his health”. Ronald, agitated, asked for the prescription for his new supply of medication and, after the doctor had given that to him, told the doctor she had no right to impose her ideas upon him, that she had to respect him as a patient and human being, and that he would try to seek another doctor if she failed to do so again during the next appointment.

As the interaction between PLWHA and their doctors can be understood as an aspect of medical power relations that are produced by both patients and health care professionals, this is also a site of resistance in the struggle against exclusionary structures. As a consequence of the invisibility of PLWHA, resistance often comes down to personal resistance in the medical setting. Because this is so fractured and often remains invisible beyond the doctor’s office, it is almost impossible for organizations such as Equidad, or patient groups for PLWHA, to make a fist and challenge prevailing exclusionary constructions. Equidad thus is limited to empowering individuals in the political and medical space by handing them tools and knowledge. This has, for instance, led to PLWHA taking an active role in their own health care experiences. Some of Equidad's visitors see their hospital visits and interactions with medical professionals and the health care system as a lonesome process, others seem supported and inspired by their advice in the medical area.

PLWHA's resistance has influenced small changes in the provision of medical care. In combination to political resistance on a collective scale, these should, in time, lead to more radical legislative, policy, and medical reforms.

#### **4. Conclusion**

My research looked into sexuality, HIV/AIDS, stigma and citizenship. I investigated whether and how biosocial circumstances that people living with HIV/AIDS within the LGBTI community share make them put up forms of resistance and (collectively) claim rights, inclusion, and better treatment in and outside of the medical setting. I did so in Quito, Ecuador, where my main field site was the office of Equidad. I studied both activities of the NGO and individual acts.

I started off by relating how my informants, all belonging to the LGBTI population, felt they were treated with regards to their sexual orientation or gender identity. I then continued to add another source of discrimination and exclusion: being HIV positive. LGBTI people living with HIV/AIDS still experience discrimination and stigmatization, which they prefer to avoid by remaining silent about their sexuality and/or HIV status. The narratives of my informants illustrated some of the common issues LGBTI living with HIV/AIDS deal with, such as stigmatization, social isolation, and conflicts with the health care professionals who treat them. I also showed the problems faced by Equidad as it was trying to amp up education, prevention and testing efforts.

After a discussion of ways in which sexual health-related stigma negatively affects HIV prevention, treatment, and care, I shifted my focus to what the LGBTI community and PLWHA have done to challenge stereotyped beliefs, marginalization and stigma; whether and how they transform their suffering into a force of social change. Despite the pervasiveness of HIV-related stigma, sexual rights groups and groups claiming access to treatment have found some ways to resist categories of exclusion using various strategies. However, members of the Ecuadorian LGBTI community who claim a more inclusive citizenship based on shared social experiences and biological circumstances mostly seem to do so in individual ways rather than putting up a collective resistance. This can be explained by the secrecy and invisibility most PLWHA are still living out of fear to be excluded or discriminated against. Equidad helps them to shed this secrecy, but simultaneously, the invisibility of individual PLWHA makes reaching out to them and fighting for their rights difficult. The state also functions also as a limiting factor, for example by neglecting the possibility of sensitization campaigns amongst health care professionals and sexual education campaigns in educational institutions, which can lead to less discriminatory attitudes amongst health care professionals and society at large. While exploring the attitudes of LGBTI people towards the current forms of LGBTI organizing, Equidad's failure to effectively reach out to PLWHA populations was mentioned by some informants, although they did confess it was hard to think of ways in which Equidad could successfully reach out to an invisible group of people.

Inclusion and political participation are at the heart of an ongoing negotiation between state and civil society actors, but the rules of the game have been dramatically changed with the advent of Correa's Citizens' Revolution. Ecuador's recent political turn to the left and a constitutional, all-inclusive warranty for equal rights and a provision for non-discrimination have provided more opportunities for Ecuadorian LGBTI living with HIV/AIDS to make claims to cultural, social and political rights. Expectedly, this should give civil non-state actors (both groups and individuals) more options to demand respect for their rights and hold state actors accountable for discrimination and violations of rights, for example in the gender or health arena. State institutions like the Ombudsman embolden the promise of equal treatment of all citizens. But from the time I spent in Quito I can conclude that such a vision is somewhat too optimistic. While proclaiming the ideal of full, equal citizenship for all its citizens, the Correa administration upholds a hierarchy through bureaucratic regulation. Ostentatiously, it creates spaces for citizens to claim rights and reaches its hand to civil society under the motto of collaboration, holding up the idea of a society where all citizens have equal rights and are fully acknowledged citizens who can engage in open dialogue about questions that are important to them, such as identity, sexuality, and health. But these spaces are created within a particular set of boundaries, on the government's terms and according to its wishes.

Social discrimination, and fear of judgement remain the main barriers to HIV testing and care and to collective resistance. Negative attitudes towards sexual minorities and the strong stigma that persists in relation to HIV/AIDS make that the majority of PLWHA in the LGBTI community prefers to not disclose their HIV status or sexual orientation. The silence and marginalization that PLWHA endure make it difficult to enjoy a sense of community and difficult to spread the prevention message, claim broader citizenship, fight against discrimination, and create a culture of safe sex practice, because doing so inherently means speaking up and becoming visible. The only space where PLWHA can put up a form of resistance that does not become public, is in the doctor's office. For that reason, and for the fact that these are often the most direct opportunities for confrontation with discriminatory behavior, the medical environment is where most of my informants put up resistance. Resistance like this remains fragmented and is unlikely to rupture social isolation, but it can be effective in improving patient-doctor interactions and minimizing discriminatory attitudes. Although it might seem insignificant when thinking of the great number of PLWHA in the LGBTI community faced with discrimination every day, some of my informants have at least been able to temper down discrimination in their own particular cases through acts of individual resistance in the medical encounter.

However, although stigma remains a powerful enemy in the battle against HIV/AIDS, there is a slowly spreading open attitude towards people with a sexual orientation or gender orientation that diverges from the heteronormative standard, partially on account of the ceaseless work of Equidad over the past fifteen years. The growing acceptance of the idea of same sex marriage and the ever increasing number of participants in the Gay Pride attest to that. Plans to run sensitization campaigns will hopefully come to fruition soon. More accountability mechanisms mean goodwill on part of the state, at least rhetorically, and the office of the Ombudsman seems eager to fight for the rights of each and every Ecuadorian citizen.

I think that in terms of advancing inclusion of PLWHA, there are lessons to be learned from the larger LGBTI community, even as they continue their struggle with discrimination. The fight against discrimination of LGBTI has benefited from individuals opening up about their sexuality and engage in dialogue about being LGBTI. The stories of Alberto and Pamela show that once PLWHA step out of the shadows, they can effectuate changes. Pioneers like these are essential to advance the discussion about HIV and make it a more 'common' discussion topic. An NGO that is organized like Equidad, with LGBTI people living with and without HIV, is a good place to start an exchange of dialogue on a small scale. Furthermore, Equidad already functions as a ligature between individuals and accountability mechanisms like the Ombudsman, and they could exploit this position more transparent to make the step from individual to accountability mechanism smaller, with perhaps, if possible, a guarantee of anonymity outside the courtroom. (Though I argue that visibility is a key feature to advance inclusion of PLWHA, if individual battles need to be fought behind closed doors, it would be a loss if the fear of disclosure of HIV status would stop people from taking legal action.) Now some informants said they took a complaint to Equidad, but felt discouraged when Equidad provided them with nothing more than a phone number; they expected more guidance. Individual, medical resistance in the consultation room is helpful in particular instances, but I doubt whether it is enough to make a significant difference for the collectivity, especially not if individuals are reluctant to take their complaints out of the hospital and into the courtroom if necessary. I think a key role lies with NGOs like Equidad and La Coalición, where people already gather and at least have stepped over the first hurdle and shared their HIV status with others. Organizations could involve these groups more in political activities. They already have programs focused on political involvement, but they do not use them to their full potential. Many users are unaware of the existence of politically themed meetings. Furthermore, involving the public in dialogue about HIV/AIDS by organizing activities linked to the topic, could be a low-key approach to make the larger public or specific groups such as doctors or employees of

the Ministry of Justice better acquainted with the topic. Such activities, like movie screenings, have proven useful when related to LGBTI themes.

The citizenship debate is both a process and an outcome, that takes place on a collective and individual level. So far, improvements have been made and inclusion has been slightly increased. Although there is still a long way to go, I believe that as long as PLWHA in the LGBTI community continue to push forward, with slow steps and the support of civil society organizations like Equidad and state institutions with a mission to defend citizens' rights, eventually resistance will lead the way to ever greater inclusion and guarantee of rights, and less discrimination regardless of sexual orientation, gender identity and HIV status.

My research time for this project was limited. Therefore, I want to make the reader aware that I could not give my project the span and depth I would have liked to. Nonetheless, I hope that with this thesis, I can, however slightly, contribute to more insight into the situation of people living with HIV/AIDS in the LGBTI community and the battle against the spread of HIV/AIDS. Ten weeks may not be that long, it is long enough to get a grip on how hard discrimination and exclusion hit the lives of LGBTI living with HIV/AIDS, long enough to observe how hard everyone at Equidad works to squash discrimination and HIV transmission, and it is a very long time to wait for condoms.

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